Positive Growing . . .

The Way Ahead

Adolescents and HIV
Maharashtra State - level Consultation
29th - 30th October, 2013, Pune
A Report

Forum on Child Protection and HIV
We acknowledge and deeply appreciate the support and inputs of UNICEF Mumbai team, especially, Alpa vora, Specialist, Child Protection, Tushar Rane, Specialist HIV/AIDS and Kamini Kapadia, Consultant, Child Protection, in bringing out this Report.
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Background

There has been a shift in child protection interventions - from sheer survival programming to comprehensive efforts towards ensuring quality of life for children infected and affected by HIV. The latter is assuming increasing importance in the Anti-Retroviral Therapy (ART) regimen, which has enhanced the quality and span of life, with HIV infected children reaching adolescence or even young adulthood. This is the first such generation of Children Living with HIV (CLHIV) or Adolescents Living with HIV (ALHIV). However, they face stigma and discrimination, which impinge on their future in terms of their vocational training and livelihood support. These issues pose an even greater challenge in the case of orphans and children in institutions, particularly, in the area of after-care when they leave the protected space of the institution.

<table>
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<tr>
<th>National AIDS Control Organization (NACO) data</th>
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<td>• One-fifth (18% or 420,000) of the HIV/AIDS population in India is in Maharashtra, considered one of the high prevalence states in the country.</td>
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<td>• Approximately 4.4% of these people are Children Living with HIV (CLHIV).</td>
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<td>• About 3,500 – 4000 children are born with HIV in Maharashtra as per annual estimates.</td>
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<td>• There are an estimated 6300 Adolescents Living with HIV (ALHIV) in Maharashtra.</td>
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The above data indicates the importance of various interventions including prevention, treatment, protection, care, policies and schemes for them. A group of civil society organizations working with CLHIV came together to form the Forum for Child Protection in the context of HIV. Key areas of work were identified, namely, health, education, care and support and advocacy. This initiative was followed by a State-level Consultation on 8th-9th August 2012, which saw the participation of 83 organizations from across Maharashtra. The outcome was acceptance by the state departments to take forward issues on double ration for children in Anganwadis (ICDS centres for basic health care and nutrition), free transport to visit the ART Centre, a Government Resolution (GR) related to non-discrimination of Children Living with HIV (CLHIV) in schools; and waiver of court fees for CLHIV. The Forum’s core group continues its initiative in providing technical inputs for advocacy and support to maintain dialogue between groups and the state departments to ensure follow-up on implementation of the key areas identified.

State-level Consultation on the Issues of Adolescents Living/Affected by HIV

With increasing access to ART, more and more children born with HIV are now surviving into adolescence and adulthood. As this was not expected a decade ago, society is not geared to deal with this unprecedented situation. This is the first generation of children living with HIV transitioning to adolescence and adulthood.

The needs of the adolescents and youth living with HIV vary from that of children as well as adults. The needs include access to HIV-prevention information, education and services, and increased access to treatment for those infected with HIV. They are in a phase where they require age-appropriate education empowering them to live a meaningful sexual life, develop essential skills and protect them from exploitation. In this newly evolving scenario, the experiences and insights of people working with ALHIV are few and far between.
Moreover, even structured interventions for this group are limited in number and reach. ALHIV working with some of these organizations are able to articulate their issues. Active participation of these adolescents through experience sharing and discussions can help set criteria to evaluate adolescent-friendliness of community systems and structures. This can help evolve linkages of HIV infected and affected adolescents with specific government schemes.

As a step forward, the Forum for Child Protection and HIV organized a State-level Consultation, which focused on the issues and needs of adolescents and youth living/affected by HIV. The voices of the adolescents were actively heard. Their names have been changed in the report to protect their right to confidentiality.

The theme of the consultation was *Positive Growing ...The Way Ahead.*
Day 1

Welcome And Inauguration

The programme began with the welcome speech by Dr. Vinay Kulkarni, Trustee, Prayas. He said, “This is the second consultation organized by the Forum on Child Protection and HIV (CP-HIV), consisting of individuals and organizations working on the issues of child protection and HIV. Formed two and a half years ago, the participants of the consultation are a good mix of academicians and practitioners.” He explained the theme of the consultation - Adolescents and HIV.

The consultation was inaugurated by Rajeshwari Chandrasekar, Chief of Office, UNICEF, Maharashtra, Dr. Raman Gangakhedkar, Dy. Director, National AIDS Research Institute (NARI), Dr. Malathi Pillai, Trustee, CCDT; and Purnima*, a representative of adolescents living with HIV. It was an unique inauguration involving the unveiling of an Ashoka sapling. Ashoka means one who has no sorrow! Dignitaries and participants were invited to express their views on the themes of the consultation at the venue’s display area.

Dr. Vinay Kulkarni, Trustee, Prayas, pointed out that the work with adolescents raised many issues as they enter adulthood and feel the need to be independent. He stated that the consultation would explore their concerns of dealing with sexuality in the context of HIV, appropriate time and process of disclosure and after-care on leaving the institutions. In this context, Prayas introduced its own efforts in the area of psycho-social counseling for treatment and dealing with other issues. The outcome of providing a support structure to ALHIV led to the formation of So What! - a group of adolescents who were infected with HIV through vertical transmission and were associated with Prayas since their childhood. After going through counseling sessions and a workshop, the adolescent group members decided to form their own support group to take initiative in addressing their issues. Prayas continues to nurture So What!.

* The names of the adolescents have been changed to protect their right to confidentiality.
Purnima, Representative, So What!, welcomed everyone on behalf of the group and expressed her thoughts. As a representative of the first generation growing with HIV, she could see and experience many issues of adolescence while living with HIV. But the formation of the group lent strength to address these issues and now she knows that there are many more people out there to support these adolescents in their journey. She felt nice to be a participant in the consultation and was confident that the deliberations would help in taking issues forward.

Dr. Malathi Pillai, Trustee, Committed Communities Development Trust (CCDT), spoke of the importance of taking up the issues of adolescents living with HIV as there are no structured interventions. She mentioned the importance of the issues, not only of survival but also of the social protection and safety of girls, enhancement of employability and skills, need to have policies and laws and the need to listen to the adolescents. She also said that young people at the World Summit had emphasized that they should be seen as resources and not as problems.

Rajeshwari Chandrasekar, Chief of Office, UNICEF, Maharashtra, pointed out that “access to antiretroviral therapy and knowledge of HIV” is included in the United Nations Millennium Development Goals. She emphasized the need to address the issues of ALHIV in a sensitive manner. She stated, “Participation of the adolescents living with HIV in this consultation is a very important thing to recognize. They are the ones who will guide and give direction and set the agenda of what needs to be done. We have invested a lot in survival of children and women, but what about adolescents? There is a lacuna in services for this category of people. This may be traced to the absence of a specific department to deal with their issues.” She reiterated, “Now it is high time to invest in adolescents and work with them. Linking experiences with a rights-based approach and participatory decision making will herald a bright future.”

Building Perspective: Adolescents and HIV

The first session began with panelists discussing aspects of HIV and adolescents so as to gain a holistic understanding and clarity on the issue.

Rohan, Adolescent Representative, Prayas, spoke of his childhood experiences. He noted that had he had the opportunity to grow as a child without infection, his childhood would have been different. He stated that now he is confident that his life is like that of any other youth in society. He takes up all the responsibilities at this stage of life while also trying to make up for all that he had missed. There are many things which children need to adjust to while growing with HIV, such as financial problems, the absence of a parent, lack of support from relatives, etc. He said, “We think about our problems too much and make them bigger. We try to sort these out ourselves. But that is not right. From my experience I am saying there are many options. We need to see them and choose them. I want to convey to other children living with HIV that they are not alone, we all are together.”
Saurabh, Adolescent Representative, Snehalaya, narrated his experiences. He grew up in an institution and now works and lives on his own. He stayed and studied in Snehalaya. He has been on medication since his treatment began from NARI in 2005. In his life, he has seen a minimum 40-50 children dying. But the situation has changed a lot. Now, very rarely does one come across a child dying from HIV. In 2008, he left the organization. And then it was a reality check for him. He learnt about life outside the organization. He spent days without food. He started working in a hotel. He returned to Snehalaya in 2009 and started studying. He did a computer hardware course. He now works in a company. He wanted to tell other children to take care of themselves. They should not get tense about anything, but focus on increasing their CD4 count and live a happy life.

Sachin, Adolescent Representative, CCDT, shared his life experiences and how the organization supported him to be independent.

Ashvin, Adolescent Representative, CHIRAG (Community Health Initiatives and Research Action Group), Mumbai, spoke of having lost his father in 2005 and being put into an institution where no one visited him. His mother took him out of the institution and took him back home. He completed his 10th-12th schooling and now wants to be a Bachelor of Commerce (B.Com) graduate. He is in the first year of graduation. CHIRAG supported him and his mother through protection schemes, counselling and guidance. They helped them access education support, get the yellow ration card, and a card of Sanjay Gandhi Niradhar Anudan Yojana for financial assistance.

The adolescent voices underscored the need for institutional intervention to provide shelter, treatment, counseling and education with vocational training. ALHIV experiences of staying independently also reflected the reality that organizational linkages are imperative for integration with society even after leaving the institution. Also highlighted was the positive benefits and importance of facilitating access of families living with HIV to social protection, that can contribute to de-institutionalization and prevent children from being institutionalized and separated from their family.
After the adolescents spoke on their experiences, Dr. Raman Gangakhedkar, Dy. Director, NARI, compared the spread of HIV in India and Africa and provided reasons like the success of the ART roll-out, to explain why the HIV epidemic did not assume its projected magnitude in India. Data was presented to outline the overall scenario and epidemiology of HIV among adolescents in India.

- Overall trends of HIV epidemic as regards total number infected in India show a decline when all ages are taken together; but the trends in those below 15 years show little decline.
- Prevalence rates among those below 15 years have remained steady.
- There were a lot of unmet needs; 49% of the more-than-15-year-olds and 68% under-15-years population had unmet needs.
- For 11 - 19 age group and more so for 20 - 24 age group: Unprotected sex is the predominant mode of acquisition of HIV, followed by transmission from parent.
- Only 30% of the adolescents are aware, and of them 30% are linked to treatment.
- Children and young adults are disproportionately less represented in the populace on Anti-Retroviral Therapy (ART).
- There is a big disparity in retention in ART treatment, for adolescents registered and continuing treatment as well as disparity between adults and adolescents registered and continuing treatment.

As regards young children, the challenge is low coverage of Prevention of Parent-to-child Transmission (PPTCT) programme and low retention in ART centres. The other challenges are the leaky cascade, non-conducive environment and low empowerment of women. Maternal empowerment and stigma issue is a paradoxical challenge in a society that “lives to leave behind genetic lineage”. Delays in HIV testing of mothers, perceived fears of being ostracized, lack of courage to test the child and death of parent/s further complicate matters.

Although a lot of emphasis is on perinatally HIV infected children surviving till adolescence, there are a lot many adolescents getting infected due to other risky behavior patterns. Therefore, controlling HIV infection in children will need different strategies and/or a mix for young children and adolescents. For adolescents, there is a need for an effective, quality package focusing on appropriate HIV status disclosure, reducing unprotected sex, preventing substance use as well as adolescent-friendly prevention services for Sexually Transmitted Infections (STI) and a stronger component of positive prevention and linkage to care services. A major challenge for the future of ALHIV is the fact that age-related diseases like cancer, cardiovascular diseases, liver and kidney failure and cognitive decline is more prevalent in the treated-HIV populace than the age-matched uninfected populace. His friendly advice to ALHIV was, “See your canvas. You all can think well, much better than all adults. You have got a good forum to come together. You all together can voice your concerns/issues. Always keep learning. Speak out, demand for your needs and rights. It’s very important that you control your life. Someone from you can become like Dominic D’Souza and fight for accessing services. Still, at the same time, be what you are - children. Do not try to behave like adults.”

Pramod Nigudkar, Director, Programmes, CCDT, shared his views on Child Protection in the context of HIV, highlighting issues related to adolescents. He spoke about different groups of adolescents such as those who are infected since birth; those infected later, those who are single or double orphans, those who are on ART and those who are not.

He underlined the importance of understanding transition from childhood to adolescence in the context of HIV; in particular, the inquisitiveness which develops in this stage leading to questions like, “What may have happened to my parents, and what is happening to me?”, and dealing with this situation in a very sensitive way. He said, “The challenges during this stage can be seen in three areas, namely, knowing self, caring for
self and proving self. And these should be considered when we think about protection of children with HIV infection.”

He spoke on the importance of overcoming fear by claiming common spaces that serve as youth hangouts, like nukkads (nooks), schools, colleges, cinema halls, sport clubs and in the context of ALHIV, ART centres as well; Child protection initiatives can help in supporting the skills to be able to claim these spaces. However, he acknowledged that confidence and strength, otherwise a part of this age group, become difficult for those living with HIV. He reiterated the need to concentrate on issues of these children’s future.

Rajeshwari Chandrasekar, UNICEF concluded the session and shared the areas of action. She broadened the canvas by saying that there were other vulnerabilities, too, such as caste, gender and class. There is a need to understand the nuances and develop strategic responses. She emphasized that the efficiency of service provision is very important and needs to be focused on. Reach of services to children and adolescents is more difficult than to adults. Only 0.9% adolescents are getting their unmet needs fulfilled in the last 11 years. Adolescent-friendly services, in particular, are required. The JJ Act has provisions for Group Homes for adolescents to stay independent of the institutions. Such options of after-care, which would be particularly helpful for ALHIV who exit an institution, need to be explored.

Current Intrventions with Adolescents Living with HIV

The second session focused on good practices, programming challenges and lessons learnt while examining various aspects in current interventions with adolescents. The session was chaired by Dr. Malathi Pillai, Trustee, CCDT. Prayas shared the experience of So What? in addressing psycho-social needs as an adolescent self-support group and its nurturing. NMP+ spoke of its experiences with adolescents as part of its work with People Living with HIV (PLHIV) in various districts. Founder-member of Muktaa Charitable Foundation, Dr. Rupa Agarwal, shared the calls from adolescents to the Muktaa helpline dedicated for HIV counseling.

Dr. Malathi Pillai, Trustee, CCDT, emphasized the importance of monitoring information and evidence-based advocacy to present facts scientifically. She outlined the issues related to current interventions:

- Age – the definition of age varies according to context.
- Impact on girl children.
- Mode of transmission – sexual or otherwise.
- Sexuality – not about reproduction but related to personality.
- Peer influence during adolescence.
- Youth-friendly health services - counseling/testing services and care in a holistic sense.
- Spaces - physical, psychological and emotional, which should not be violated, abused.
- Home-based Care – to deal with stigma and discrimination and to get help from family.
- Transition Homes, Group Homes.
Dr. Mohan Deshpande, Dr. Sanjeevani Kulkarni, Manik Paradhe and Ankur shared Prayas’ initiatives with adolescents in addressing psycho-social and sexuality-related aspects and the evolution of the peer support group So What!. Dr. Mohan Deshpande mentioned that actually So What! was the name of the workshop, which was later adopted by the group as its name. Manik Paradhe, Counselor, Prayas clinic, pointed out that these children were not ready to open up even after providing them a space to ask questions. Their reticence was self-imposed. To address this silence, Prayas conducted a four-day workshop with these children. The topics covered in the workshop were mainly self-image, image in the minds of peers, dreams, hopes, stress and all these in the context of relationships. The topics were handled through group discussion, story boards, case studies. Overall, an important aim was to inculcate awareness, provide information and support with sensitivity. And during the workshop the miracle took place. The children opened up, asked many questions, took part in finding solutions to them from informed sources and discussed several issues which were troubling them, which helped banish negativity from their minds.

Ankur, Adolescent Representative, Prayas, shared his experience of the workshop and the changes he noticed in himself. He said that like other adolescents, he, too, was teeming with questions about changes in body and mind, attraction towards girls, his sickness, tests, medication, etc. HIV infection had started affecting his studies. Even though the atmosphere in Prayas clinic was quite open, it was difficult to ask questions which were haunting him. But the workshop brought the change in him and the relations at Prayas changed. Moreover, he started feeling that he is not alone. Since the workshop, other participants also started looking at life positively. They formed a group So What! and kept meeting each other. They are planning such workshops for other HIV infected children, too.

Dr. Sanjeevani Kulkarni, Trustee, Prayas, highlighted other efforts carried out at Prayas. A group of seven ALHIV wrote a book namely Kalala Tevha regarding their process of disclosure. She also mentioned that two more workshops on the same lines are scheduled. A One Plus workshop is on the anvil, which will see participation by ALHIVs and their uninfected peers. The So What! group is taking increasing interest in organizing such workshops and is working on improving their capacities to facilitate sessions on different issues.

Vaishali Naik, NMP+ shared the experiences of working with positive people and adolescents by elaborating on the Saksham Project. Through
this project, they realized the importance of talking about physiology and sexuality. Initially, children were not that comfortable, but over time started talking freely. As another part of Saksham Project, they initiated activities for making children economically self-reliant once they transition to adulthood. They organized vocational courses like MSCIT (an IT literacy course), tailoring, beautician training, etc. Some of the aspects that came to light in the course of their work:

- Sexuality is seen as a dirty topic - not to be discussed in public, though in recent times the situation and approach are changing.
- While working with children in school, they realized that children have many questions but were not sure whether they have the opportunity to get them addressed. They wondered whether they can ask these questions to their parents.
- Parent education and counseling is very important in the context of adolescents having questions regarding marriage, courting, etc.

Dr. Rupa Agarwal, Founder-member of Muktaa Charitable Foundation, opened her session with a film song, *Aa chalke tujhe main leke chalu ek aaise gagan ke tale, jahan gam bhi na ho, aasoon bhi na ho, bas pyar hi pyar pale* (Come along with me, such a vista will I show you, where sorrow has no place, nor tears, and where only love prevails). Muktaa Charitable Foundation’s Ankur Project with children is an attempt to realize this dream.

Dr. Rupa Agarwal spoke of calls by adolescents to the Muktaa helpline dedicated for HIV counseling since many years. She shared the example of a phone call made by a 14-15 year old child who asked how he should take care of his mother’s health. The issues evident in the calls of adolescents included:

- Often, adolescents are considered either as big children or as small adults.
- Generally, girls face many difficulties as they do not find spaces to talk or express themselves so that their concerns may be addressed.
- Interventions should be designed taking into consideration the situation of adolescents.

**Living in Institutions and Leaving the Institutions: Addressing the Transition**

The theme of transitioning from living in the institutions to leaving the institutions was taken up in the second part of the same session. Presentations were made by panelists from organizations such as Prerana, which provides institutional services for children affected by HIV; Manavya, which runs a residential home for CLHIV; and Sahara, with long experience in caring for HIV infected as it runs a free Home to offer care for children who cannot be managed at home.

Cedric Fernandez, Sahara, outlined Sahara’s care component for HIV infected adolescents in the Home:

- The organization tries to create a friendly environment using toys, drawing material etc.
- The basic approach is to be patient and give the children freedom to decide.
- There is no time-bound approach. The child is phased out, not discharged, as and when the child wants to move on.
• There are children who are adults but not ready to face adulthood and the world outside, but are too grown-up to be helped through child care.

Dr. Asha Patil, Manavya, shared the experience of running a residential home for HIV infected children for more than 15 years.

• When a child is orphaned and is HIV infected from Mother-to-child Transmission (MTCT), his/her relatives do not come forward to take responsibility. In spite of the laws and rules being in place, the children and their guardians face a hard time in getting school admission. Manavya had to start its own school to circumvent this problem.

• Manavya organizes vocational training for the children, tailored to the child’s abilities, aptitude and the situation. Training sessions explain the importance of being self-reliant.

• After leaving the organization, the first question which children face is that of accommodation. The issue becomes much more acute in the case of girls.

Priti Patkar, Prerana said that though Prerana is not involved in any direct interventions with the children and adolescents living with HIV, it has vast experience in working with affected children and children of stigmatized groups. Priti shared some of the insights from this experience.

• Although the organization provides everything, no institution can be an option to the home.

• The presence of HIV greatly impacts reactions to life and institutional placements of ALHIV. Networking, introducing adolescents and involving adolescents in working out their own care plans are some of the important interventions appropriate for growing children.

• There is a need for a very strong after-care programme for all adolescents.

• Prerana has a peer group of adolescents, which would like to connect with So What!
Current Interventions with Adolescents Living with HIV

In the next part of the session, chaired by Kamini Kapadia, Consultant, UNICEF, had adolescent representatives, Anita, from Sangram/VAMP, Sulochana from Snehalaya and Manas, from Sahara; sharing their experiences regarding access to services including health care services. Sanjay Deshpande, a member of the Child Welfare Committee (CWC), spoke on the protection of adolescents living with HIV. Leena Rane, NMP+ spoke on the outcome of the state-level consultation on advocacy organized by Positive Women's Network (PWN+).

Anita, Adolescent Representative, Sangram, stated that she learned that her mother died of HIV from her aunt. Her aunt helped her out through the tough times. Anita now works at Sangram.

Sulochana, Adolescent Representative, Snehalaya, presented her experience in two ways, as an individual or CLHIV accessing services and as an Auxiliary Nurse Midwife (ANM) now helping others accessing the services. Snehalaya had made it easier to access services as a child. She realizes the difficulties now when she accompanies children to the civil hospital for follow-up and medicines.

Manas, Adolescent Representative, Sahara, shared his experience on the attitude and approach of service providers. He narrated an incident where one of his friends was admitted to Sassoon Hospital for blood cancer. An attendant at Sassoon told him not to touch his friend as he happened to be HIV infected. He mentioned that even many doctors would not touch the patient, but just read the files and go. He also spoke of the reactions of the hospital authorities when an eight-year-old HIV infected girl died in a hospital. Let alone touching her body, no one was even willing to bring the stretcher to shift her. He had to take her dead body from the hospital while the entire hospital staff just watched. He said that such experiences occur quite frequently in government set-ups.

Sanjay Deshpande, Child Welfare Committee (CWC), Kolhapur, shared his opinions on the CWC and his experience as a CWC member. He presented some questions for discussion:

- It is a challenge to decide whether HIV positive children are to be admitted to institutions meant exclusively for them or allowed to share Homes with their uninfected peers. The concerns this quandary raises are as follows:
  - Is their health care considered or not?
  - Is follow-up being done or not?
  - Are other children at risk of infection if the infected and uninfected are put together?
  - Will medication schedules of ART be maintained or not?
  - Will disclosure-related care be taken or not and if undertaken, will it lead to discrimination, and in the event it does, how is this to be addressed?
- Should efforts be made to access services such that institutionalization is a last option?
- As per the new policy, there should not be separate institutions for the children with special needs; they should be integrated into the existing set-up. There are organizations like CCDT, Snehalaya who do not segregate positive children.
Many participants felt that notwithstanding the reality, it is a challenge to overcome such misconceptions rather than circumventing them. An important point of discussion was that there is an urgent need for orientation of the new CWC members before they actually start taking decisions. They may not be sensitized to the dimensions of the issue at hand. For instance, the CWC personnel may use terms like “HIV child” and “surrendered mothers”. The cumbersome procedure at the CWC adds to the discomfiture of the CLHIV and ALHIV.

Leena Rane, associated with NMP+ Vihan Project spoke on the outcome of the Maharashtra State-level consultation on the adolescents infected and affected with HIV. PWN+ had organized this consultation. A major part of her presentation consisted of feedback from adolescents on access to services and their experiences, positive and negative, with other people in the course of their lives. Their concerns were multi-fold: ART, education and relationships.

- Concerns Related to ART:
  - Only some counselors try to understand the children and adolescents and the psycho-social aspects of their life.
  - Second-line ART is not available at the district level (only Mumbai, Nagpur and Sangli have this provision). This entails a lot of travelling to access the medication. At many places, posts of lab technicians remain vacant. This is the reason CD4 is not done every 6 months as per guidelines.
  - Related to Link ART centres – parents do not choose this option fearing discrimination at village level.
  - Often, there is shortage of ART medicines.
  - Information, Education, Communication (ICE) material is good, but needs improvement for children.
  - In Mumbai, there is a separate ART centre for children. At other places, at least one day in a week should be assigned for children.

- Concerns Related to Education:
  - Children are willing and eager to learn.
  - If the status is disclosed to friends, they provide support like reminders for the medication, but often, children are not in a position to continue schooling.
  - Most children stay with grandparents, who are already in financial difficulties and who expect children to earn at a tender age.
  - Stigma and discrimination continue to exist in schools. There are examples of children being made to sit separately.
  - Due to side-effects of ART, children do miss their classes, but teachers do not co-operate at such times.

- Concerns Related to Adolescence:
  - Children/adolescents are not yet open and comfortable.
Girls are not provided information related to menstruation and other related aspects. Sanitary pads are not provided at all places. Along with other areas of education, education on sex and sexuality is very important and it’s necessary to involve parents in it.

There are issues related to marriage, selection of partner and having children.

Most parents force youngsters to get married without disclosing the status.

- Other Issues:
  - There are problems related to nutrition.
  - The lengthy procedures for social schemes impede access.

To conclude the session, Kamini Kapadia, UNICEF provided information about the follow-up on last year’s consultation. She gave an update on the GR for double ration and advocacy related to bus transport. The circular related to waiver of court fee and efforts for the same continue. She stated that co-ordination between NGOs and the government is ongoing but the government should be involved extensively for capacity building as well as provision of services.
Day 2

The second day started with a film prepared by St. Catherine’s Home on issues of CLHIV. This was followed by a discussion on the same.

Issues raised from the previous day’s sessions were then taken up for discussion:

- Children should not be separated because of their HIV status, but rather, efforts should be made to mainstream them. Though there remains a possibility of children being stigmatized, the focus should be on ways and means to overcome misconceptions. Media should be used positively.
- DWCD should not give permission to start special Homes for HIV positive children, as this increases stigmatization.
- It is possible to bring up infected and affected children together. Proper nutrition and ART medication must be provided to infected children. A child with opportunistic infection can be isolated for the requisite duration.
- Institutions and organizations do not admit ailing children and this poses a problem.
- Institutions also face difficulties as care-givers are unwilling to work with these children.
- Institutional authorities also face practical problems such as in the case of orphan children, for whom there is no one initially, but as the children grow up, gradually, relatives come into the picture and then the responsibility of the organization becomes complex.
- When the children need to go outside the campus for anything, they are always sent as a group and this marks them out as different from other children. Children are always accompanied by a staff member when they go out of the institution such as to pursue medical treatment, counselling or attend a special course. Often due to constraints in human resources, such individualized needs are not addressed.
The type of treatment, support and love children get at the institutions is reflected in their lives after they leave the institution. Adolescents/youths face problems when they are moved out of the institution after 18 years of age. If an adolescent above 18 years of age does not have any support, then such a Adolescents/youths cannot be sent out of the organization but needs to be supported till s/he becomes independent. After care is an urgent priority.

- Financial burden on the organizations/institutions is increasing daily as funding declines.
- Licensing of Homes is time consuming. There are several pending applications with the DWCD.
- Institutions housing children are rendered illegal at times. There are no clear procedures with regards to safety, security and transfer of children to other institutions. These need to be defined.
- One participant expressed discomfort at the tendency to call the HIV positive as sick or ill.
- An adolescent representative stated that even doctors have misconceptions, which need to be addressed. Another adolescent representative said that groups like So What! need to be formed everywhere as they could be a great support for adolescents.
- Since they are not organized, positive children remain under-represented. There needs to be a focus on the issues of adolescents living with their families.
- A parent representative pointed out that adolescents need emotional strength more than they need financial support to enable them to take responsibility for themselves.
- Government GRs on various issues are available, but implementation remains a problem.
- Advocacy efforts could reduce the documentation required to access government schemes and services like Sanjay Gandhi Niradhar Anudan Yojana.

Dr. Tushar Rane, HIV Specialist, UNICEF, summarized the issues of the discussion session:

- It is important to identify the gaps to be filled up.
- Empowerment of people should be focused.
- People need support to support the children.
- Documentation to access the services and scheme needs to be reduced.
- Mainstreaming should be focused and of prime importance.
The last panel discussion theme was 'Addressing Disclosure - Parent’s Experiences, Organizational Efforts and Mainstreaming'. Dr. Nandita Kapadia-Kundu, an independent health researcher, chaired the session. Poonam Patkar, CCDT, Kumudtai, parent representative, Vaishali Naik, NMP+, Dr. Ritu Parchure, Prayas, participated in the discussion related to disclosure. Anil Gawade, Snehalaya, Pankaj Bedi, Centre for Advocacy and Research (CFAR), Krishnakant, CHIRAG and Adv. Nitu Sandhya, Lawyers Collective, spoke on mainstreaming.

At the outset, **Poonam Patkar, CCDT**, provided a perspective on disclosure and its importance. She focused on the meaning of disclosure, its necessity and ways and means to disclose HIV status. She explained the impact of disclosure on families with the help of statistics. The presentation focused on strengthening families so that the child does not end up in an institution.

**Kumudtai, a Parent Representative**, shared her views and experiences related to raising her two HIV infected daughters. She said that her introduction to HIV was in 2002, when she was diagnosed as HIV infected. She did not know much about HIV then, but it scared her as doctors told her that medicines were not available. Her husband was not alive to support her and she had to move ahead. Her daughters were very young. Hospital visits became a part of life. Children asked questions seeing the posters in the clinic. They did not know anything about the infection. But as they were growing up, a few questions started troubling them such as, “Why do we need to visit the clinic so frequently? Why are we all infected? From whom did we get the infection?” She said that she shared all information with them. It was important to address their curiosity and at the same time make them aware about their life situation so that they will be able to start taking care of themselves independently. She was of the opinion that children should be able to get information about the HIV infection at home, and it is much better if it comes from the parents. There should be understanding about what the children must be going through, what their mindset would be, what they need to face. It is very important to realize that children are not in a position to be able to express and share what they feel. Adults’ contribution should be to make them comfortable, give them space to express themselves and share their feelings and stress. Being tension-free helps children to grow and lead a comfortable life.

**Ms Vaishali Naik, NMP+** expanded on disclosure with reference to the experience of networks working with children and parents of children with HIV.

- In case of children/adolescents, the report first goes into the hands of parents. Children get confused with the changes in the atmosphere, in reactions, in the behavior of adults around, and so many other things, such as having to take medication daily.
• She shared the example of a child who learned about his HIV status at the age of 16, what the child went through and how, ultimately, he defaulted on his ART medication.

• When HIV status is not disclosed to children on time, they go into depression.

• It is very important to share as much information as possible with children, appropriate to their age and understanding level, in a manner that lends them strength.

Dr. Ritu Parchure, Prayas, shared disclosure-related aspects with reference to the initiatives at Prayas and experiences with the children and their parents. She started her presentation with a painting by a girl after the disclosure of her HIV status. She spoke about the child who created the painting and her aspirations and achievements till date.

She said, “The reactions of children when they come to know about their HIV status are varied. Some become very negative about their parents, some feel bad for their mothers and because of that do not ask much about it. It is very important that children are told about infection and HIV status by their parents. They feel better if their parents tell them before they come to know about it from others or before they face the reactions related to it.”

Dr. Nandita Kapadia-Kundu concluded the session by emphasizing the importance and proper ways of disclosure and opened the forum for discussion in which the following issues came up.

• How to disclose the status at school or college is a big challenge for children. People face difficulty when they try for a job after 18 and they are asked for a medical certificate. Even for studies or jobs abroad, HIV testing is not mandatory, however but in India there is an inherent assumption that PLHIV are unfit. So, the opportunities may be unduly denied.

• For disclosure, first, talk to parents/guardians, prepare parents to tell children and explain that it must be shared with children depending upon the situation of children. It may take a long time. One way suggested was to share the counselor’s personal phone number with the parents and tell them to get the child to the agency if they felt that children are getting stressed and the situation becomes too much for parents to handle.

• Uncontrolled disclosure is more challenging. After the disclosure, it takes time for children to cope with the situation and the first six months after disclosure prove most taxing. Both one-to-one counseling and peer support are important.

• One participant shared the experience about not waiting a long time for disclosure. The family is seen as a unit, which must manage the disclosure with the support of the organization.

• Another example was the experience of a child who had written down the word “HIV” in his diary and with his friend tried to find the meaning in the dictionary. They could get the words of the abbreviation, but the question is how would they get the meaning and complete information regarding HIV?

• It is very important that children know about their status and that they have the courage to share it with people around if required. Another experience shared was of a rescue operation of a child infected with HIV. He shared his HIV status and people who were providing help could access the required medicines for him.

• There is a need to work at the broader level at ART centers as doctors and counselors at ART centers do not have information about how, when and where disclosure was made.

In the next part of the session, the discussion was focused on Mainstreaming which began with a talk by Anil Gawade, Snehalaya, who spoke on the following:
• The background of Snehalaya and how it started work in the red light area. Many people and children were supported by the organization, which has impacted the situation related to HIV and people vulnerable to HIV.

• Since 2005, the situation is changing. A few years ago there was a situation when there were 1-2 deaths per month. Now there are 1-2 deaths per year.

• In the context of adolescents and mainstreaming, the role of adults and organizations is very important. They should play a key role in providing guidance.

• Children/adolescents are insecure about their future. They worry about their families. There should be open communication with adolescents to give them clarity about their life.

• For mainstreaming purposes, it is very important that medication should be easily available and accessible. Efforts need to be made towards increasing awareness among private practitioners regarding the situation, people and their responsibilities.

• Education and rehabilitation are the focus areas of intervention. It is important to develop life skills among the children. Discrimination at school needs to be addressed.

Pankaj Bedi, Centre for Advocacy and Research (CFAR), spoke about mainstreaming in the context of advocacy. He made a presentation on the demonstration-cum-pilot project, "Enhancing the Mainstreaming of Socially Marginalized and Excluded Populations by Assessing and Designing a Social Inclusion Plan" launched on 18th August 2012 for the states of Andhra Pradesh, Maharashtra and Karnataka.

• HIV/AIDS is not merely a health issue but influenced by a number of socio-economic factors. Hence, mere health interventions are insufficient. A concerted, collaborative effort is required from all organizations through their work and programmes.

• The ownership of HIV/AIDS and related issues has to be transferred and subsequently shared by various stakeholders.

• Some achievements in the areas of mainstreaming include, providing travel concessions to People Living with HIV (PLHIV) to visit ART centers, addressing nutritional requirements and provision of free legal aid by some states, etc.

• There are certain limitations such as limited awareness and training activities. Inclusion and ownership of multi-sectoral actors is not visible. The programme could not integrate concerns of PLHIV in other developmental schemes like Integrated Child Development Services (ICDS) scheme, National Rural Employment Guarantee Scheme (NREGS), pension scheme, etc., on a larger scale.

• For instance, integrating ALHIV and CLHIV could also lift up the general nutritional standards for all children under the ICDS scheme.

• Involvement of community and community structures is imperative to enhance any mainstreaming engagement. There is a need to create social accountability and policy responsiveness to the concerns of the community.

Manoj, NMP+ added that among the barriers of mainstreaming, 10% are health issues and the remaining are social issues.

Krishnakant, CHIRAG project, Nirmala Niketan College of Social Work, started his presentation by giving an overview of the activities of CHIRAG and put forth the challenges which affect mainstreaming and the steps which can be taken to address them.

• Some of the challenges in mainstreaming include making various government schemes accessible to ALHIV.
• The interventions which can help in addressing mainstreaming include vocational training after completing formal education, e.g., driving, computer courses, mobile repairing, etc.

• Support groups for ALHIV- Peer Role Models.

• Some other activities like career counseling, life skill training, vocational training may work immensely.

• Maintaining a stable environment for growth and development of ALHIV (Family is the best support system), building a more aware community of students and teachers, who understand issues related to ALHIV.

Adv. Nitu Sandhya, Lawyers Collective spoke about mainstreaming in the context of legal and ethical aspects related to adolescents. The focus of the presentation was on issues of consent, confidentiality, disclosure and property related issues.

• Legal position of minors in the context of consent, consent for health services.

• For certain health information/services, minors do not want to be accompanied by their guardians, e.g. sexual health information, abortions, contraceptives, STI treatment, counseling and services for drug users, HIV/AIDS testing etc.

• The other important points are – lack of support from relatives, especially in the case of orphans. Access to parental property is a long-drawn battle when property is taken over by a relative.

Dr. Tushar Rane, UNICEF, said that mainstreaming is in the mindset. He also stated that there has been good progress in GR-related activities, which will contribute immensely in supporting ALHIV and ultimately in mainstreaming. Importance of youth-friendly services was also discussed; especially the mainstreaming efforts for orphans or those who do not have anyone to take their care and responsibility.
Recommendations

The last session was a summarization of outcomes and recommendations arising from the presentations, experiential narratives and discussions during the consultation. Following the summarization by Alpa Vora, Child Protection Specialist, UNICEF, Maharashtra, all the participants shared their views and opinions. The session was chaired by Vandhana Kandhari, Child Protection Specialist, UNICEF, ICO, New Delhi.

The recommendations made during the Consultation were presented as addressing two broad areas:

1. Recommendations that pertain to the ongoing work of the Forum on Child Protection and HIV.
2. Recommendations that require continuing advocacy with the State and with the Department of Women and Child Development, Health and Education.

1. Recommendations for the Forum on Child Protection and HIV towards facilitating formation of adolescent groups and strengthening efforts of adolescent groups to know, manage and prove themselves.

It was unanimously felt by participants that adolescents in institutions as well as those living with families need opportunities to come together. The questions that need to be addressed and taken forward by the Forum are:

- What is the common vision of such efforts?
  - Space to discuss problems and solutions as adolescent groups
  - i) Issues related to growing up
  - ii) Sharing with others
  - iii) Supporting others
  - Taking help from experts whenever required (e.g., Saksham Project).

- What are the elements that make such programmes effective – from meaningful activity to empowerment
  - Mandate for every institution to form its own adolescent/youth group and initiate empowerment-oriented interactions.
  - Sharing and networking between adolescents from different organizations on a periodic basis.
  - Development of livelihood skills, including options such as ANM, medical care-givers, social workers, etc.

- Review where initiatives with adolescents have reached: What are the crossroads – how do we move forward?
  - Need for continuing collective platforms for representatives of groups to come together, share and build on good practices.
  - Children and adolescents becoming animators to support other children.

Recommendations for Department of Women and Child Development, Health and Education

The recommendations for the DWCD pertain to procedures in relation to licensing of Institutions, and streamlining procedures that would facilitate improved coordination between the management of Institutions and the CWGs in relation to admission of children into institutions, review of children's placement and extension of the duration of admission in the institution and Aftercare.
• Experiences with Juvenile Justice Procedures and the Law (licensing, funding, documentation etc.) – Recommendations for change
  - Registration of all Homes under JJ Act in a time-bound manner.
  - Department to put systems and procedures for rehabilitation in place.
  - Capacity building of Integrated Child Protection Scheme (ICPS) functionaries.

• The challenges and strengths of running institutions on the principle of integration: recommendations for overcoming challenges (staff, funds).
  - Proper directives on implementing the same. Non-negotiable Framework for all institutions if children with HIV have to be integrated
  - Special needs to be kept in mind while integrating children/adolescents.
  - Capacity building of CWCs and institutional personnel to integrate children with HIV.
  - Adherence to Standards of Care for institutions to integrate children with HIV, with focus on health, regular access to ART.

• Experiences with Competent Authority (CWC) – Recommendations for change/areas for coordination
  - Improvement in co-ordination between CWCs and the institutions through review and reduction of cumbersome administrative processes.
  - Need for review of CWC-related Standard Operating Procedures (SOPs) vis-à-vis HIV children and procedures for regular appraisal and renewal/extension of admissions of children in institutions.
  - Sensitize the newly appointed CWC members on issues of CLHIV and ALHIV.

• Deinstitutionalization and reaching children living with families, sensitizing parents to be informed on HIV and ways and means of disclosure of their own and/or child’s HIV status.

• Aftercare – Key components and recommendations; It was agreed to set up a meeting between organisations and adolescents with the State level Task Force working on After-care and Alternative Care to pursue the following recommendations:
  - ICPS funding of 5 lakhs per district to be utilized towards promoting various models of aftercare.
  - Establishment of more Group Homes, especially for girls.
  - Protection of property rights and legal identities for youth in After-care.
  - Exit plans (prepared with the child) to be in place much before the child leaves the institution.
  - Separate exit plans/preparation for adulthood to be carried out for children from institutions and children in the general community.
  - Reduction of discrimination in different settings particularly for the Departments of Health and Education
  - Engagement with doctors to clear misconceptions on HIV
  - Sensitization of teachers to prevent separate seating of CLHIV in classrooms and to get their support for children who miss classes due to side-effects of ART.

• Access to ART at the district level so that there is a reduction in travel time, filling lab technician vacancies, and separate days/centres for CHLIV, strengthening retention in ART.
### Annexures

#### Programme Schedule:

<table>
<thead>
<tr>
<th>TIME</th>
<th>TOPIC</th>
<th>SPEAKER</th>
<th>FACILITATOR/ CHAIRPERSON</th>
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<tbody>
<tr>
<td>11.00 to 11.30am</td>
<td>Registration and Tea</td>
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<td>Participants sign an undertaking of confidentiality</td>
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<tr>
<td>11.30 to 12.00am</td>
<td>Welcome</td>
<td>Dr. Vinay Kulkarni - PRAYAS</td>
<td>Dr. Sanjeevani Kulkarni – Trustee, PRAYAS</td>
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<td>Inauguration</td>
<td>Song by members of the adolescent group, So What!</td>
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<td>Opening Remarks</td>
<td>An address by adolescent representative Purnima – Prayas</td>
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<td>Dr. Malathi Pillai – Trustee, CCDT</td>
<td>Rajeshwari Chandrasekar - Chief of Office, UNICEF, Maharashtra</td>
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<tr>
<td>12.00 am. to 1.30 pm</td>
<td>Perspective building: Adolescents and HIV</td>
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<td>Dr. Vinay Kulkarni - Trustee, PRAYAS</td>
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<td></td>
<td>Growing up with HIV</td>
<td>Sharing by ALHIV representatives Rohan - PRAYAS, Sachin - CCDT, Ashvin - CHIRAG, Saurabh – Snehalaya</td>
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<td>Epidemiology and Overall Scenario of Adolescents and HIV</td>
<td>Dr. R. R. Gangakhedkar – Dy. Director, National AIDS Research Institute (NARI)</td>
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<td>Child Protection in the context of HIV: Highlighting Issues Related to Adolescents</td>
<td>Pramod Nigudkar – Director, Programmes, CCDT</td>
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<td>Conclusions and areas of action</td>
<td>Rajeshwari Chandrasekar - Chief of Office UNICEF Maharashtra</td>
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<td>1.30 to 2.15 p.m.</td>
<td>LUNCH</td>
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<td>2.15 to 4.00pm</td>
<td>Current interventions with adolescents living with HIV: Good practices, programming challenges, lessons learnt while examining aspects of:</td>
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<td>Dr. Malathi Pillai - Trustee, CCDT</td>
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<td>Psycho-social needs and addressing issues around sexuality</td>
<td>Dr. Sanjeevani Kulkarni and Group members - Prayas, Vaishali Naik - NMP+, Dr. Rupa Agarwal - Muktaa Helpline</td>
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<td>Living in Institutions and Leaving institutions: Addressing the transition</td>
<td>Priti Patkar - Prerana, Dr. Asha Patil - Manavaya, Cedric Fernandez - Sahara</td>
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<td><strong>4.00 to 4.15 p.m.</strong></td>
<td>Access to Health, ART and Counseling for ALHIV. Experiences with Other Services</td>
<td>ALHIV representatives, Anita-Sangram/ VAMP, Sulochana - Snehalaya, Manas - Sahara. Kamini Kapadia – Consultant, UNICEF</td>
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<td><strong>4.15 to 6.00 pm</strong></td>
<td>Current Programming of DWCD around institutional and non-institutional care services and nutrition support through ICDS</td>
<td>Rahul More - Dy. Commissioner, CD, DWCD. (could not attend)</td>
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<td>Role of CWCs in Care and Protection of Children Living with HIV - Challenges faced</td>
<td>Sanjay Deshpande – Member, CWC, Kolhapur</td>
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<td>Advocacy Efforts of PWN+ around Adolescents: Issues Emerging from the Maharashtra State Consultation and the Way Forward</td>
<td>Leena Rane - NMP+</td>
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<td>Conclusion</td>
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**DAY 2**

ANCHOR: Dr. Tushar Rane – HIV Specialist, UNICEF

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<th>Time</th>
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<tr>
<td><strong>10.00 am to 1.00 pm</strong></td>
<td>Addressing Disclosure - Parent’s Experiences and Organizational Efforts and Mainstreaming</td>
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<td>Poonam Patkar - CCDT</td>
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<td>Kumudtai - Parent representative</td>
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<td>Vaishali Naik - NMP+</td>
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<td>Dr. Ritu Parchure - PRAYAS</td>
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<td><strong>Mainstreaming:</strong></td>
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<td>Anil Gawade - Snehalaya</td>
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<td>Pankaj Bedi - CFAR</td>
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<td>Krishnakant, CHIRAG</td>
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<td>Adv. Nitu Sandhya - Lawyers Collective</td>
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<td><strong>1.00 to 1.45 pm</strong></td>
<td>Summary of the Outcomes of the Sessions</td>
<td>Alpa Vora – Child Protection Specialist, UNICEF</td>
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<td><strong>1.45 to 3.30 pm</strong></td>
<td>Programming and Policy Imperatives and Way Forward</td>
<td>Group Discussion</td>
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<td>Vote of thanks</td>
<td>PRAYAS</td>
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Vandhana Kandhari-Child Protection Specialist, UNICEF, ICO, New Delhi
Organizations in the Forum on Child Protection and HIV (CP-HIV)

UNICEF Maharashtra, along with CCDT, the nodal agency and a group of partner organizations, initiated a civil society initiative to strengthen advocacy on behalf of this group of vulnerable children and adolescents, aiming to move beyond sheer survival-related programming to more comprehensive efforts towards ensuring quality of life for children infected and affected by HIV/AIDS. The partner organizations in the Forum include:

**Prayas** from Pune, working on care and counseling of HIV affected adults, mothers and newborns as well as adolescents and pediatric ART.

**Network of Maharashtra by People Living with HIV/AIDS** (NMP+) advocating for rights of HIV infected persons and working on treatment adherence and stigma discrimination issues.

**CHIRAG** from Mumbai that works on the entitlement rights of marginalized people.

**Lawyers Collective**, a legal advocacy and support organization from Mumbai.

**St. Catherine’s Home**, running an institutional care programme in Mumbai for women and children.

**Centre for Advocacy and Research** (CFAR), Pune, working on media advocacy related to HIV/AIDS and its impact.

**Mamta** from Nagpur works towards optimizing the health and development of adolescents/young people.

**Snehalaya** from Ahmednagar works with towards holistic development of children and developing awareness and capabilities of deprived children, women, people living with HIV/AIDS.

**RTM SAP Mandal** from Amravati enhances health status of the rural marginalized community.

**List of Participating Organizations:**

1. CHIRAG, Mumbai
2. Prerana, Mumbai
3. St. Catherine's Home, Mumbai
4. Lawyers Collective, Mumbai
5. MSF, Mumbai
6. World Vision, Mumbai
7. D. Y. Patil Medical College, Pune
8. CFAR, Pune
9. NMP+, Satara, Pune, Ahmednagar
10. Saheli, Pune
11. Soudamini, Pune
12. SOFOSH, Pune
13. Muktaa Charitable Foundation, Pune
14. RTM SAP Mandal, Amravati
15. Manavya, Pune
16. Sangram, Sangli
17. Sahara Alhad, Pune
18. Janakalyan, Latur
19. Karunalaya, Kolhapur
20. Arogya Bhan
21. Guruprasad Trust, Ratnagiri
22. Keep Child Alive, Pune
23. CASP, Pune
24. CCDT, Mumbai
25. UNICEF, Mumbai
26. Prayas, Pune

**Press :**
- Indian Express
- IBN Lokmat
- Mid Day