

# Facilitating HIV Testing and Disclosure with Children and Adolescents





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**A report on barriers and challenges in facilitating testing and disclosure for children in 0-6, 7-14 and 15-18 age groups, an operations research conducted in Andhra Pradesh and Manipur**

**June 2009**

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Design and Print: New Concept Information Systems Pvt. Ltd.

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Published: June 2009

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Note: The names of children living with/affected by HIV, given in the case studies, have been changed to protect their identity.

# 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. Lastly, reduce 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.

# Acknowledgements

Alliance India acknowledges the significant contributions of its partner NGOs: Rural Environment and Education Development Society, Annamma School for Hearing and Physically Handicapped and Baby Care Centre, Deepthi Socio-Educational Society, Hyderabad Leprosy Control and Health Society, and People's Action for Creative Education (Andhra Pradesh); and Dedicated People's Union, Sneha Bhawan (Manipur). These NGOs not only extended field support to this research but also provided timely feedback and comments on the processes followed during the study. The execution of this study was possible because of the invaluable support provided by the three Sub-Recipient (SR) organisations—Vasavya Mahila Mandali (VMM), Lepra Society of Andhra Pradesh, and Social Awareness Service Organisation (SASO) of Manipur. Special gratitude is paid to the community members and facility providers, who gave their time and shared their rich experiences with the team. Without their individual and collective contributions, this report would have been incomplete.

A special word of thanks is due to G. Ramanujaiah, B. Honey Praveen, G. Rashmi, and B. Keerthi from VMM; Uma Akula from Lepra Society; and Basanta Moirangthem, Gilbert Chinir, Ranjana. L and Y. Shasikumar Singh from SASO, for their support in facilitating smooth conduct of the study and providing their valuable inputs.

Alliance India acknowledges the contribution of the research agency – the Development and Research Services Private Limited (DRS), based in New Delhi, who conducted the study and provided support in preparing this report. A special thanks to Dr. M. Vijaya Kumar, DRS Delhi, who led the research. The research team deserves a particular mention and acknowledgement that comprised the following: Manipur Field Team – Dr. Naorem Dayabati Devi, Laikhuram Hemjit Singh, Chabungbam Gourachandra, Thoidingjam Thajamanbi Devi, Meera Pheiroijam and Moirangthem Chandrama Devi; Andhra Pradesh Field Team – Dr. P.V. Vijay, Dr. Ravikanth, K. Vijayamma, Dr. P. Sowjanya, Dr. D. Sridevi and Vinaya Pai; and Support Team – Dr. N. Veerabhadra Rao and A. Venkataramana Murthy from DRS Hyderabad, and Ajeet Vishen and Brateen Das from DRS Delhi.

Alliance India's staff—Alexander Matheou, Pankaj Anand, Shaleen Rakesh and Tanu Chhabra—are acknowledged for reviewing the report and for providing their valuable insights. The report in its final version, with necessary review, compilation, data analysis and design, is attributed to Vaishakhi M. Chaturvedi.

This study and publication was made possible through the support of GFATM. The opinions expressed herein do not necessarily reflect the views of this donor.

Suggested citation: Chaturvedi, Vaishakhi M., K. Vijay, Facilitating Testing and Disclosure for Children and Adolescents, India HIV/AIDS Alliance, 2009.

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# Abbreviations

AIDS	Acquired Immuno-deficiency Syndrome
ART	Anti-Retroviral Treatment
CBO	Community-Based Organisation
CLHIV	Children Living with HIV
CSO	Civil Society Organisation
DBS	Dried Blood Sample
DPU	Dedicated People's Union
DRS	Development and Research Services Private Limited
EID	Early Identification and Diagnosis
FGD	Focus Group Discussion
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HCBCS	Home and Community-Based Care and Support
HIV	Human Immuno-deficiency Virus
HLCHS	Hyderabad Leprosy Control and Health Society
ICTC	Integrated Counselling and Testing Centre
IDI	In-Depth Interview
IDU	Injecting Drug User
IEC	Information, Education and Communication
KII	Key Informant Interview
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-Governmental Organisation
ORW	Outreach Worker
PCR	Polymerase Chain Reaction
PEACE	Peoples Action for Creative Education
PR	Principal Recipient
REEDS	Rural Environment and Education Development Society
SASO	Social Awareness Service Organisation
SR	Sub-Recipient
SSR	Sub-Sub-Recipient
STI	Sexually Transmitted Infection
VMM	Vasavya Mahila Mandali



# Executive Summary

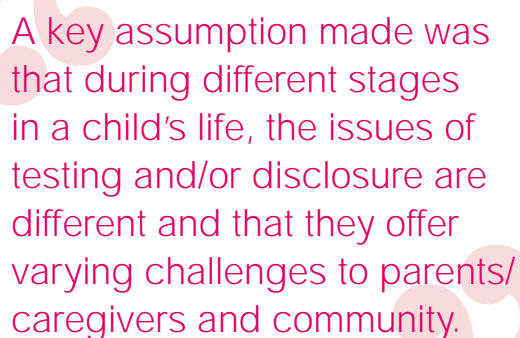
It is a given scientific fact that any treatment must precede complete knowledge of the problem, clinching diagnosis and necessary cooperation of those being treated. The crucial barrier in treating children living with HIV (CLHIV) is confirming whether they are positive. In the absence of timely testing and diagnosis, many of them are lost before appropriate treatment could have been initiated. Recent discourses on the subject and experiences derived from similar initiatives have increasingly pointed towards taking CLHIV into confidence in providing successful treatment and ensuring longevity for them. Diagnosis among infants is itself a key challenge as much as the burden of socio-economic environment in which their affected families are situated. Disclosing HIV status to children and adolescents is arguably a prudent step in simplifying a complex issue. Considering children's limited understanding of the subject as well as its related effects on their bodies, disclosure is in itself a challenge for parents/caregivers. The extremely stigmatising nature of HIV/AIDS, resulting in highly emotional responses, makes disclosure challenging. Finally, extreme care and subtlety is required while taking children into confidence as unintentional outcomes may be ingrained in terms of inferiority complex, diminished psychological strength, and negative attitude.

The India HIV/AIDS Alliance (or Alliance India) initiated CHAHA (meaning 'a wish' in Hindi), an expanded child-centred Home and Community-Based Care and Support (HCBCS) programme in 2007, through grant

received from Round 6 of GFATM. As a civil society Principal Recipient (PR), Alliance India has been implementing this programme along with its consortium of nine Sub-Recipients (SR), in the states of Andhra Pradesh, Tamil Nadu, Maharashtra and Manipur. The programme caters to the needs of children living with and affected by HIV from the age of 0 to 18 years, and aims at reaching 64,000 children by 2011. CHAHA, besides providing direct services and linkages, works towards reducing stigma and discrimination through community mobilisation strategies, and improving the quality of life of the affected children and their families. Although the programme has been making some efforts in dealing with issues surrounding testing and disclosure locally, the issues are more complex than what is apparent.

This Operations Research is specifically aimed at understanding current barriers, and to provide possible short to medium term solutions, thereby strengthening CHAHA as well as others working to provide child-centric care and support. The study focuses on three broad objectives:

- Identifying challenges and factors that prevent the community from seeking HIV testing of their children
- Understanding issues related to disclosure of HIV status to children, and the social impact related to disclosure faced by parents and children
- Using the study findings in formulating practical solutions to address these issues, and to come up with practical recommendations on building synergistic links between policy and practice.



A key assumption made was that during different stages in a child's life, the issues of testing and/or disclosure are different and that they offer varying challenges to parents/caregivers and community.

The study was conducted in Hyderabad, Nalgonda and Krishna districts of Andhra Pradesh, and Bishnupur, Chandel and Imphal East districts of Manipur.

The research is exploratory in nature, and has 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 categories covered in the study were 0-6, 7-14 and 15-18 years.

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 members, village school teachers, religious leaders, village leaders, and service providers such as Integrated Counselling and Testing Centre (ICTC) staff, field health functionaries, Outreach Workers (ORWs), and NGO representatives, were also part of the respondents.

A key assumption made was that during different stages in a child's life, the issues of testing and/or disclosure are different and that they offer varying challenges to parents/caregivers and community. For example, during the age of 0-6 years, the challenge of testing is mainly determined by technology, as a Polymerase Chain Reaction (PCR) test would be required for diagnosing HIV in children aged

0-18 months. Needless to say, while an early diagnosis is crucial for timely treatment, the related issue of confidentiality and consequent fear keeps parents from getting their children tested. For children in 7-14 age group, while availability of testing technology is not a problem, insensitivity of ICTC staff and issue of confidentiality is a recurrent feature. Disclosure of HIV status to children, coping mechanisms, and access to psychosocial support for children become critical determinants of the child's overall well-being. The adolescent age group (15-18 years), is a critical period when one is ready to take charge of life. Along with sensitivity of staff at testing centres and the confidentiality issues, other important factors like direct access to testing centres, access to timely and reliable information on testing and disclosure emerge. Therefore, access to testing and meeting the information needs of an adolescent are crucial issues in this age group.

Although it was assumed at the beginning of the study that the issues of testing and disclosure for children from the three age groups would be quite distinctly defined, the findings from the study are not very different and are quite overlapping. The key findings have helped us to put forward some important recommendations for child-centric care and support programmes designed for affected children and their families, and the services provided to them.

Key findings of the study have highlighted several factors that prevent parents from taking their children for HIV testing across all age groups. The stigma and discrimination associated with HIV and AIDS was reported to be the most common barrier. It creates a psychological fear and prevents many children and adolescents from getting tested. Financial constraints closely follow as a barrier. Primarily, the time and travel costs involved in visiting the testing centre, and fear of losing a day's wage have been reported by a majority of parents and adolescents (15-18 age group) to be the inhibiting factors. Disclosure in their localities

was another fear expressed by many parents. This fear compelled some of them to visit testing centres located in other districts. Lack of awareness about HIV and AIDS was reported as another challenge. Among the parents of children in 7-14 age group, no or little awareness makes it difficult for them to explain to their children about HIV testing. Closely linked to this barrier is low motivation level, followed by the attitudinal issues of service providers. Reasons which de-motivate parents and few adolescents from getting HIV test done are – parents' inability to overcome the shock/grief of their own positive status, fear of finding their children also positive, fear of confronting stigma and discrimination, financial expenses involved, and the disillusionment that if found positive, Anti-Retroviral Treatment (ART) will just extend life but will not cure HIV. There is limited awareness and understanding about HIV and AIDS amongst the healthcare service providers as well.

The challenges and dilemmas of disclosure found in the study are put forth here. For parents of children in 0-6 age group, disclosure is ruled out as it is an age where children are too young to comprehend the meaning and significance of their HIV status. In fact, these parents reel under psychological turmoil as a result of not being able to disclose and for suppressing the knowledge of their children's status. For parents of children in 7-14 and 15-18 age groups, it was dilemma, in the first place, to decide whether to disclose or not, and then, to decide the right age for disclosure. It was found finally that no parent agreed to disclose until their children reached a minimum age of 10 years. The following reasons have emerged as the causes of fear which inhibit parents to disclose—children may undergo enormous stress and pain, and the information may spread to neighbours. The fears of parents of children in 7-14 age group were compounded by the difficulties involved in explaining or discussing the modes of transmission. At the facility level, the parents

felt that the way in which counselling service is provided to children is not appropriate as it doesn't simplify the process of disclosing their positive status in an age-appropriate manner.

As for channels of disclosure, parents and/or healthcare service providers disclosed HIV status to most children in 7-14 age group, and mostly doctors to adolescents in 15-18 age group while examining their parents, as also immediate family members. Overhearing and suspicion on the part of children and adolescents were also cited, however, in a few cases. Disclosure by parents is the most preferred channel, a view that has been endorsed by parents who have already disclosed to their children as they think that they are best placed to decide the right time. Almost equally preferred were NGO staff who share a good rapport with the community. Discussion with adolescents in 15-18 age group revealed that parents who disclosed their HIV status to children were mainly those who had come in contact with the NGOs. Although ICTC staff also form a significant part of the preferred channels of disclosure, they find many gaps in the services provided, and have great expectations from them, especially related to counselling and guidance.

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The study brought forth pain, fear, worry and helplessness, in descending trend, as the immediate psychosocial effects of disclosure on children and adolescents.

Key recommendations aim at modifying healthcare service delivery to make testing centres more approachable and affordable to parents and their children. Expanding the number of testing centres, filling up gaps in infrastructure, equipment and manpower, flexible timings and expansion in days of functioning of centres, and monitoring the scheduled time of staff are some relevant suggestions.

Improvement in diagnostic services for children below 18 months is recommended, for which awareness should be built, both at community and healthcare service levels, about special techniques like DNA-PCR for testing children below 18 months of age. This would help generate informed demand and thus, advocate strongly for making this facility available with healthcare providers. Alternatively, adopting the DBS (Dried Blood Sample) method for children will enable Early Identification and Diagnosis (EID).

Stigma and discrimination should be addressed in communities and even healthcare settings, by involving communities and key stakeholders in the programme and in framing policies, using participatory techniques like street theatre and support groups to enhance community participation, and scaling up training and sensitisation of healthcare service providers.

Improvised and focused counselling through specialised counselling techniques, and adequately trained and professional counsellors is an important recommendation for encouraging timely testing of children and helping the process of disclosure.

Capacity building and training at different levels—parents, healthcare workers, counsellors, outreach workers from NGOs, formation and strengthening of support groups for children, adolescents, and parents, and strengthening of Information, Education and Communication (IEC) coverage—are some additional steps suggested.

## Key Findings

Factors Preventing HIV Testing	Issues Related to Disclosure
<b>Fear of stigma and discrimination:</b> Lurking fear of associated stigma; incidences of discrimination in neighbourhood; probability of hurdles in marriage especially for girl children	<b>Challenges and dilemmas:</b> 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 process of disclosure; lack of counselling and guidance by ICTC on disclosure
<b>Financial constraints:</b> Fear of wage loss; travel to testing centre; time and opportunity cost incurred	<b>Channels of disclosure:</b> 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; the lack of focus on post-test counselling, especially about the 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
<b>Fear of disclosure in the locality:</b> Issues of maintaining confidentiality and the fears emanating from this deter few parents of children in the 0-6 age group, from taking their children for testing	<b>Immediate psychosocial effect of disclosure:</b> 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 parent' loss, loosing rented house, denial in marital alliance especially for girls
<b>Lack of awareness about HIV and AIDS:</b> Lack of awareness on the part of parents makes it difficult for them to explain to their children in the 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	<b>Helplessness:</b> parents' health condition and the extreme thought of their death, taking up family responsibilities, discontinuation in education to earn a livelihood
<b>Low motivation level:</b> 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	
<b>Attitudinal issues of service providers:</b> Unfriendly hospital environment and procedures; discrimination by service providers; overburden of work on counsellors; lack of specialised trainings for counsellors	

## Key Recommendations

<b>Modifying healthcare service delivery</b>
Expand the number of testing centres; fill gaps in infrastructure, equipment and manpower; feasible and flexible timings of testing centres, and expansion in days of its functioning; and monitor the scheduled time of staff.
<b>Improving diagnostic services for children below 18 months:</b> Create awareness about DNA-PCR technique to generate informed demand from communities and healthcare providers.
<b>Addressing stigma and discrimination in neighbourhood, communities and healthcare settings:</b> Sensitise service providers; involve children and families in programmes and framing of policies; enhance role of community leaders; use theatre technique and strengthen support groups.
<b>Establishing improved and focused counselling services:</b> Use services of professionally skilled counsellors; re-look at budget allocation for improved counselling services; use child-centred counselling technique; scale up youth friendly testing and counselling facilities; develop systematic plan to aid parents in disclosure, including post-disclosure issues; focus on positive living.
<b>Capacity building and training:</b> Scale up capacity building at different levels -parents, healthcare providers, counsellors and outreach workers from NGOs; develop training modules with specific guidelines for each category aforementioned; train counselors in specialised techniques and specific areas of sex and sexuality, SRH issues, and issues specific to different age categories of children.
<b>Formation and strengthening of support groups:</b> Involve children in play therapy and group counselling through support groups; form and/or strengthen adolescents' and parents' support group to discuss and learn from experiences of disclosure.
<b>Strengthening IEC coverage:</b> 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.

# Statement of Problem

According to the National AIDS Control Organisation (NACO), 33,000 newborns contract HIV every year from their positive mothers, and over 50% of these children die within two years of birth while 80% of them die within five years. CLHIV are susceptible to far greater episodes of illness followed by 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.<sup>1</sup>

Worldwide, every day 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

Worldwide, every day 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.

through parent-to-child transmission. Global trends suggest that infants living with HIV frequently present with clinical symptoms in the first year of life, and 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 CLHIV is only identified clinically once he/she is ill, it may be too late for 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.

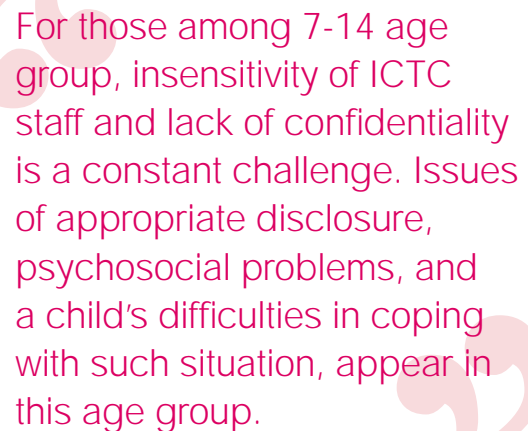
There are many significant challenges in testing children for HIV. Non-availability of PCR test and other specialised techniques in testing children below 18 months is a major deterrent. The stigma surrounding HIV/AIDS plays a big role in children's parents/ caregivers' unwillingness to take them for HIV test, even if they know that there is a risk. For a parent 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, field experiences suggest that the child is tested for HIV only after the mother has been tested before and in some stray cases the other way round. Testing of children with asymptomatic conditions even if the mother is found HIV positive, experience suggests, is particularly difficult to facilitate.

<sup>1</sup> UNAIDS/WHO (2006, June), Progress in Scaling Up Access to HIV Treatment in Low and Middle-Income Countries

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. Timings of ICTC, quality of services and receptivity of the staff are additional problems faced.

Once tested positive, disclosure of status of parents 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 to deal with the various manifestations of stigma, adherence to life long treatment, battling the illness, and end-of-life issues.

Apparently, testing and disclosure also pose various challenges differently to different age groups of children. For example, testing for 0-6 years 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 situation, appear in this age group. In dealing with adolescents (15-18 years), lack of access



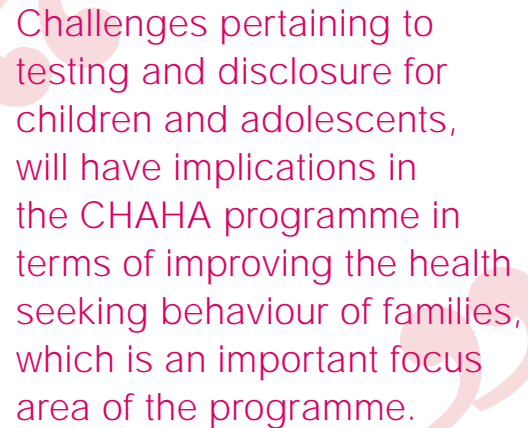
For those among 7-14 age group, insensitivity of ICTC staff and lack of confidentiality is a constant challenge. Issues of appropriate disclosure, psychosocial problems, and a child's difficulties in coping with such situation, appear in this age group.

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 shapes 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.

It is apparent that problems run deep and wide, although field realities reveal that some efforts are being made to locally deal with the vexed issues surrounding testing and disclosure. As has been captured above, community voices from CHAHA programme re-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 them. Parents fear, or more often, are at a loss to understand as to how to disclose the status to the 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 the CHAHA programme in terms of improving the health seeking behaviour of families, which is an important focus area of the programme. 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.



Challenges pertaining to testing and disclosure for children and adolescents, will have implications in the CHAHA programme in terms of improving the health seeking behaviour of families, which is an important focus area of the programme.

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.



# Background of the Study

Alliance India initiated an expanded child-centred Home and Community Based Care and Support (HCBCS) programme in 2007, in line with the strategic priorities of National AIDS Control Programme Phase III (NACP-III). The project named CHAHA (meaning 'a wish' in Hindi language), receives funding support from Round 6 of GFATM. As a civil society Principal Recipient (PR), Alliance India is implementing this project along with its consortium of nine Sub-Recipients (SR) in the states of Andhra Pradesh, Tamil Nadu, Maharashtra, and Manipur. These SRs, in turn, work with a network of Sub-Sub-Recipients (SSRs), numbering 54 in total 59 intervention sites in 40 districts. CHAHA is working closely with different stakeholders and Government Ministries to find ways to help keep children 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 2011.

The overarching goal of CHAHA programme is to work towards reducing stigma and discrimination through community mobilisation strategies, improving the quality of life of children living with and/or affected by HIV and their families through provision of certain key services as well as build sustainable linkages appropriately at the local level.

A network of significant number of 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.

However, the programme is not following any disclosure guidelines at present. Although some child friendly counselling approaches are being implemented within CHAHA, yet an important aspect that needs to be understood well is whether the testing facilities are child friendly or children fear the centres. It is widely reckoned that in the absence of a child friendly environment at the testing centres, promoting the cause of testing becomes difficult.

While the known problems on supply side are with regard to ICTC timings, travel expenses, transport problems, receptivity of counsellors, and quality of services, that have a bearing on

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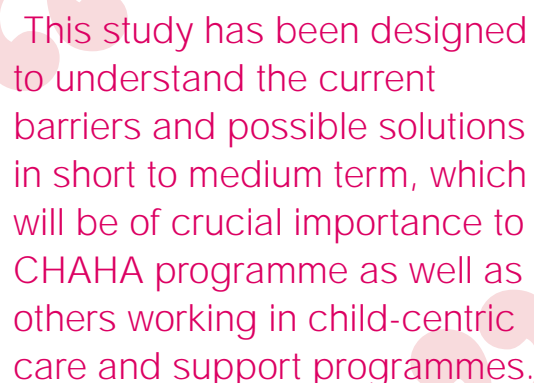
the accessibility to HIV testing for children, the confirmation of the same through this study would be useful.

On the demand side, causative factors that facilitate or hinder the accessibility are important to know because field experiences in CHAHA programme suggest that many parents do not want their children to be tested. Also, disclosure of HIV status to a child invites a lot of psychosocial issues and questions. The study could also help to arrive at different ways to address such issues and support disclosure process for children, adolescents and their parents/caregivers.

Thus, this study has been designed to understand the current barriers and possible solutions in short to medium term, which will be of crucial importance to CHAHA programme as well as others working in child-centric care and support programmes.

### Study Objectives

- To identify challenges and factors that prevents the community from seeking HIV testing for their children.



This study has been designed to understand the current barriers and possible solutions in short to medium term, which will be of crucial importance to CHAHA programme as well as others working in child-centric care and support programmes.

- Understanding issues related to disclosure of HIV status to children including psychological issues and the social impact relating to disclosure faced by parents and children.
- To use the study findings in formulating practical solutions to address these issues (related to both testing and disclosure) in short to medium term and to come up with practical recommendations on building synergistic links between policy and practice.

# Methodology

The study has been conducted in two states, Andhra Pradesh and Manipur. The districts, selected in consultation with respective SRs were Hyderabad, Nalgonda and Krishna in Andhra Pradesh, and Bishnupur, Chandel and Imphal East in Manipur.

The research is exploratory in nature, and has 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 are 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 members, village school teachers, religious leaders, and village leaders, and service providers such as ICTC staff, field health

functionaries, ORWs, and NGO representatives, were also a part of the respondents.

The survey method was used within which structured questionnaires were used for the study as quantitative tools to collect data from HIV affected families as well as the general households. The affected population/families surveyed comprised:

- HIV positive parents with children in 0-6 age group
- HIV positive parents with children in 7-14 age group
- Adolescent boys (15-18 years) with HIV positive parents
- Adolescent girls (15-18 years) with HIV positive parents
- Parents of children visiting ICTC for testing of children in 0-6 age group
- Parents of children visiting ICTC for testing of children in 7-14 age group
- Adolescent boys (15-18 years) visiting ICTC for testing

**Table 1: Implementing NGOs selected for the study in Andhra Pradesh and Manipur states**

S.No.	INGO	Location	District	State
1	Sneha Bhawan	Imphal East	Imphal East	Manipur
2	Sneha Bhawan	Chandel	Chandel	Manipur
3	Dedicated People's Union (DPU)	Bishnupur	Bishnupur	Manipur
4	Deepthi Socio-Educational Society	Vijayawada	Vijayawada	Andhra Pradesh
5	Annamma School for Hearing and Physically Handicapped & Baby Care Center <i>(Note – This NGO was associated with the project at the time when the study was being conducted. Currently they are not involved)</i>	Kanchikacherla	Vijayawada	Andhra Pradesh
6	Rural Environment and Education Development Society (REEDS)	Kanchikacherla	Vijayawada	Andhra Pradesh
7	Peoples Action for Creative Education (PEACE)	Bhongir	Nalgonda	Andhra Pradesh
8	Hyderabad Leprosy Control and Health Society (HLCHS)	Hyderabad	Hyderabad	Andhra Pradesh

**Table 2: Qualitative coverage  
(all age groups of children)**

Tools	Target groups	Total sample size per state
FGD	<ul style="list-style-type: none"> <li>• Adolescents (15-18 years)</li> <li>• Mothers</li> <li>• Fathers</li> <li>• Teachers</li> </ul>	6 FGD 6 FGD 6 FGD 3 FGD Total = 21 FGD
KII	<ul style="list-style-type: none"> <li>• ICTC</li> </ul>	3 KII Total = 3 KII
IDI	<ul style="list-style-type: none"> <li>• ICTC staff</li> <li>• Health facility in-charge</li> <li>• PRI</li> </ul>	3 IDI 3 IDI 6 IDI
	<ul style="list-style-type: none"> <li>• Religious leaders</li> <li>• CLHIV</li> </ul>	6 IDI 3 IDI Total = 21 IDI
Case studies	<ul style="list-style-type: none"> <li>• CLHIV</li> <li>• Parents of CLHIV</li> </ul>	9 case studies 9 case studies Total = 18 case studies

- Adolescent girls (15-18 years) visiting ICTC for testing.

The general population interviewed through the survey method included:

- Parents with children in 0-6 age group
- Parents with children in 7-14 age group
- Adolescent boys (15-18 years)
- Adolescent girls (15-18 years).

A total of 10 respondents were interviewed from each of the 12 categories above. In all, 80 parents of children belonging to age groups of 0-6 and 7-14 years, and 40 adolescents (including 20 boys and 20 girls) were interviewed in each district/project. Thus, a total of 120 interviews per district/360 interviews per state were undertaken for the study using quantitative research tools.

### Ethical Guidelines Adopted for the Study

Ethical guidelines, especially in line with those recommended by NACO, were followed throughout the study. Principles of

voluntarily opting for testing, informed consent and community agreement, privacy and confidentiality, professional competence, and accountability and transparency, were adhered to. All possible efforts were made to maintain the confidentiality of study respondents. For instance, HIV positive parents as well as their children were interviewed at a central location that was convenient for them as far as protecting their identity was concerned. Investigators were specifically trained to safeguard the confidentiality of research data, and names of all the respondents have been changed in the report to maintain their anonymity. Informed consent was obtained from every adult participant in the research. In case of children, their guardians were approached for consent. Community representatives were informed prior to the survey at each location.

### Study Limitations

- Mobilising the individual respondents for interviews was quite difficult, especially in the difficult tracts of Chandel in Manipur.
- The sample size of adolescent boys and girls required for the study could not be met completely as the probability of finding youth in 15-18 age group was quite low.

Investigators were specifically trained to safeguard the confidentiality of research data, and names of all the respondents have been changed in the report to maintain their anonymity. Informed consent was obtained from every adult participant in the research.

**Table 3: Quantitative coverage (all age groups of children)**

Quantitative coverage through structured questionnaires	• Parents of CLHIV	223 out of 240 in AP 230 out of 240 in Manipur
	• Parents of children from general population groups	120 out of 120 in AP 88 out of 120 in Manipur

Most of the HIV positive parents were either not old enough to have adolescent children or they had contracted HIV several years after the birth of the child who is currently in 5-18 years age group.

- The sensitive nature of the enquiry also limited the mobilisation of young

respondents who did not wish to interact with the investigators who were strangers for them.

- School or college timings and examination schedules prevented several youth from attending the interview sessions despite the best attempts.

# Findings

## Challenges and Factors Preventing HIV Testing for Children and Adolescents

(refer to Figure 1)

### Fear of stigma and discrimination

The lurking fear of stigma and discrimination in the minds of positive parents, often associated with HIV and AIDS, stands out as the most common barrier when it comes to HIV testing of children in 0-6 and 7-14 age groups. At least half of the parents of these children mentioned this as an inhibitor for testing as well as treatment. The probability of the child being detected positive creates in them the psychological fear of facing discrimination in society.

The above-mentioned fear was found to be a factor inhibiting many adolescents too in 15-18 age group. Many cases of neighbourhood discrimination were reported in terms of

restrictions imposed upon children, including mingling with children from affected families, and ill-treatment of the affected at public places.

A little less than half of the parents of children in 7-14 age group expressed fear of discrimination by sections of the community even when children had tested negative. The fear of positive parents usually aggravated in case of girl children (even though they were negative) as unforeseen challenges would have to be met with at the time of their marriage. This has been found mostly true for parents who have girls aged between 12 and 18 years.

Notwithstanding the above, there have been aberrations and though only a few, these have shown the way in mitigating barriers and challenges. The study has brought forth that in very few instances (only 2-3 cases in 0-6 age group, 5-6 cases in 7-14 age group, and 2-3 cases in 15-18 age group), especially in Manipur, communities have supported the HIV affected families by accompanying them to the doctor for health check-up and ART, and sometimes by providing financial assistance for travel to ICTC or ART centre. Community support has been reported from only one group of fathers in Andhra Pradesh. Not surprisingly though, community support has been reported more in cases of children in 7-14 age group as compared to adolescents in 15-18 age group.

### Financial constraints

Wage loss, travel to testing centre, time and opportunity cost incurred by parents/caregivers for undertaking testing of children in 0-6 and 7-14 age groups were cited as

## Case Study

**RINA** is a 6-year old girl and has one sister aged 8 years, who is not HIV positive. Her mother had no idea about HIV before she and Rina were diagnosed positive. Even now, she has incomplete knowledge about HIV and whatever little information she has, she got from the ICTC staff and outreach workers. Rina is not aware of her HIV status as her mother feels she is too young to understand.

Rina's mother works in a stone quarry and earns around Rs. 3000 per month. They do not take any treatment because her mother loses one day of work for visiting the centre and has to spend around Rs. 200 for ARV medicines.

common factors by more than half the parents. The same was reported by half of the adolescents in 15-18 age group.<sup>2</sup> Quite understandably, such considerations get further escalated for people living largely in physically and economically challenging environments. The costs are likely to increase even more in cases where people go to testing centres in other districts due to fear of being stigmatised in their own locality. For them, it involves spending around two to three days including travel and sometimes, staying at the place where the ICTC is located. Travel costs involved in going for a test usually range from Rs. 50 to Rs. 150. Opportunity cost, on an average is Rs. 50 which is mostly wage loss for a day's work.

Most of the adolescents (15-18 age group) said that they usually travel a long way to go to a clinic. It usually takes away a whole day to reach there and come back, especially if they are from distant villages. Those who are studying have to take leave from school. Two of the working adolescents from Andhra Pradesh, who have HIV positive parents, said that they take leave from work to go to the hospital,

**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.

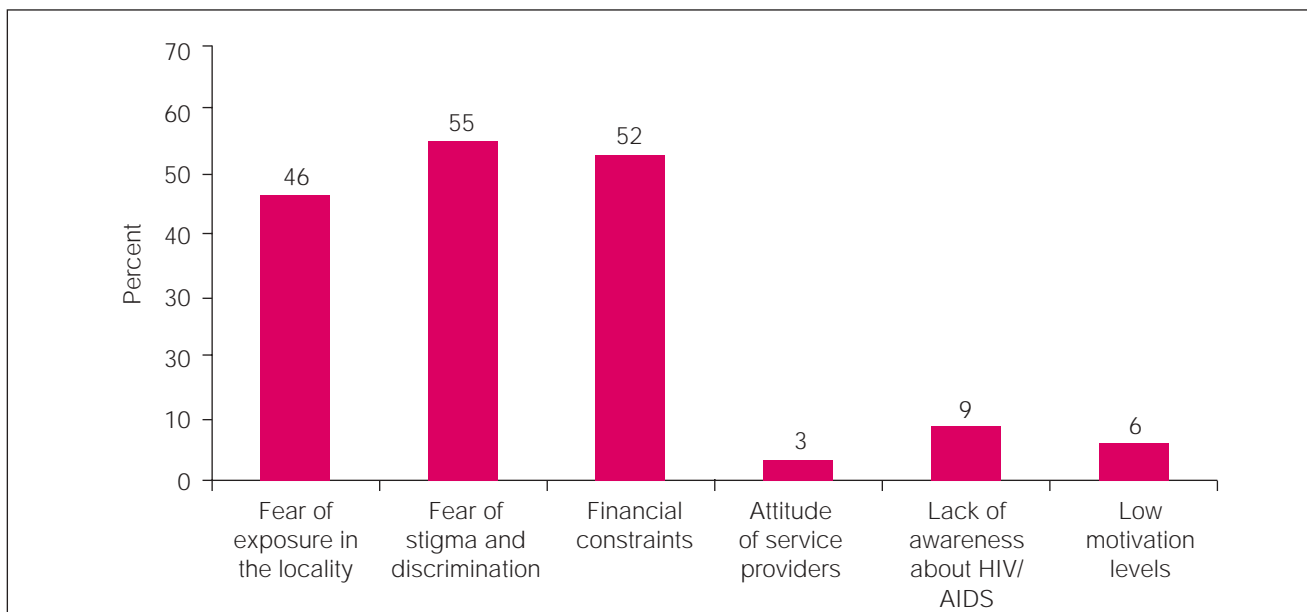
Ana's mother has to cover a long distance (from Chandel to Imphal, Manipur) to get medicines for her daughter and spends Rs. 200 each month for the same. Sometimes she has to spend the night at Imphal. For herself, she gets ART from Chandel Hospital.

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.

thereby losing their wage for the day. Also, some prefer to go to private clinics because of their accessibility. However, most of the youth had to make a one time visit to testing centres as they were found negative.

Figure 1: Challenges and factors preventing HIV testing among children and adolescents (n=173)



<sup>2</sup>It was informed by the respondents that the test results usually arrive the same day of the test. If one tests positive, s/he is asked to go for a re-test to confirm the result. If the re-test is also confirmed, the person is asked to take counselling.

**SHAHID** is a 6-year old boy from Andhra Pradesh (AP) 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 in Hyderabad. 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.

The adolescents said that their positive parents suffer from frequent illnesses; therefore, they have to earn a livelihood and take care of them. They generally take their parents to the hospital for regular check-ups. When these adolescents fall sick themselves, they tend to postpone their own visit to the hospital till a later stage, due to financial difficulties.

A key finding stated by a majority of parents of children in both 0-6 and 7-14 age groups was that they opted to go to the government hospitals for testing their children as they are less expensive. Additionally, they cited guidance and support from NGOs and their ORWs who gave them information about the facilities available at government hospitals. They also prompted and motivated them to take their children for testing. NGOs were reported for being rigorous on follow-ups. In few cases, doctors have advised parents to go for their children's testing (20 out of 60 cases in 0-6 age group). Some youth in Andhra Pradesh expressed reservations on the quality of testing at government centres and said that they had little means to afford private services. However, more than half of the respondents in Manipur preferred private clinics.

This preference can be understood with the target population there having easier access to private clinics, higher incidence and urgency, and relatively better economic conditions.

Most doctors and counsellors, while appreciating ICTC's contributions at large, were of the view that the travel costs to visit these centres is a challenge for people—a view expressed by most service providers in both the states (6 doctors and an equal number of ICTC staff, along with ORWs working with NGOs).

### **Fear of disclosure in the locality**

According to many parents of children in 7-14 age group, as well as of adolescents in 15-18 age group, a visit made to a private clinic, for instance Sexually Transmitted Infection (STI) clinics, can be easily noticed as they stay in small localities where most of the people are known to each other. The issue 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. Such fear also develops due to the issue of sensitivity to children's needs at the ICTC.

Most of them in all the three age groups feel that visiting a general government hospital is more convenient from a confidentiality point of view as one can go there for any illness like fever or any other common ailment.

Some NGO staff said that due to the fear of exposure, many people preferred going to ICTC and ART centre located in other districts. Staff and counsellors at some ICTCs (6 staff and 5 counsellors across both the states) said that some parents fear bringing their children to the ICTC as they are afraid that their status may be disclosed unknowingly by their children to others.

### **Lack of awareness about HIV and AIDS**

Lack of awareness about HIV and AIDS on the part of parents makes it difficult for them



to explain to their children in 7-14 age group, whose reasoning capacity by this age is quite developed. This has been expressed by almost all the parents of children in this age group. Not surprisingly, almost all children in this age group were not told the reason for taking them for test, but merely told to accompany their parents to the testing centre on the pretext of a routine check-up. However, few sharp children were able to relate to the posters on display and the body language of the staff at the testing centres. Two children in 7-14 age group actually reported that they could make out the seriousness of the situation from the ICTC atmosphere and staff behaviour. Such difficulties, however, do not usually arise for parents of children in 0-6 age group.

Some children, considerably aware about HIV and its symptoms, agreed to undergo the tests at the ICTC without much ado, when referred by doctors or NGO workers. Consequently, in both the study states, testing of adolescent boys and girls does not appear to be as much of a problem as compared to dealing with younger children. Their usual sources of information are not peer groups but meetings with NGOs and discussions with teachers. Some adolescents from the intervention sites of Bishnupur (Manipur) reported regular interaction with the NGO and high awareness about HIV.

However, a small group of adolescents from Hyderabad reported lack of awareness on HIV, e.g. its mode of transmission, though they knew it was infectious and widespread. It was observed that some healthcare service providers including ICTC staff had little knowledge on the subject and were treating it as a common ailment. There have also been cases of not following the ART regimen and discontinuing after initial recovery of health.

### **Low motivation level**

Lack of self-efficacy and low motivation has been found to be another inhibitor for getting children tested. One of the reasons

**AMAR**, 15, and his brother, 11, stay with their aunt who runs a soda shop. At 10 years, Amar lost his parents to AIDS. His father died without knowing about his HIV status. After his death, the mother was bed-ridden and sent to a government hospital where also tested positive; and died after some days.

Amar had suffered from herpes, chicken pox, continuous fever and weight loss, because of which his aunt took him to the government hospital where he tested positive. He feels it is his parents' fault that is causing him the trouble for no fault of his. His brother is also positive.

Amar's teachers and friends are not aware of his status. When he discussed about HIV with his friends, they didn't take it too well and asked, "Why are you talking about HIV?" Once he asked them, "If I have HIV, what will you do?" They said, "We will not talk and sit with you in the class." He is scared that his constantly falling sick may raise suspicion among the teachers and they may start discriminating against him.

He has complete information about HIV as he is in regular contact with a hospital, Chest Plus, where his relatives take him whenever he falls sick. He has also attended many awareness camps. He also got information from posters, pamphlets and videos at the ART centre.

is—parent(s) are unable to overcome the shock/grief of their own positive status that leads to low motivation level to get their children tested. Also, the fear that their children might also test positive prevents them further. However, while the fear that their children may test positive is a major factor, callousness in approach that their children will not be positive is another. For parents as well as adolescents, financial expenses involved in testing and treatment followed by a positive test also de-motivate them. Disillusionment on the part of few (found only in 4 to 5 cases) parents that if one is found positive, ART will just extend life but is not a cure for HIV, makes them feel that it is not worth going for testing in the first place.

**POOJA**, a 6-year old girl from AP, is negative; her mother is HIV positive and used to work as a daily wage labourer but regular sickness made her quit. Her husband works as a daily-wage labourer... Pooja's mother came to know about HIV/AIDS from TV and radio. However, she did not have a clear understanding of the disease. After visiting the ICTC, though she knew that HIV is life threatening and can get transmitted to others, she quit taking ARV medicines as the couple feels the government hospital is too far for them. Owing to this, her CD4 count has come down to 80.

### Attitudinal issues of service providers

Unfriendly hospital environment and procedures has been reported as the inhibiting factor for utilising services by close to half of the adolescents (15-18 age group) interviewed. Some youth have reported dissatisfaction with the way ICTC staff deal with them. One adolescent from Manipur shared his personal experience where he was so displeased with the ICTC staff, that he detested visiting the centre for fear of interacting with them again. Some adolescents, especially females, said that they prefer the ORWs of NGOs more than the ICTC counsellors for information related to sex and sexuality.

For few children and adolescents in both the 7-14 and 15-18 age groups, the affected family members have experienced instances of discrimination by healthcare service providers. Few of them were actually not physically examined but instead, referred to other service providers. Adolescents in 15-18 age group (but very little in number) reported discrimination by paramedical staff after disclosure of HIV status. As reported by adolescents (15-18 age group), such discrimination may also be due to lack of awareness of HIV/AIDS and its preventive measures among the service providers.

From the service providers' point of view, it was reported by most counsellors that they are over burdened with work every day and are unable to dedicate enough time to each patient. Some counsellors reported that few people hesitated

in opening up if the counsellor is from the opposite sex.

However, most parents of children in 0-6 age group, expressed satisfaction with the ICTC services, and found the staff friendly and understanding, and the children did not face any problem with the testing. This may be attributed to the age group of these children (0-6 years) which is a period of innocence. At this stage, it is difficult to infer whether the children have been discriminated *per se*.

## Issues and Challenges Related to Disclosure of HIV Status to Children and Adolescents

### Dilemmas

- The biggest challenge for children in 0-6 age group is that they are too young to understand the meaning and significance of their HIV status. Therefore, a majority of the parents of children in this age group in the study felt unanimously that the question of disclosure, either of the parents' status to the child or of the child's own status, must be withheld until children become relatively more mature.
- Almost all parents of children (0-6 age group) felt deeply concerned about their children's future, and guilt for not being able to provide a normal childhood environment to them.
- These parents undergo severe mental turmoil and feeling of guilt as a consequence of not being able to disclose their HIV status to their children (0-6 age group). Such feeling also develops as a result of suppressing the knowledge of their children's status.
- Most of the parents of children in 7-14 and 15-18 age groups did not know how to come to terms with the

feeling of guilt while disclosing the status to their children. They were not sure how to explain to their children how they contracted HIV, and felt largely responsible for all the pain they might cause to their children. They wished to avoid dealing with the situation directly.

- Almost all the parents in the above-mentioned two age groups agreed that the biggest dilemma is to decide, in the first place, whether to disclose to children or not. On one hand, they fear that disclosing the information might cause a great deal of pain and stress to the children. This is corroborated by the fact that the children who did not know their parents' HIV status, or the children who came to know about it at a later stage, said that they only remember going for a blood test without knowing why they were getting tested. Similarly, many adolescents in Andhra Pradesh were never told about HIV when they were taken for testing, and thought that it was a routine medical examination. Neither the parents nor the ICTC staff told them what HIV was all about. A point to be noted here is that most of the respondents in 15-18 age group were in 7-14 age group when they were tested.

On the other hand, parents also felt that the family would be able to handle the problem better if the children knew about the situation. Some parents of children in 7-14 age group said that they wanted to share their lives' ups and downs with their children, and felt that the children had the right to know their parents' life situation so that they were prepared for any adverse situation that they might have to face due to HIV.

- Deciding on the child's right age for disclosure was yet another challenge for parents of children in all the three age groups. While almost all the parents agreed that children who have not

**BABY**, 11, stays with her grandmother as she lost both her parents to HIV. She and her elder brother, 13, are not positive. Both attend a nearby local private school. The grandmother runs a tea shop. She has not disclosed the cause of death of Baby's parents in the neighbourhood as she fears the children may be stigmatised and even removed from the school.

The children feel that the counsellors at ICTC are friendly and explained to them what is HIV, why testing is done and what happened to their parents. Baby feels that her parents made a mistake. The children also know that HIV positive people are stigmatised in society. Now they are more aware, having heard about it from doctors, counsellors, posters, radio, and pamphlets from the ASHA programme. Baby would like to spread awareness on HIV/AIDS amongst people. The children are worried about their life after their grandmother, also because there is a huge loan to be re-paid which she had taken to educate the children and run the tea stall.

reached high school, i.e. 14 year olds, should not be told about the status; also; most of the parents and other respondents that included service providers and teachers, did not have a clear idea about the right age to disclose the information. Many parents found themselves groping for the right time to talk to their children in the early teenage years, and in many cases, they could not resolve that dilemma. However, no parent agreed to disclose until their children reached a minimum age of 10 years as they felt that at a younger age than this, they would not be able to understand HIV and cope with its effects on life. Thus, almost all the adolescents in 15-18 age group knew about their families' HIV status.

- For most of the parents of children in 7-14 and 15-18 age groups, disclosing HIV status to children might incur unnecessary exposure, evacuation, discrimination and even ostracism. Due to such fears, most parents disclosed incomplete information to their children, giving them a strict direction to keep the

**RAJU**, 14, lives with his brother, 13, and mother Kumari, who is an ORW. Her husband died of AIDS around one and a half years ago. She is the only earning member and supports her family. Kumari's husband did not inform her about his HIV status. Somehow, her parents came to know and got her tested; she was diagnosed positive. It is almost 10 years now since she tested positive and her children do not know how their father died nor about their mother's HIV status because Kumari feels they are not mature enough to understand.

information to themselves. In fact, parents felt that the level of discrimination faced by them from their neighborhood is quite low. Consequently, they have not made their status open outside their own family. Some parents do feel that they made the right decision in not informing their children as they feel that they may not understand the issue because of their age.

- Almost half of the parents of children in 7-14 and 15-18 age groups, who had already disclosed their status to their children, reported their inability to deal with issues that came up during and after the process of disclosing. Some of the reported experiences were – emotional weakness on the part of parents and being devoid of courage to inform their children; parents believing that with time, the crisis will be handled eventually; and that their children would understand the situation as they grow up.
- Almost all the parents of children in 7-14 age group said that their children were not counselled at the testing centre, both at the time of testing and after testing. Further, neither did the ICTC staff nor those from the private clinics, provide them information on disclosure or counselled them on issues related to it.
- Many parents of children in 7-14 age group went through severe mental turmoil when

they conveyed the information to their children. Parents experienced additional discomfort when they had to talk to them about how HIV was contracted by them especially through the sexual route.

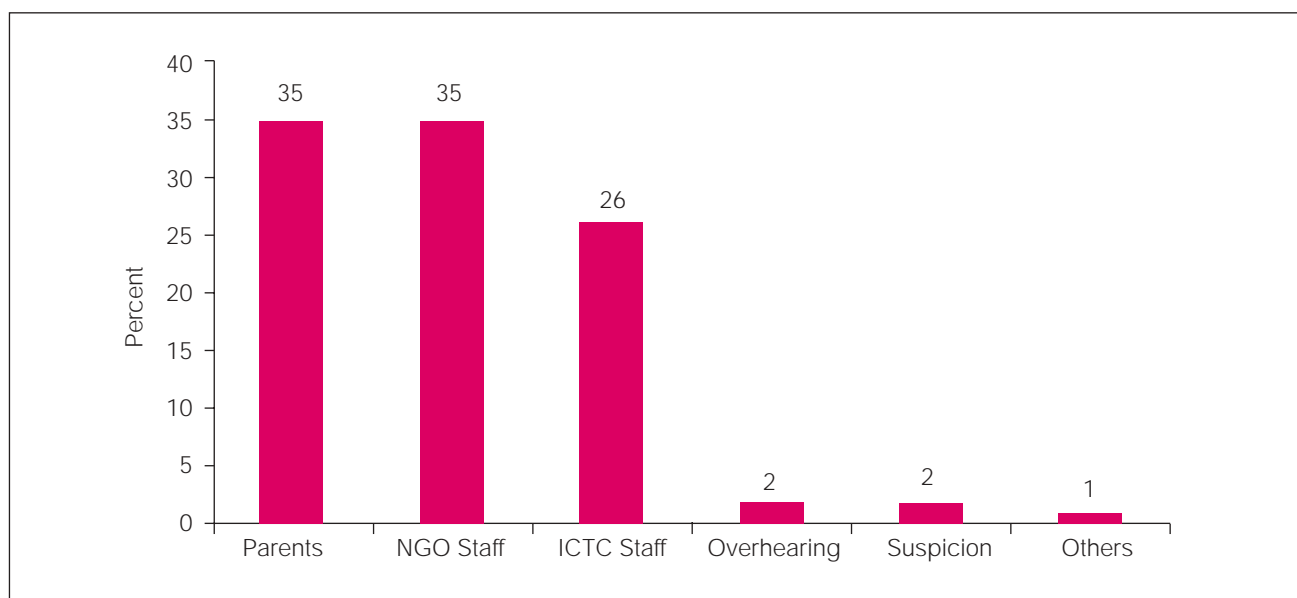
### Channels of disclosure

Although parents of children in 0-6 age group more or less rejected the idea of disclosing their HIV status to their children, yet they felt that the issue of disclosure would arise some time or the other, when they grow up. The study revealed that most children in 7-14 age group were told about their HIV status by their parents, whereas most in 15-18 age group found out themselves. As far as children in 7-14 age group are concerned, the initial information regarding their family's HIV status is usually given to them by their parents, or the health service providers who diagnosed the test results, and in some cases, by other immediate family members. Disclosure about the same to adolescents in 15-18 age group is mostly made by doctors who examined their parents, or by other immediate family members. However, it has been observed, across both the age groups aforementioned, that few children and adolescents already had an inkling as they had some knowledge and understanding of HIV. These children and adolescents also did not pose much problem while they were asked to go for their HIV test, as found in the study.

The following channels of disclosure (*refer to Figure 2*) may either be in current practice or those preferred by their parents, added with some expectations with regard to disclosure for children in 7-14 and 15-18 age groups:

- **Parents:** Those parents who disclosed the status to their children were of the strong opinion that they did the right thing in disclosing the facts themselves. None of them felt that they were unsuccessful, and felt quite relieved after the disclosure. In their view, the children's reaction was very positive and they accepted the situation quite easily. As parents are best placed

Figure 2: Channels of disclosure to children and adolescents (n=173)



than others to assess the opportune time, psychological status, and temperament of their children, therefore, they felt that parents are the best channel for disclosure to children.

It was also felt that disclosure by parents of their own HIV status would set them up as role models, and that this would bring them some confidence and self-respect. This will help parents also in taking constructive steps to address various challenges and issues related to their positive status. However, they expressed hesitation in disclosing to children the mode of transmission especially when it was sexual and preferred delaying it until the children acquired some maturity.

In a rare case, a parent of adolescent children, aged 15 and 17 years, said that he would not disclose the information to them at all because, according to him, his children do not need to know about it as it does not directly affect their life, and that, the children are better off leading their life without knowing.

- **NGO staff:** A majority of the parents spoke positively about the role of the NGO staff, especially from the CHAHA project, in

aiding disclosure of status to children. NGO staff are seen as trustworthy and the communities look forward to their support. They are seen, by most parents themselves, as the next best channel of disclosure after parents. Also, given the fact that the NGO staff sensitise the community about HIV, it becomes easier for parents to address any concern

**ASLAM**, 13, from AP, has two sisters, and his father, Ali, works as a labourer and earns Rs. 200 daily. His wife, Begum, does embroidery work and is the chief wage earner in the house. Ali is HIV positive. He came to know about his status when he got a job in the Gulf and he had his blood test done for the passport clearance. Later, his wife tested positive and children negative.

Ali does not go to the government hospital; instead, he buys his medicines from a druggist and it costs around Rs. 25-30 for eight days. The travelling costs are high.

Their elder daughter knows about her father's HIV status but never asks him. The parents feel that disclosure to children is not good as children get emotionally disturbed and may not actually understand their parents. They also fear that, their daughters will not get good alliance for marriage. They are afraid of losing their rented house and even the job because of stigma.

# Case Study

**Jaurina**, 6-months old, belongs to Tabokpi Chakpikarong, Chandel, Manipur, and is HIV positive. There are five members in her family—her parents and two siblings aged 2 and 4 years. Her parents are HIV positive, but her siblings are not. Her father H. Larhing is a plumber (ex-serviceman suspended from Assam Rifles). He came to know about his positive status in 2003 and his wife's status was confirmed in 2006. Since he got tested positive, he has not discontinued ART. His family visits ICTC periodically, as advised, for getting treatment and counselling. But they face problems in seeking treatment like time consumed, cost of travel and cost of medicines. They have to go to Chandel District Hospital or RIMS, Imphal for testing and stay there for a day. The cost of travel per person to ICTC/ART centre is around Rs. 150. He has lost his job so they face lot of difficulties. They have not disclosed their positive status to their children as they feel they are too young to understand.

the children have when the status is disclosed. According to most parents, NGO workers are believed to be better equipped at dealing with these situations. They have made efforts in educating and sensitising the neighbours and communities about HIV in order to address the associated stigma and discrimination. This way, they have helped parents alleviate their fear and inhibitions to make disclosure an easier process.

The discussion with adolescents in 15-18 age group revealed that parents who disclosed their HIV status to children were mainly those who had come in contact with NGOs. It has been reported in the study that CHAHA staff played a crucial role in disclosing the status to children. They developed a rapport with the children and their families, involved the children in various activities such as support groups, and then gradually disclosed the status to them. Some staff from Annamma School for Hearing and Physically Handicapped (SSR, VMM, Vijayawada, AP) and PEACE (SSR, Lepira Society, Nalgonda, AP) mentioned using means such as street theatre, rallies

and other events to create awareness about HIV. Once the basic understanding is developed, it becomes easier to talk to children about their parents' and/or their own HIV status.

Most adolescent groups (15-18 age group) felt that the ORWs of CHAHA supported them greatly with all the resources at their disposal. Some said that their awareness level is quite high because of their frequent interaction with the NGO staff. As compared to their parents, they were more articulate on HIV. One-to-one counselling and some assistance to the youth in terms of finding them a job or a vocation, have been reported as important steps taken by NGOs to aid them in facing reality and coming to terms with it.

- **ICTC staff:** While the pre-test counselling seems perfunctory, the lack of focus on post-test counselling, especially about the disclosure of status, makes a significant difference in the way children come to know about their own and/or their parents' HIV status. A little less than half of the parents expressed that if the ICTC staff had adequately counselled them about disclosing the information to their children, it would have helped them deal with the issue better. Most of the adolescents (15-18 age group) also said that they were never given any information about HIV by the ICTC staff.

Facility interaction revealed that they were not given any training on this particular aspect. It would have helped them in counselling parents who were in need of some support and guidance with regard to disclosure to their children. Some ICTC staff in Andhra Pradesh specifically said that a great deal of psychological disturbance could be addressed if they were advised at the right time and in a right way to disclose to children, and the appropriate ways to deal with issues that arise out of disclosure.

- **Overhearing:** Few parents of children in 7-14 and 15-18 age groups, who had neither disclosed to their children themselves, nor had used NGO support in disclosing, said that the children themselves came to know by overhearing the parents' conversations with friends and/or family members at home. However, this view is merely based on the parents' belief as there is no conversation/discussion that could be cited to have taken place between the parents and the children.
- **Suspicion:** In a few cases, it was mentioned that children came to know the status of their parents by observing some activities around the time when their parents fell sick that created suspicion in them. They referred to incidents such as, frequent visits of parents to the clinic, bouts of fever and illness affecting them, and the books/literature the parents carried with them while visiting treatment centres. Interestingly, the mother of a 15 year old girl quoted, during a FGD conducted in Hyderabad, an instance about how her daughter found out her parents' status. She copied the prescription on another piece of paper and went to a pharmacist shop and learnt about it.

Another common cause of suspicion in children was the visits made by their parent(s) to the NGO. Accompanying them to the NGO further led to disclosure of the HIV status of parent(s). A large proportion of adolescents from Manipur suspect either their drug using habits or unprotected sex as the cause of their positive status.

### Immediate psychosocial effect of disclosure on children and adolescents

There was a wide gamut of reactions reflecting the inner thoughts of children who had to go through the process of learning that their parents, immediate family members, or they themselves were HIV positive. Following are some of the reactions of children and

**RINI**, 13, and her mother tested positive in 2005. She was very young then, so her mother explained that her sickness was due to diarrhea and cough. Eventually, her mother told Rini clearly about the HIV status and she wept a lot, even complained why her father did it.

Rini's three sisters have not been tested because the mother thinks that there are no serious symptoms evident in them.

Rini and her mother go for monthly check-up to RIMS Hospital and every six months for CD4 count. Her mother has faced many problems for her treatment because of limited facilities available at the District Hospital. She spends Rs. 200-300 per trip to hospital for her treatment.

adolescents in 7-14 and 15-18 age groups (refer to Figure 3):

- **Pain:** Children felt pain when they came to know about the status of their parents, primarily because of the illness that comes along with a person who is HIV positive. This finding is contrary to what most parents felt as a barrier to disclosing to their children because of the fear of expressing the mode of transmission of HIV especially the sexual route. The feeling of pain is found to be true for almost all adolescents in 15-18 age group. In fact, it has been found that most adolescents in this age group feel that they should take up some economic activity to support their families, as they are aware of their parents' limitation to earn enough due to their health condition. However, they felt that their job prospects and opportunities may be hindered if their or their families' HIV status is exposed.

Children were aware of the stigma and discrimination that a positive person has to face, which leads to a secretive life and supposed seclusion. However, it

**BABU**, aged 4, and his sister, aged 7, live in Santhosh Nagar in AP. His mother Yellamma tested HIV positive during her pregnancy in 2004. She works as a cook, while her husband works as a granite worker earning around Rs.1500 per month. Both Yellamma and her husband have little knowledge about HIV. They feel the children should be told about it so that they can take care of their mother and help her in household work.

was found overall that as compared to children in 7-14 age group, adolescent boys and girls in 15-18 age group came to terms more easily and quickly, and some immediate tensions followed. A majority of them reported that they are fully prepared for any eventuality. However, it took them close to one year on an average before they came to terms with it. It is important to mention here that adolescents from Manipur were at an additional risk given the context of injecting drug use.

- **Fear:** As mentioned elsewhere in the report, disclosure by parents was generally accompanied with a strong warning of keeping the information strictly confidential. Consequently, such restriction instills great fear in children with regard to HIV. Fear of hostility to the family and isolation from society, if others come to know about the family's HIV status, is imposed on them in

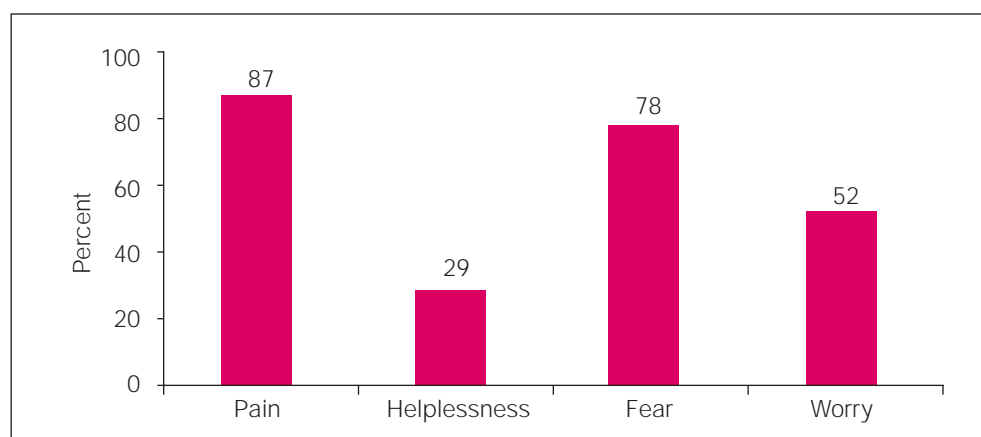
the process of disclosure. Fear of losing a rented house has been reported amongst half of the adolescents (15-18 age group) in Andhra Pradesh.

- **Worry:** All the respondents were greatly worried about the future of children living with HIV and for those whose parents were HIV positive. Given the fact that most of the respondents were from economically weak background, financial insecurity, sustenance of children after parent(s) pass away, and the possibility of an insecure life when the parents' income is drastically reduced due to HIV, were some primary concerns of respondents that included people living with HIV, those affected as well as those involved in a caregiver's/supportive role.

Some adolescents were extremely worried that they would lose the rented house in which they reside with their family, as the house owners had started enquiring about their parents' health condition especially when they found them falling sick regularly.

There was a distinct worry amongst adolescents, especially girls from 14 years of age onwards, about the probability of them getting married being reduced if their parents' status is known to others. As expressed by many young respondents

Figure 3: Immediate psychosocial effects of disclosure on children and adolescents (n=173)





from Andhra Pradesh, though their HIV negative status was a relief for them, they were worried that they will be denied any marital alliance within their own ethnic community because of their parents' positive status.

- **Helplessness:** Parents' health condition and the extreme thought of their death put them in a helpless situation. Factors such as poverty, missing out on the daily wages especially for many in 15-18 age group, and the pressure to discontinue their education in order to earn a livelihood adds to their helplessness, which they think others do not experience. Such feeling is, however, only partially true in the case of children in 7-14 age group, especially if the child is 13 or 14 years old.

Two adolescents in one of the adolescent groups (15-18 age group) in Andhra Pradesh said that they had to drop out from school and take up full time work to make a living for their HIV affected households. While many young persons, especially from Manipur, reported bouts of depression and anger as an initial reaction, the concern that they have to bear the financial burden of the family was more serious for them.

Some adolescent boys and girls (15-18 age group) also reported their initial feelings of shock, disillusionment, disheartenment and being visionless when they heard that they were affected by HIV. A small proportion of adolescents from Manipur reported their tendency of drifting towards delinquency or committing suicide at some point of time.

# Conclusion and Recommendations

The key findings from the study have 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.

The study's findings for the three age groups of children, 0-6, 7-14 and 15-18 years, have not been very different, unlike assumed at the beginning of the study. Several factors that play a crucial role in testing of children in the three age groups studied, and disclosure of their or their parental HIV status are common across all age groups. These factors are mostly related to the service delivery aspects. However, it is also observed that there are some factors that are unique to each age group, and need special focus while looking for solutions.

## 0-6 age group

- While testing and disclosure are not critical issues with children in this age

group as they are too young at this stage of life to comprehend any such thing, parental guilt appears to be more critical. Parents go through a complex set of emotions and feel even more guilty due to the fact that they cannot express themselves to their children. This also probably forces them to escape the situation and thus, mentally deny the imminent problems that their children may be getting into.

- Counselling should play a more significant role in handling the cases of parents of children in this age group to stabilise their state of mind and help them overcome the feeling of guilt. Only after they are able to handle their own psychological situation, are they prepared to disclose to the children at a later stage.

“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.”

- The right age for disclosure, as perceived by almost all parents as well as service providers, is 10 years or above. Although the suggestion seems to be practical, ensuring a sound physical and mental health of the child till such age is necessary to make the disclosure process easier. Therefore, the ORWs should keep track of children from such families, and specialised counsellors should be appointed to observe children in 0-6 age group to identify any behavioural changes that need urgent attention.
- In the case of school-going children, involvement of teachers could work in favour of the affected family as children's interaction with teachers is the maximum after that with parents, and children develop a sense of trust and understanding with teachers on several issues.

### 15-18 age group

### 7-14 age group

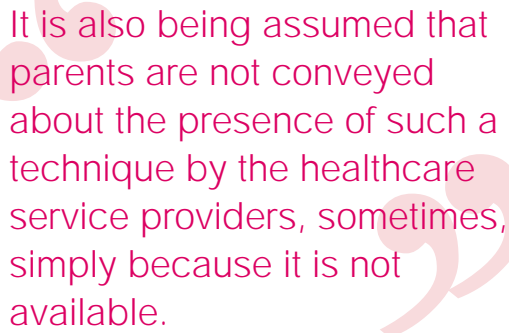
- Children in this age group begin perceiving stigma and isolation shown by their peers and neighbours. Some cases where the child is aware of the family's HIV status through self-investigation (like overhearing or reading prescriptions) are emerging in this age group, leading to an atmosphere of suspicion/secretcy in the family and thus, creating a feeling of guilt on the part of the concerned parents. This sub-group requires the guidance of a counsellor for their unique problems.
- A healthy procedure of disclosure to children, with a joint effort by parents and NGO(s) could ease the situation to a large extent, and thus, lead to the psychological well-being of parents.
- Testing should precede disclosure as the test result could have a bearing on the approach taken for disclosure.
- This age group appears to be unique and demands specific attention with reference to the protocols concerning disclosure of HIV status of these children or their parents.
- These adolescents are more mature in comprehending as well as understanding the situation, and probably think one or more steps ahead regarding the HIV status of their family.
- After an initial short period of panic, their concern is more towards questions of economic sustainability of the family, continuing education, career opportunities or even marriage prospects. It appears that children in this age group are quite prepared for parental loss and for taking up family responsibilities.
- While these children reluctantly accept the need for testing, a proper process for disclosure still needs to be put in place. NGO(s) should play a crucial role here as the bond between the parent and children is not necessarily strong and mature. At this age, children are more inclined towards their peer group as far as sharing of inner thoughts and feelings is concerned. However, since the issue of HIV is too sensitive and confidential to be shared, the need for a counsellor to specifically monitor such interactions emerges very strongly.

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## Recommendations: Testing of Children and Adolescents

### Modifying healthcare service delivery

The number of HIV testing centres should be increased so that the families don't face



It is also being assumed that parents are not conveyed about the presence of such a technique by the healthcare service providers, sometimes, simply because it is not available.

difficulties in accessing them for timely testing of their children. The number of ICTCs in each district can be worked out on the basis of its population and/or size. Additionally, in hilly districts like Chandel in Manipur, infrastructure, equipment and human resource at ICTC and other centres are very limited, and require necessary initiatives to fill such gaps.

Also, it is deemed important for key players, including primary and secondary stakeholders, to advocate for feasible and flexible timings of testing centres for parents and children. Such a step will prevent—firstly, the parents and adolescents (15-18 age group), mostly daily wage earners or sole breadwinners of their families, from being frequently absent from work. Secondly, it will prevent children from being absent from school. Many respondents have strongly favoured the idea of increasing the number of days that the testing centres function to at least five days a week. In addition to this, monitoring the scheduled timings of the ICTC staff in terms of presence and punctuality is necessary. This will taper the parents' and children's problems of prolonged waiting time and consequently returning home, that means—either losing the day's wage unnecessarily and spending additional money to make another visit; or not visiting the centre again for the test.

### **Improving diagnostic services for children below 18 months**

The non-availability of DNA-PCR testing facility in the ART centre for testing of children below 18 months contributes to a high number of losses for infants. This test is expensive (approximately Rs. 3000) and is available only in a few major Indian cities.<sup>3</sup>

However, the study did not come out with any specific finding about this barrier to testing for children in 0-6 years age group. Lack of awareness about this specialised technique, on the part of respondents, including parents and service providers, is being attributed to this. It is also being assumed that parents are not conveyed about the presence of such a technique, sometimes, simply because it is not available. Thus, parents are forced to wait until the child is 18 months old so that he/she could be tested through routine diagnostic procedures.

Alternatively, if it fits well with the government's strategy, they can also consider adopting the DBS method (Dried Blood Sample) for children to enable Early Identification and Diagnosis (EID).

### **Recommendations: Disclosure to Children**

#### **Capacity building and training**

Training at different levels—parents of children and adolescents, healthcare workers, counsellors, outreach workers from NGOs—is suggested. Developing training tools with guidelines for each is suggested, with practical guidance notes on disclosure to children.

Most healthcare workers and counsellors were found lacking in certain specific skill sets, especially pertaining to children's issues. Some of these are appropriate counselling about disclosure, the right way and time to disclose information, and to deal with issues arising out of the process. Such

<sup>3</sup> Protocol for Child Counseling on HIV Testing, Disclosure and Support; Family Health International, P 74

direct inferences from statements by many parents were echoed by the ICTC staff who also expressed the need for training on this particular issue, as it would help them counsel parents better. Family being at the centre of disclosure, counsellors' efforts should aim at working around it. Focused training of healthcare workers and counsellors is an important recommendation, particularly with regard to helping parents handle the process. Perhaps, for counsellors, training in child-centred counselling as a specialised counselling technique is also required.

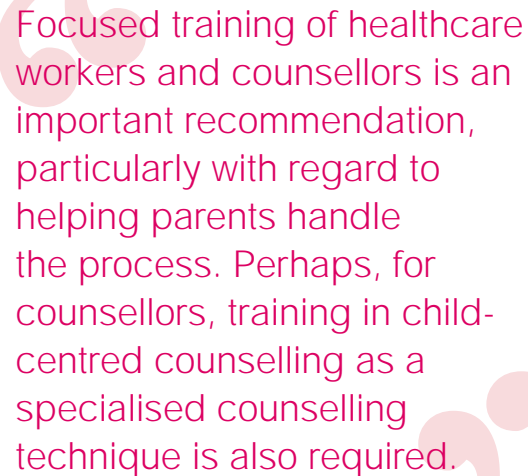
The knowledge of counsellors should also be strengthened on issues related to sex and sexuality and sexual and reproductive health, as far as adolescent children are concerned. Adolescents, especially girls, are unable to open up with counsellors from the opposite gender, and are more comfortable talking to ORWs, rather than counsellors.

It is recommended that there is a focus on various aspects of disclosure while designing trainings for counsellors, healthcare providers and ORWs in care and support interventions for children.

## **Recommendations: Testing and Disclosure of Children and Adolescents**

### **Addressing stigma and discrimination in neighbourhood, communities and healthcare settings**

Stigma and discrimination associated with the HIV status of a person, prevented many parents from either taking their children for tests, or from disclosing to them about their own or the children's HIV status. They feared exposure in their locality while they visited testing centres, and feared revelation of the family's status to friends and neighbours through children after it was disclosed to them. Therefore, scaling up efforts to address stigma and discrimination at the locality and community level is important. Some respondents also reported facing



Focused training of healthcare workers and counsellors is an important recommendation, particularly with regard to helping parents handle the process. Perhaps, for counsellors, training in child-centred counselling as a specialised counselling technique is also required.

discrimination from the healthcare providers. Instances such as avoiding physical examination of children and referring them to other service providers have been reported. Such instances indicate lack of knowledge on their part, and call for awareness generation, training and sensitisation.

At the community level, awareness and sensitisation should be brought about by involving children and families actively in care and support interventions and framing of policies. Wider support should be built within the community through enhanced role of community gatekeepers, village leaders, school teachers, and religious and spiritual leaders. Theatre campaigns should be used as participatory tool of edutainment with a focus on testing and disclosure, its barriers and ways of addressing them. Support groups should be involved to build awareness amongst children and parents. All the above steps should be directed towards making a conducive environment for encouraging timely testing of children and disclosing HIV status to them.

### **Establishing improved and focused counselling services**

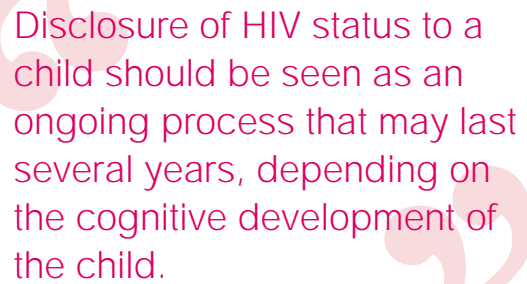
Focused counselling through professionally skilled counsellors is advisable for addressing the barriers to testing and disclosure to

children and adolescents. However, the challenge is also to find professional child psychologists, and trained and experienced counsellors at the grassroots level. Therefore, allocation of budget for counselling services should be commensurate with qualifications and experience so as to attract them to be part of the programmes.

Since counselling children requires specific skills as compared to counselling adults, services of specialised child counsellors, trained particularly in child-centred counselling, should be availed. Refresher training courses for counsellors in tune with the needs of the different age groups, must be organised on a regular basis. The important elements of such counselling should be—assessing the 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 they experience when they discover they/their parents have HIV, and helping them to make choices and decisions that will prolong and improve the quality of their life. Play therapy could be helpful here as contrary to talk therapy, as it helps children express themselves better. Other techniques like, storytelling, drama, dance/movement, drawing, and art could help the counsellor engage a child in conversation. Such techniques will help not only the process of disclosure to children, but also enable a child to express emotions and overcome fears during and after the process of disclosure.

For adolescents, youth friendly HIV testing and counselling services should be scaled up and integrated with adolescent reproductive health programmes. Counsellors who have experience of working in areas of injecting drug use and sex and sexuality should be engaged.

While planning the counselling modules for parents, the following issues should be



Disclosure of HIV status to a child should be seen as an ongoing process that may last several years, depending on the cognitive development of the child.

considered – how to come to terms with guilt, how to deal with the issues that come up during and after the process of disclosure, and how to overcome the fear of children disclosing the information to others. Simultaneously, ICTC staff need to suggest ways to parents about how to disclose, the right way to disclose, and deal with consequent issues, to save them from the ensuing agony. The key players should advocate for strengthened counselling services at ICTC and other testing centres, and focused monitoring of the services. Disclosure of HIV status to a child should be seen as an ongoing process that may last several years, depending on the cognitive development of the child. Healthcare providers need to develop a systematic plan that will enable them to support parents on disclosure.

Scaling up counselling services with regard to post disclosure is recommended. The study findings showed that while disclosing to their children, parents convey the message with great fear and disdain, and focus on keeping the information confidential. It is inferred that parents impose their fears and self-stigma on children. Another inference from some of the study findings is that the concerns on the part of parents are more towards death and the assumed conditions of their children thereafter, but knowledge on prolonging life seemed to be lacking. Resultantly, children acquire a negative attitude towards their or their parents' HIV status. It is suggested that counselling efforts, for both parents and children, should specifically focus on positive attitude, positive

living, and transfer of knowledge regarding timely testing, adherence to medicines, and nutritional requirements.

### **Formation and strengthening of support groups**

In HCBCS interventions for children living with and affected by HIV, support groups play an important role, as participation of communities and local leadership is quite crucial in such programmes.

Children's support groups should be strengthened to help children know about HIV and AIDS, and to allow them discuss more about the barriers to testing and disclosure. As a peer group, they can help each other overcome the fears and effects of disclosure. Support groups should be used as an effective platform to involve children in various play therapies, street plays, and life skills education. Group counselling should be conducted for children facing disclosure through support groups.

There is a need to form adolescent support groups and parents' (adult) support groups as well. These groups can discuss issues of disclosure specific to their categories. In the

parents' support groups, discussions and information transfer can take place about the barriers to disclosure, ways of appropriate disclosure, and time of disclosure. Parents who have already disclosed to their children, can be helped in overcoming and handling the issues thus emanating. Within the support groups, parents can learn from the experiences of others in a similar situation, and gain the much needed psychosocial support to overcome feelings of fear, guilt and mental turmoil, as reported by parents in the study.

### **Strengthening IEC coverage**

Creating awareness through IEC materials, and strengthening their reach in all the intervention areas is required. One ORW from Chandel, Manipur, reported that the coverage of IEC packages is quite low as compared to other districts. The study highlighted the need to facilitate special observation periods at least one week in a month, and all relevant CSOs should be engaged in the same. The IEC materials should be extensively used by ORWs, counsellors and trainers in training sessions, counselling sessions and support groups.

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