CONSULTATION REPORT ON

ADVOCACY INITIATIVE AROUND CHILD PROTECTION AND HIV

8th-9th AUGUST, 2012 MUMBAI

COMMITTED COMMUNITIES DEVELOPMENT TRUST

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STATE LEVEL CONSULTATION

ADVOCACY INITIATIVE AROUND CHILD PROTECTION AND HIV

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CENTRE FOR ADVOCACY AND RESERCH

Lawyers Collective HIV / AIDS Unit

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune-Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
AWW	Anganwadi Worker
B.ED.	Bachelor of Education
BSY	Bal Sangopan Yojana
CABA	Children Affected by AIDS
CCC	Community Care Centres
CD	cluster of designation or cluster of differentiation
CLHIV	Children Living with HIV/AIDS
CWC	Child Welfare Committee
DIC	Drop-in Centre
DWCD	Department of Women and Child Development
EID	Early Infant Diagnosis
GR	Government Resolution
HIV	Human Immunodeficiency Virus
ICDS	Integrated Child Development Scheme
ICTC	Integrated Counseling and Testing Centre
IEC	Information Education Communication
ICPS	Integrated Child Protection Scheme
MDACS	Mumbai District AIDS Control Society
MSACS	Maharashtra State AIDS Control Society
NACO	National AIDS Control Organization
OVC	Orphaned and Vulnerable Children
PHC	Primary Health Centre
PLHIV	People Living with HIV
PPTCT	Prevention of Parent To Child Transmission
RTE	Right to Education
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations International Children's Education Fund

BACKGROUND

The State Level Consultation of 8th-9th August 2012, conceptualized and planned by a group of organizations providing home based and institution based care, health, education, legal and advocacy support, was convened by Committed Communities Development Trust (CCDT) in partnership with UNICEF. It was conceived out of a need 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 group identified that with advancements in medical technology, the treatment options available for people infected or affected by HIV/AIDS are greater. However, the quality of such services as also accessibility continues to remain a challenge. Additionally, stigma and discrimination increase the severity of impact. The presence of HIV in the life of a child adversely impacts his or her development process. If the child is from economically poor and marginalized settings, then the impact could have grave consequences. Therefore, protection issues assume paramount importance particularly while dealing with vulnerable and marginalized children.

The group felt that the gravity of the situation demands immediate, consolidated and forceful reaction from all stakeholders. It also needs us to have a much more coherent understanding on the nature of vulnerabilities and marginalization of our children, to develop appropriate programs. The Consultation was an attempt to achieve this convergence and consolidation of best practices and recommendations. It aimed at outlining a strategy for advocating the rights of children, infected and affected by HIV/AIDS, thereby promoting their development and well-being.

The welcome address by Mr. Tejinder Sandhu, Chief of UNICEF Maharashtra Field Office, emphasized this decisive backdrop. With HIV/AIDS as the context, Child Protection assumes a challenging concern. Taking stock of the current situation, the existing policies, programs and practices, therefore, would precede an energetic response. The Consultation would serve a purpose in consolidating our responses and beginning a process of dialogue with the State government. This process, Mr. Sandhu reiterated, would have important consequences in bringing together significant stakeholders such as Mumbai State AIDS Control Society, Department of Women and Child Development, Department of Public Health, and Department of Education. He underlined the three major expectations from the Consultation:

- Formulating concrete steps towards creating a collective forum of likeminded organisations and individuals working with HIV/AIDS impacted children and child protection
- Finding direction to draw a clear plan of action and guiding principles
- Beginning a process of creating a strong platform for advocacy on Child Protection and HIV as well as facilitating engagement between the State and Civil Society.

SPECTRUM OF PARTICIPANTS

Since November 30, 2011 a process of discussion began between UNICEF and CCDT on the need for a more comprehensive intervention as well as sharing around existing practices to offer protection to children impacted with HIV. Subsequently, between January and May 2012, a small group of practitioners working with HIV affected children have been meeting to discuss and deliberate on issues and challenges affecting children as well as mapping various initiatives towards achieving their rights. The organizations which formed a core group in spearheading efforts included Prayas (Pune) which works on care and counseling of HIV affected mothers and newborns, The Network of Maharashtra People with HIV (NMP+), an organization advocating for rights of HIV infected persons and working on treatment adherence and stigma-discrimination issues, Chirag (Mumbai) which works on entitlement rights of marginalized people, Lawyers Collective (Mumbai) working on legal advocacy and support, St. Catherine and Oasis which run institutional care programs for women and children, Centre for Advocacy and Research (CFAR) working on media advocacy related to HIV/AIDS and its impact and CCDT, providing institutional and non-institutional care and support to children infected, affected, and vulnerable to HIV/AIDS. The HIV and CP sections of UNICEF have tirelessly partnered the process. Together, the partners have been united in their vision and have interminably executed their ideas culminating in preparation of thematic papers and a platform for consolidating advocacy efforts. This platform became alive through the dedicated participation of Mumbai-based organizations like PRERNA, Act, MAMTA-HIMC(Nagpur), MSF (Medicines Sans Frontiers), Save the Children, IMCARES (Intermission Cares), World Vision and Community Development Initiative. The Consultation Meet registered active participation from organizations across Maharashtra, namely, Saheli HIV/AIDS Karyakarta Sangh (Pune), Soudamini (Network of positive women and children, Pune), Krupaprasad Kendra (Nashik), SOFOSH (Society of Friends of Sassoon Hospitals, Pune), Seva Dham Trust (Pune), Dilasa (Sangli), Armed Forces Medical College (AFMC, Pune), Muktaa Charitable Foundation (Pune), Rashtrasant Tukdoji Maharaj Shikshan Va Arogya Prasarak (RTM SAP MANDAL, Amravati),

Manavya (Pune), CFAR (Pune), Sangram (Satara), Social Development Education Trust (Parbhani), Vimala Sadan (Aurangabad) and Gramin Samaj Mukti Trust (Yavatmal).

Project Director, Maharashtra State AIDS Control Society (MSACS), and other distinguished government officials and ministers were also present. The Honourable Minister of Women and Child Development (WCD), Smt. Varsha Gaikwad and Minister of Health (Maharashtra), Shri Suresh Shetty as well as Shri Ujjwal Uke, Principal Secretary, DWCD, not only gave an encouraging response to the issues raised by the group but also presented perspectives of their own in addition to pledging their commitment to the same.

SITUATION ANALYSIS-PERSPECTIVES AND CONCERNS

The preliminary session to the Consultation, Situation Analysis, aimed at exploring the current status of policies and programs for children infected/affected by HIV/AIDS, thereby enabling identification of gaps in programmatic interventions and policy-making. Prof. Vimla Nadkarni from Tata Institute of Social Sciences (TISS), who chaired this session, began with the hope that emergent discussions would mirror different perspectives of looking at Child Protection. Pointing out different causes for the high prevalence of child-headed families, Prof. Nadkarni opined that such a situation should not be encouraged since it deprives children of a fulfilling childhood and is, therefore, a violation of their rights. She pledged her support to the beginning of a process that earnestly focused on the right of children to live with dignity.

Dr. Tushar Rane, HIV/AIDS Specialist, UNICEF, provided statistical and geographical context of the current situation of HIV/AIDS globally as well as nationally. Dr. Rane's presentation brought forward the following statistical appraisal:

› Around the globe 34 million people are living with HIV/AIDS of which 3.4 million are children. About 1.6-1.9 million people died due to AIDS in 2010, of which, 2,50,000 were children.

› Although Sub-Saharan Africa has the highest prevalence of HIV/AIDS in the world, 4 million people are estimated to be living with the infection in South and South-east Asia. Deaths due to AIDS in South-east Asia amounted to 0.27 million in 2010.

› India, with a population of 1.1 billion, has an estimated 2.27 million people living with HIV/AIDS.

› Among 440 million children in India an estimated 75 million are orphans (due to all causes), 3-4 million children affected by AIDS (CABA) of which, 1,25,000 are children living with HIV/AIDS (CLHAs). Admittedly, the number of children affected by HIV/AIDS cannot be arrived at accurately.

› An estimated one-fifth (18% or 4.20 lakh) of the people living with HIV/AIDS in India are from Maharashtra, which is considered as one of the High Prevalent States in the country. It is estimated that annually about 3,500-4000 children are born HIV positive in Maharashtra. Far from being uniform, the impact of the epidemic has been felt particularly in three zones of Maharashtra, namely, districts of Sangli, Satara, Sholapur and Kolhapur in South Maharashtra, Nagpur, Chandrapur and Yavatmal in East Maharashtra and urban areas of Mumbai, Thane and Pune.

› Available evidence on HIV epidemic in India points out to a declining trend. However, the HIV epidemic in India is characterized by heterogeneity in its spread among people (most concentrated in high risk group population; women accounting for 39% per cent of the infected population) and across geographical area (presence of high prevalence pockets in low prevalence areas and an increasing rural spread).

› Heterosexual mode of spread is predominant (85.69%), followed by parent to child transmission (5.4%), intravenous drug abuse (1.6%) and blood and blood products (1%).

› A scale up of the numbers of ICTC and ART Centres and the availability of second-line ART treatment in many of the hospitals across Mumbai is a robust response to decrease the medical suffering of children. However, linkages between available services continue to remain a daunting challenge. The issue of stigma and discrimination compounds the situation further, making it difficult for several PLHIVs and CLHIVs to access health services.

› The following challenges were identified:

• Unavailability of reliable estimates of children in need of ART and data on AIDS orphans

• Inadequate access to bio-medical prevention tools

• Inadequate knowledge of the determinants of stigma and discrimination

• Inadequate infrastructure and technical resources in comparison to the need

Dr. Mamta Manglani from the Pediatric Center for Excellence laid emphasis on collective efforts to counter the impact of HIV/AIDS on children. She shared her experience on the nature of medical services available and the bottlenecks that could be overcome through concerted effort from doctors as well as the community. Her presentation focused on the ramifications of specific aspects of medical care:

› HIV prevention in adults is difficult to deal with, but zero new prevalence in children is possible. Similarly, zero discrimination is also up to the communities. However, at present communities are not geared to accept that HIV is just another infection.

› 30% of children living with HIV die before their 1st birthday if they do not have access to ART. This alone proves the necessity to remove stigma and discrimination. Dr. Manglani proposed that to overcome stigma and discrimination in the community more sensitization and awareness on HIV/AIDS have to be created apart from sensitizing the medical fraternity. Currently, 10 out of 65 cases reported on stigma and discrimination are against children. As part of the best practices of the Pediatric centre for Excellence, periodic trainings are organised. These trainings are aimed at addressing instances of stigma and discrimination.

› An improvement in Prevention of Parent to Child Transmission (PPTCT) coverage would make a meaningful difference in children's lives.

› Transport often becomes a problem for economically marginalized communities to access health services. Specifically, in case of EID, mothers do not often understand that their children are positive and even when they do, travelling to a distant location becomes problematic for them. Therefore, they 'drop-out' from accessing those services. NGOs could have an important role to play in tracking such cases and ensuring that they could be put on ART treatment.

› Early Infant Diagnosis (EID) shows promise in terms of extending medical treatment to infants even before they turn symptomatic and irrespective of their clinical and CD4 status.

› With stigma and discrimination against HIV infected being so strong, disclosure to young children becomes

difficult. Most of the children are too young to understand the nature of the infection. Instead, one should discuss with them the methods to address the manifestation of the infection.

› Building essential linkages among all stakeholders would ensure that an estimated 8% per cent mortality rate would come down drastically, thereby improving health services in terms of accessibility and availability.

› As recommendations, Dr. Manglani, cited the need for a comprehensive health care model for orphan and vulnerable children with a special focus on adolescents and a need to address stigma and discrimination, to be crucial in increasing the efficiency of existing medical services.

Dr. Vinay Kulkarni from Prayas (Pune) delineated the psycho-social impact of HIV/AIDS on children and the ways through which we could minimize them. He said that the efficiency of Anti-retroviral Therapy (ART), Early Infant Diagnostics (EID) and other medical treatment has increased the longevity of children and adolescents infected by HIV/AIDS. However, predominant stereotypes surrounding children and adolescents persist in such proportions that their unique psycho-social needs remain unaddressed. Highlighting the need for individualized understanding and action on the psycho-social issues typical to children and adolescents, Dr. Kulkarni's observations and suggestions were:

› The current response to customized care for children infected with HIV/AIDS has several shortcomings. EID is being rolled out but it has not been universalized; pediatric counseling issues are being addressed in trainings only recently; legal provisions (the definition of child as 14 years in the health sector) makes it difficult for adolescents to seek testing; available quality of pediatric HIV treatment and care remains wanting; stigma and discrimination are still widely prevalent; children's views are rarely taken into account while formulating policies and programs.

› Children, like adults, are entitled to informed consent, confidentiality and non-discrimination. But their legal status as children prevents them from having a degree of autonomy in decision-making and makes them more reliant on adults. All categories of children - infected, affected, and vulnerable to infection, those undergoing multiple hospitalization as well as those who do not have accessibility to medical services or face institutionalization - need individualized care.

› Some of the challenges faced by orphan and vulnerable children include painful investigations (children go through mental trauma even to do simple tests), long duration treatment (adherence to medication), peer rejection and separation from parents/siblings.

› Pediatric Counselors should be rigorously trained on the unique needs facing each child. An understanding of the social locations of children is an important precursor to this. Involvement of parents in the process of counseling is desirable. Counseling must be adapted to the needs of the child based on mental status, clinical status and level of compliance.

› Institutionalization of children should be minimized to ensure children's right to family. The quality of care in institutions which shelter infected and affected children should be closely monitored to prevent violation of child rights.

› Almost 25 per cent children/adults access care in private healthcare sector (no regulatory protocols exist for the private sector) leading to inadequate therapy and lack of psycho-social support.

› Delay in disclosure denies children an understanding of their medical condition and the need for treatment adherence. Disclosure is mandatory and should be done by parents. In their absence, a professionally trained counselor should be entrusted with disclosure. The appropriate age is twelve years.

Ms. Vaishali Naik and Mr. Manoj Pardesi of NMP+ shared a series of crucial experiences that form hurdles in the path of accessibility of medical services:

› Facilities for monitoring of the nutritional requirements of infected and affected children are inadequate.

› Stigma and discrimination present in institutions like medical hospitals disallow mothers bearing infected children to deliver.

› Transport expenses are a major economic burden for infected children in marginalized communities to access existing health services.

› Minimum standards of care and protection essential for any institution running shelter homes for infected children are not being implemented.

› Political will needs to be built around these issues. The numbers often become a deterrent in generating political interest to push for policy level changes.

Mr Pramod Nigudkar, Director of Programs at CCDT, presented a detailed analysis of what Child Protection encompasses. Children are, definitely, the focus, not because they are our future citizens but because they have a right to live like children. Mr. Nigudkar vociferously argued that when talking of Child Protection in the context of HIV/AIDS, one needs to move beyond numbers of infected to the even larger number of affected and those who remain vulnerable to HIV/AIDS. Only then can we position the discourse of limited numbers in a broader perspective. In his appeal to introspect on how far the existing provisions facilitate Child Protection, Mr Nigudkar, raised the following questions:

› Do we have any platform to interact with the children, their families and extended families and the community about HIV/AIDS? Are we doing that enough?

› Child Protection encompasses protection from stigma and discrimination in the process of accessing key services in health and education. Are we looking at Child Protection in such a broad sense such that it encompasses protection of the violation of child rights across all areas?

› Child Protection ensures quality health services to children infected, affected and vulnerable to HIV/AIDS. Is there enough infrastructure to ensure children their right to health?

› In mapping vulnerabilities of children, should poverty not be considered an important dimension of vulnerability and therefore Child Protection?

› Are our programs really addressing the issue as to what kind of physical environment is available for children? Do we have sufficient caregivers in institutional facilities (trained and sensitized human resources)?

› Are we pushing for creating a socio-political environment that looks into creating child-friendly policies?

Challenges include lack of data on infected, affected and vulnerable children, scarcity of trained human resources, associated stigma and discrimination in all spheres and lack of comprehensiveness in our policies, programs and practices.

Conclusion and Key Areas of Action:

The presentations brought in different but equally relevant perspectives of looking at Child Protection. They provided a balance between macro and micro perspectives, recommendations for change and challenges that face us, stressing the need for more such platforms to facilitate greater interaction and collaboration. Some of them were:

› Ensuring inheritance and property rights of HIV affected children.

› Waiver of court fees for legal process for children needing support.

› Ensuring confidentiality and continuity of treatment (largely an issue with children in government institutions).

› Enhancing availability of ICTC and ART Counselors and their capacity building

› Paying special attention to the availability of counselors and skill building of pediatric and adolescent counseling to provide child centered counseling

› Monitoring the number of children who get linked to further care and support after EID

› Encouraging Community based home based care to supplement the medical treatments available.

› Encouraging self-reliance and capacitating communities to take care of their children , which is the ultimate goal of all interventions.

THEMATIC PRESENTATIONS

HEALTH RIGHTS

The significance of health as an important domain of Child Protection in the context of HIV/AIDS has emerged as a shared experience. The right to health is not restricted to freedom from diseases but includes within its ambit a state of complete physical, mental and social well-being. The speakers of this session focused on how this complete state of well-being for children infected/affected by HIV/AIDS could be brought about. To bring about development and

well-being of children in terms of accessibility to quality health services and knowledge about the same would comprise protection of health rights of children.

Chaired by Dr. Daniel, the session found its speakers in Dr. Vinay Kulkarni and Mr. Manoj Pardesi. Hon'ble Health Minister of Maharashtra, Mr. Suresh Shetty, actively joined in receiving recommendations and providing suggestions on the issue.

Dr. Kulkarni's presentation pointed out that even though HIV prevalence in India has been steadily declining in comparison with Sub-Saharan Africa, the overall disease burden continues to remain high. Similarly, 1,15,000 CLHIVs throughout the country, indicates a declining number. Still, due to high burden of adult HIV (of whom almost 40% are women of child bearing age) the number of children in families with HIV is going to be large (NACO Annual Report 2011). Highlights of his presentation were:

- To focus on children infected and affected by HIV/AIDS is not enough. Children vulnerable to HIV/AIDS should also come under coverage of Child Protection.
- Reflecting further on the intersecting factors that cause marginalization of children, Dr. Kulkarni, argued for a greater involvement of the State in ensuring the protection of the child in case the child has no family.
- The securing and protection of the rights of children should be guided by the principles of UNCRC. Therefore, involvement of children in decision-making and keeping the best interest of children is a primary concern
- There is very little access to HIV prevention information, education and services, and little access to paediatric treatment if infected with HIV for affected adolescents and children.
- The global financial downturn has negatively impacted HIV/AIDS service provision and funding. This has resulted in increased vulnerabilities faced by those living with the infection or caring for infected family members.
- Due to unavailability of child-specific policies, CLHIV, HIV affected and vulnerable children will remain invisible unless there is urgent policy attention.
- Identified challenges are low prioritisation, lack of resources, want of training and learning opportunities and IEC material

Response from MDACS:

- There has been a scale-up of treatment options in Maharashtra with 61 ART Centres, 142 Link ART Centres and over 800 ICTC Centres
- Linkages have been made between Community Care Centres (CCCs) and Drop-in Centres to provide care and support
- Networking with NGOs is important to improve coverage

Issues raised for discussion were:

- How do we make use of existing schemes like Integrated Child Protection Scheme (ICPS) in addressing the needs for children infected, affected, and vulnerable to HIV/AIDS?
- Coverage and quality of health services accessible by infected and affected children leaves much to be desired. The government should be taking up the responsibility of creating conducive policies and programs to increase coverage to reach out to more numbers as well as upgrade the quality of care provided.
- The psycho-social issues need to be paid adequate attention along with medical ones.

Inputs by the Hon. Minister of Health, Shri Suresh Shetty:

Active cooperation and presence of the Honourable Minister generated a meaningful exchange between the advocacy groups and State authorities. Hon. Health Minister commented that HIV/AIDS has always garnered attention and interest from international organisations as well as national policymakers. In recent times, however, the diminishing numbers of HIV infected has resulted in a proportionate decrease in the funds of several organisations which have been working on this issue. Simultaneously, the Minister remarked, several organisations that have established good practices of working on the issue of HIV/AIDS can always look towards the State and Central Governments for resources. The State has given adequate consideration to the issue of HIV/AIDS. A number of Departments in the State Government of Maharashtra, including his own, have several programs that cater to the unique needs of women and children. The need of the hour is to stimulate greater convergence among all existing programs and the work of relevant Departments. The Minister pointed out that PPTCT has been earmarked as the flagship program of the Department of Health in Maharashtra. The success of PPTCT lies on awareness building. Even after several attempts through government as well as non-government bodies, knowledge about HIV/AIDS among some sections of the population continues to remain low. This hinders the accessibility to health services like the ART. Mr. Shetty argued for strengthening the system of surveillance whereby pregnant mothers visiting Primary Health Centres (PHCs) can be tested for HIV. Consequently, it would become easier to prevent mother to child transmission. Increasingly, however, more number of parents is going to private institutions. The condition of the surveillance systems in private institutions needs to be monitored rigorously in order to make PPTCT successful and in ensuring that lesser number of children is born infected. The Minister expressed concern about the growing number of reports of children being abused in institutions of care and support. This rising trend is disconcerting since the abusers are the ones who have been

entrusted to be the custodians of orphaned and vulnerable children. The primary purpose of any institution providing care and support to children is to ensure a safe and secure environment. Hence, strict monitoring and evaluation of the quality of services rendered by the government as well as NGOs, needs to be carried out religiously. The funding of organizations that indulge in child abuse or practice any form of discrimination should be promptly terminated. Citing economic marginalization as a significant hurdle in the accessibility of ART and other services addressing HIV/AIDS, the Minister articulated the need to strengthen the systems whereby health services could reach the most marginalized and vulnerable population. Identifying after-care as an important intervention for infected and affected children, Mr. Shetty urged the advocacy groups as well as MSACS to come forward with recommendations and guidelines that would secure children their future after they have attained the legal age of adulthood. He argued for a more comprehensive model of Child Protection instead of having individual programs

for specific diseases. Inviting representatives from the advocacy group to discuss in detail the issues raised during the Consultation, the Minister extended his commitment in carrying this initiative further.

Conclusion and key areas of action for the Session:
Strengthening the systems under the Juvenile Justice Act:
› Creating mechanisms to ensure Child Protection from trafficking and any physical or emotional abuse or violence.
› Expansion in the scope of work of CWC to include cases of stigma and discrimination as well.
› Sensitization and train the CWCs to ensure effective protection of infected as well as affected children's rights.

› Ensuring minimum standards of care and protection for institutions sheltering children infected and affected by HIV/AIDS.
› Aftercare, a crucial determinant in ensuring the well-being of children infected and affected with HIV/AIDS after they cross eighteen years, could be linked up with existing policies and schemes of after-care in Maharashtra as well as with the provisions of Juvenile Justice Act.

Ensuring Education and Health related support:
› Training and sensitization of teachers and other staff in educational institutions is of foremost importance.
› Creating child centred care and support programmes to increase access to quality protocols and other required services for PPTCT as well as for continuum of care
› Creating comprehensive counselling training modules, IEC materials, and dissemination tools for raising mass awareness

Building Partnerships and involving stakeholders:
› Strengthening partners and partnerships at all levels and building coalitions among key stakeholders.
› Constituting of a Coordination Committee at the State level comprising representatives from the various Departments (like Labor, Women and Child Development) and representatives of Civil Society to facilitate greater coordination and convergence of action with regard to Child Protection in the context of HIV/AIDS.
› Giving particular attention to the roles of young boys and girls, men and women, and address gender discrimination.
› Ensuring that external support strengthens and does not undermine community initiative and motivation.
› Documenting best practices at the village level and creating a platform (like the present one) to facilitate greater convergence of efforts towards Child Protection.

INSTITUTIONAL AND NON-INSTITUTIONAL CARE AND SUPPORT

Facilitated by Mr. Suryakant Kulkarni and accompanied by panelists Sr. Shanti from St. Catherine's Home and Mr. Pramod Nigudkar from CCDT, the session predominantly focused on models of institutional and non-institutional care and support available for children infected and affected by HIV/AIDS. The scope of Child Protection was explored in the backdrop of the nature, quality and degree of care and support available, both in the community and at home, that enables HIV/AIDS affected and infected to become self-reliant.

On behalf of CCDT, Mr. Pramod Nigudkar shared experiences of institutional and non-institutional practices. Briefly, these were:
› Children affected by HIV/AIDS (CABA) include the following – children orphaned due to HIV infected parents, and infected children.
› The causes leading to severe vulnerabilities among CABA are manifold. These include lack of financial and other resources, parental care and emotional support.
› Care and support for CABA within the community is a preferable option. Dislocation of children from their natural environment is not desirable. However, many times family environment may not be conducive for the child's healthy growth, leading to the need for substitute care.
› Community based care is an attempt to enable families

and communities in which CABA live to provide care and support for the child. Although it is ideal to have interventions protecting the rights of affected children at the community level, lack of a holistic approach and enthusiasm of State bodies continue to be a problem. It is, hence, important to determine how State can be involved in this process.
› The issue of child-headed families needs to be looked in at greater detail. Such families may result in overburdening the child with responsibilities. Such families may also be seen as an effort to keep siblings together in a common habitat with adequate care and support from the community.
› Approaches to family or community based care and support include:
Home-based care and support within the family
Home-based care and support for child-headed families in the community
Providing for specific needs of CABA
Foster Care
Adoption
› Challenges facing community-based care include
› Lack of support from community due to stigma and discrimination
Difficulty in maintaining Confidentiality
Non-availability of quality foster care options
› In the absence of adequate community-based support for children affected by HIV/AIDS, institutionalization becomes the default option for orphaned children and those without adequate family care. Different forms of institutional care are provided by government as well as non-governmental organizations.
› Several institutions segregate children on the basis of their sero-status. There is a need to deliberate on this issue since it ends up stigmatizing positive children within institutional settings.
› Good practices in institutional care include a holistic approach to securing a child's overall well-being through quality care, non-discrimination on the basis of sero-status and facilitating re-integration with the community or extended family. Institutional care which is temporary in nature can be in the form of Crisis Intervention Centres.

Sr. Shanti shared her experience of heading St Catherine's shelter home:
› Provision of after-care is important since it bridges the lives of children in institutions to the outside world. Children are often overcome with fear and foreboding and need adequate support and guidance to facilitate reintegration.
› Stigma and discrimination against infected children often result in them being denied their chosen careers. There is a need to prevent disclosure of the sero-status of children in such cases.
› How can we address discrimination within schools? Greater absence due to medical reasons often causes embarrassment and needless harassment of infected children in schools.
› There is a need to document best practices of institutional care which can be disseminated and replicated elsewhere.

Inputs from the Hon. Minister of Women & Child Development, Smt. Varsha Gaikwad:
Hon. Minister Smt. Gaikwad congratulated the efforts of UNICEF and the partner NGOs in organizing the Consultation Meet. She stressed that as significant stakeholders, NGOs must come forward with recommendations on existing policies and practices.

Such recommendations are instrumental in bringing about progressive laws and programs. She reiterated the need for convergence across government departments in addressing several issues impacting children. The process whereby such convergence could be brought could be a crucial recommendation from the advocacy group. She accepted the importance of transportation in accessibility of health services and stressed the need to explore models prevalent in other states. She proposed the importance of periodic training of Anganwadi Workers on issues related to infected, affected, and vulnerable children. A similar sensitivity needs to be internalized through trainings of staff and human resources of institutional care settings. Stigma and discrimination can be challenged through policies; however, for it to get translated into reality, sensitization and awareness building in communities assumes paramount importance. Through strong and persuasive campaigns and IEC materials the mobilization of communities could be brought about. The Minister observed that all institutions must provide optimum levels of care and support to every child. Where children have special needs, they need to be catered to within institutions. However, data on how many such children (infected, affected, and vulnerable to HIV) needs to be provided first. She requested Maharashtra State AIDS Control Society to consolidate such statistics in order to steer government response to considering these realities in their programs.
Envisaging the strength of schemes like Bal Sangopan Yojana, Smt. Gaikwad, surmised whether such schemes could be strengthened to address the unique reality of infected and affected children. She approved of the need to have minimum standards of care and protection across all institutions. She invited the advocacy group to come forward with suggestions on how to monitor the

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standard of care and protection in children's institutions. After care Centres, while being crucially important to reintegrate the child back to the community, must be connected to livelihood options. She cited the "Earning while learning" Scheme and wondered whether such a scheme could be instrumental in reintegrating infected and affected children within the community. In conclusion, she reiterated her belief that the advocacy group could bring forth recommendations that are instrumental to increasing government responsiveness to children's rights in the context of HIV/AIDS. She pledged her participation and support in the entire process. The Minister expressed hope that perceived gulf between government and non-government bodies can be overcome through more frequent exchange of ideas and opinions, thereby bolstering responses.

Conclusion and Key Areas of Action:

Promoting family and community based care:

› Community home based care should be the preferred option to ensure Child Protection. It would not only prevent dislocation of the child from his or her natural habitat but would also address issues of stigma and discrimination.

› There should be specific guidelines and a pre-defined system of providing family and community-based care.

› Documentation of best practices on community home based care is necessary for replication.

Institutional care:

› Institutions should be open to children regardless of their sero-status. However, optimum standards of care and support for such institutions need to be laid out and formalised. This may apply to both government and non-government run institutional care for children. Existing challenges in affecting a change in attitude needs to be overcome first.

› In order to actualize these minimum standards of care and support in institutional as well as non-institutional settings, we need to be equipped with data about the number of orphan and vulnerable children (OVC), infected children etc. An estimation of numbers would enable the determination of the kind of infrastructure that would be required.

› After care programs for CABA graduating from institutional care and support on reaching 18 years of age need to be developed and instituted.

The Recommendations for policy as well as practice:

› Needs Assessment to draw up a holistic response to protect the rights of CABA

› Developing a comprehensive set of guidelines that govern the responses towards children infected as well as affected by HIV/AIDS beginning from diagnosis to provision of care and support.

› Replicating best practices in institutional and non-institutional care which are being carried out.

› Child centred policies with convergent action and a non-negotiable commitment to optimum standards of care and protection.

› Coordination across the multiple service providers ensuring holistic care and support for CABA with a designated government nodal agency responsible for ensuring the coordination

› Community mobilization on issues of care and support to enable communities to become self-reliant in addressing the needs of care and support of children infected and affected with HIV/AIDS.

› Networking between different organisations to support and guide each other in the process of protecting the rights of the child and right to childhood.

ADVOCACY: LEGAL AND OTHER ENTITLEMENTS

The session began with the chair, Dr. Shalini Bharat, reiterating the importance of advocacy to push for change as far as legal entitlements of children infected and affected by HIV/AIDS is concerned. She invited the panelists to a discussion on the need to have legal advocacy and the way forward.

Adv. Nitu Sanadhya from Lawyers Collective began the session by dwelling on the current status of the HIV/AIDS Bill which had been submitted in July 2006 to NACO but the passing of the Bill has been considerably delayed due to lack of ownership by any particular Department. She highlighted the following provisions in the Bill, which are relevant to Child Protection:

› Prohibition of Discrimination to address unfair treatment in healthcare services and education.

› Lowering age of consent, formulating specific protocols for counseling of children, and maintaining confidentiality

› No penalization of NGOs providing Risk reduction/ access to prevention services such as safer sex information and tools, clean needles etc.

› Recognizing right of children to health information, age appropriate information in schools

› Ensuring Access to treatment and making procedural requirements user friendly

› Ensuring treatment and counseling in cases of sexual assault including recognition of right of young person to decide who to involve in treatment- parent, family member or some other adult

› Making Social security schemes accessible for children affected by HIV

Provision of Child friendly health care

Protection of Property of Children affected by HIV/AIDS where parents, child, NGO can approach CWC for safekeeping of property documents or to complain of misuse/usurpation of property – CWC to pass appropriate orders; to take help of NGOs

Recognition of Guardianship of older sibling as 'managing member of a household' – school, bank accounts.

Provision for living wills, stand by guardianship and testamentary guardianship

She reiterated the need to create strong pressure groups in order to table the Bill in the Parliament to bring about policy level changes through its enactment.

Mr. Manoj Pardesi highlighted the following as crucial issues for advocacy:

› Mobilizing pressure groups to enable successful implementation of the HIV/AIDS Bill into a law.

› Complementing availability of services with accessibility. In most cases due to lack of resources, transportation costs or lack of awareness, available services are not being made use of.

› Strengthening and supporting the capacity of families to protect and care for children affected with HIV. This would include appointing of testamentary guardians and planning for the future of children to adequate evaluation and monitoring of existing schemes for social security.

› Mobilizing and strengthening community-based responses for the care, support and protection of infected and affected children.

› Ensuring that legislation, policy, strategies and programs are in place to protect the most vulnerable children

Mr. Anand from CFAR outlined the different social entitlements available for people living with HIV/AIDS and argued for interventions that ensure the convergence of existing policies and programs to ensure rights. The overlap between different dimensions of marginalization calls for a comprehensive response. To fight against HIV/AIDS induced vulnerability, other intersecting dimensions of vulnerability like violence, poverty, migration, displacement has to be looked into. He listed a series of available programs under the broad categories of social justice, urban development and housing, education and labor welfare. Awareness of these programs among organizations working with CLHIVs and PLHIVs would strengthen their response to HIV induced social impact.

Conclusion and Key Areas of Action:

› Forming pressure groups for the passage of the Bill

› Advocacy for special consideration of HIV affected children in the existing schemes/programmes of the Government.

› Facilitating availability of documents (like residence proofs) to access existing benefits. The process should be simplified.

› Having specific policies for special needs of high-risk groups such as sex-workers and their children.

RIGHT TO EDUCATION

Right to Education Act, 2010, is an instrument that recognizes education to be free and compulsory for children between ages 6 and 14. The moderator of the session, Dr. Sanjeevani Kulkarni emphasized the fact that the provisions in RTE make it mandatory for the State to provide quality education to all children. As such, RTE can have a major role in helping infected and affected children access quality education. However there remain serious concerns surrounding the implementation of the Act. One of them

is the lack of adequate infrastructure and personnel to cater to the Right to Education of all children in India. As such, it was felt that an analysis of the present situation regarding the quality of education available to children infected and affected needs to be made. Additionally, it is important to chart the effective way with which we can make greater use of the RTE Act and protect children's Right to Education.

Ms. Anna from Chirag shared some problems that invariably jeopardize the enjoyment of the Right to Education for children infected and affected by HIV/AIDS. Citing field experiences, she made the following recommendations:

› Child-friendly environment and sensitized teacher and staff are essential to make learning a fulfilling experience. The physical manifestations of the infection, for example, scars, often result in peer rejection of children within the school and community setting. Such children may become vulnerable to other forms of exploitation and substance abuse.

› School environment needs to be encouraging to children to avail of education. Many a time, instilled fear of being rebuked by teachers prevents children from voicing their difficulties in hearing. Periods of absence, especially where the infected child requires periodic medication, is often treated with contempt especially at the high school level.

› Lack of adequate number of government sponsored secondary schools means that children are left with two options – to drop out or to access costly education services in private educational institutions.

› Quality of education continues to be a consistent concern in government schools. Desire for English education often forces parents to spend money beyond their means in a bid to get their children educated.

› Nutritional deficiency is prominent among vulnerable children. It would be a progressive step to extend mid-day meal services to children in high schools.

Mr. Pankaj from CFAR presented key challenges faced by CLHIVs in accessing their rights under RTE Act:

› Poised as an instrument to bring about greater inclusion in the education system, implementation of RTE Act has belied its provisions. Stigma and discrimination continues to hinder accessibility of CLHIVs to quality education. Six incidents of discrimination against HIV infected/affected children accounting for 14.25% of the overall incidents of stigma and discrimination in schools and education systems, were reported after the RTE Act came into force..

› The quality of education as well as the facilities (like drinking water and toilets) available in certain educational institutions is not up to the mark

› In the context of CLHIV, accessing the Right to Education faces challenges of disclosure, unfounded fears, unaddressed rumours, lack of motivation in school and family's financial situation.

Conclusion and Key Areas of Action emerging from the session were:

› RTE provides free and compulsory education to children within the age-group of 6-14 years. The scope of the Act needs to be extended to include all children across all age-groups. This could prevent majority of drop-outs between primary and high school education, increase access and enable vulnerable children to access better livelihood opportunities instead of getting ghettoized in low paid jobs.

› Information on HIV/AIDS should be included in B.Ed. curriculum for better sensitization of teachers in educational institutions

› Trained counselors should be made available in government schools as well to address among others issues stemming from HIV/AIDS

› The role of CWCs in addressing cases of stigma and discrimination within schools should be encouraged and the capacities of CWC members strengthened

› A policy/Guideline by the Central Government on "NO DISCRIMINATION" in schools could be put into place. Periodic monitoring and evaluation of the kind of services available to children in schools need to be undertaken.

› Sex Education in schools which has been discontinued needs to be restarted. This should be seen in the light of the right of children to adequate and appropriate information regarding sexual and reproductive health. It can act as critical to prevention of new infections.

THE WAY FORWARD

SUMMARY AND RECOMMENDATIONS

The two-day Advocacy Consultation enabled participants to use different and divergent lenses in looking at Child Protection in the context of HIV/AIDS. The context of HIV/AIDS provided a continuum of realities that face children infected, affected and vulnerable to infection. Unpacking statistical numbers, questioning existing policies and programs and reiterating the need for constant linkages between various stakeholders, came up as prominent action points. The Consultation platform was enriched with the sharing of myriad experiences from the grass roots to the policy level.

Key recommendations and identified areas of action emerging from each session have been highlighted in each section. At the end of the program, Ms. Alpa Vora, Child Protection Specialist, UNICEF Maharashtra and Mr. Manoj Pardesi from NMP+ presented a summary of advocacy related recommendations for the different themes. These were as follows:

Specific Recommendations influencing policy and practice cutting across all sectors:

› Ensuring minimum standards in the quality of services and care across all sectors involving paediatric care and institutional care for children

› Human resources and capacity development of care givers and professionals with focus on child-centric care

› Mobilizing resources and support systems – human, financial, material to augment current work

› Facilitating convergence of key State departments and across all levels and civil society in this area of work

Approaches that would promote Child Protection involved the following:

› Improving coverage and access of services and their quality (Health, Education, child care and protection)

› Providing family and community centred care and support – Promoting Home based care, family strengthening and, where family is not available, care by relatives/extended families. Institutionalisation must be the last resort

› Providing child sensitive counselling to children as well as their parents/caregivers

› Providing age appropriate education especially to adolescents – empower them to live a meaningful sexual life, develop essential life skills and protect them from exploitation. Linkages with SABALA to be explored for this.

The specific areas of action with each of the Departments which have promised support have been identified as follows:

Department of Health:

› Child care and support programmes to increase access to quality protocols with emphasis on child-centred services and other required services for PPTCT as well as for continuum of care. Counselling identification and referrals through trained Anganwadi workers, ASHA workers etc.

Creating comprehensive counselling training modules, IEC materials, and dissemination tools for raising mass awareness

Psycho-social Care

› Developing standardized training programs for all counselors

› Ensuring the inclusion of child centered counseling in all training modules for counselors

› Ensuring the availability and adequate number of trained counselors in all health care settings

› Provision of Free Transportation – to access medical care and services

Department of Women and Child Development:

Linking with ICDS:

› Anganwadi Workers (AWW) and providing Training & Sensitization on Children and HIV (to be promoted through ToT)

› Effective implementation of the relevant State GR on double ration for HIV affected children – to be done through step by step approach to identification, provision of support and follow up

Legal Support Services

› Protection of Property and Inheritance Rights through free legal assistance, especially in case of orphan children
› Effective coordination with CWCs to ensure protection of children's property.
› Strengthening Juvenile Justice System and structures.
› Capacity Building and Sensitisation Required for CWCs
› SOPs on dealing with issues of children affected by HIV for CWCs

Quality Care in Institutions

› Ensuring adequate number and skilled human resources in institutions
› No segregation based on the sero-status of children in institutions
› Developing specific guidelines and standards of care for institutional care (across all departments)
› After care programs that cater to the special needs of children above the age of 18 years need to be instituted.

Non institutional Care

› Guidelines for organisations offering family based and non-institutional alternative care programmes
› Family strengthening programmes such as Bal Sangopan Yojna (BSY) of DWCD to be promoted
› Child Protection Schemes in the State to have special provisions for children infected/affected by HIV/AIDS.

Department of Education:

› A policy/Guideline by the State on "NO DISCRIMINATION" in schools could be put into place. Periodic monitoring and evaluation of the kind of services available to children in schools need to be undertaken.
› Information on HIV/AIDS and Sexuality education should be included in B.Ed. and D.Ed. curriculum for better sensitization of teachers in educational institutions
› Trained counselors should be made available in Government and Government-aided schools to address issues stemming from HIV/AIDS as well
› Sexuality education in schools which has been discontinued needs to be restarted. This should be seen in the light of the right of children to adequate and appropriate information regarding sexual and reproductive health.

The Overall strategy of work with Government could be:

Constituting of a Coordination Committee at the State level comprising representatives from the various Departments (like Labor, Health, Women and Child Development) with the DWCD as the Nodal Department and representatives of Civil Society to facilitate greater coordination and convergence of action with regard to Child Protection in the context of HIV/AIDS.

› Advocacy with the State Commission for Protection of Children's Rights (SCPCR) to ensure that there is no Stigma and Discrimination in Schools, Hospitals and Communities

As mentioned at the outset, the Consultation was not viewed as a onetime event, and it was decided that the members will continue to meet again as a Forum and also as thematic group for a close follow up of the recommendations and suggestions that emerged from the Consultation with the respective Government Departments. Periodic meetings with leadership from CCDT and active participation from all members would help to make a difference to the lives of children affected and infected by HIV. The positive responses from the different Departments were encouraging, and attempts need to be made for continuing the meaningful dialogue at different levels for the planning and implementation of programmes for this extremely vulnerable group of children.

ANNEXURE I: PROGRAM SCHEDULE

TIME	TOPIC	EXPERT SPEAKERS	CHAIRPERSON/ RESOURCE PERSON/S
DAY I **ANCHOR: KAMINI KAPADIA**			
10.00 am to 10.45 am	Registration and Tea		
10.45 am to 11.30 am	Song – Tod do Deewaren Welcome and Introducing the Consultation: Opening Remarks by Govt. Representatives	Mr. Tejinder Sandhu, CFO, UNICEF PD of MSACS – Mr. Ramesh Devkar	
11.30 am to 1.30 pm	Situation Analysis: Perspectives and Concerns	• Dr. Tushar Rane • Dr. Mamta Manglani • Dr. Vinay Kulkarni • Ms. Vaishali Naik • Mr. Pramod Nigudkar	Dr. Vimla Nadkarni
1.30 pm to 2.15 pm	**LUNCH**		
2.15 pm to 3.30 pm	Thematic Panel I: Children and their Health Rights around HIV and AIDS	Prayas and NMP+	Dr. Daniel E. E.
3.30 pm to 3.45 pm	Response by the Government Representative	Hon. Minister Health – Mr. Suresh Shetty PD MSACS – Mr. Ramesh Devkar	
3.45 pm to 5.00 pm	Thematic Panel II: Care and Support for Children in institutions & Children living in communities	CCDT and St Catherine's Home	Mr. Suryakant Kulkarni
DAY-II **ANCHOR – PANKAJ BEDI**			
10.00 am to 11.30 am	Thematic Panel III: Advocacy - Legal and other entitlement issues	Lawyers Collective, NMP+ and CFAR	Ms. Shalini Bharat
11.30 am to 1.00 pm	Thematic Panel IV: Right to Education in the context of Children and HIV/ AIDS	Chirag, Oasis and CFAR	Ms. Sanjeevani Kulkarni
1.00 pm to 1.45 pm	**LUNCH**		
1.45 pm to 2.00 pm	Representatives from the Government	Hon. Minister DWCD – Ms. Varsha Gaikwad	Ms. Tinku Biswal
2.00 pm - to 2.30 pm	Presentation on Outcome of the Consultation: Policy & Practice Recommendations around CP and HIV	Ms. Alpa Vora and Mr.Manoj Pardesi	Ms. Tinku Biswal
2.30 pm to 4.00 pm	Response from Government Representatives and interaction session	Hon. Minister DWCD – Ms. Varsha Gaikwad	Ms. Tinku Biswal
4.00 pm	Vote of Thanks		Dr. Tushar Rane

ANNEXURE 2: LIST OF ORGANIZING COMMITTEE MEMBERS

NO.	ORGANIZATION
1.	UNICEF: ALPA VORA, DR. TUSHAR RANE, KAMINI KAPADIA
2.	COMMITTED COMMUNITIES DEVELOPMENT TRUST (CCDT): PRAMOD NIGUDKAR, CHHAYA RADE, CHERIE ANN PEREIRA
3.	PRAYAS: VINAY KULKARNI, SANJEEVANI KULKARNI
4.	CENTRE FOR ADVOCACY AND RESEARCH (CFAR): ANAND BAKHADE, PANKAJ BEDI
5.	ARMED FORCES MEDICAL COLLEGE (AFMC): DR. AK JINDAL
6.	NMP+: MANOJ PARDESHI
7.	LAWYER'S COLLECTIVE: NITU SANADHYA
8.	ST. CATHERINE'S HOME: SR. SHANTI REMEDIOS
9.	CHIRAG: ANNA FERNANDES, VANITHA D'SOUZA

ANNEXURE 3: LIST OF PARTICIPANTS

LIST OF OUTSTATION PARTICIPANTS:

ORGANIZATION	PARTICIPANT/S
Saheli HIV/AIDS Karyakarta Sangh, Pune	Tejaswi Sevekari Mandakini Desale
Soudamini [Network of positive women & children] Pune	Ujwala Kadam
Krupaprasad Kendra, Nashik	Sr.Cisily Joseph
MAMTA-HIMC, Nagpur	Pallavi Bhandarkar
SOFOSH (Society of Friends of Sassoon Hospitals) Pune	Asha Ratan Kanade Purva Pandit Thakar
Seva Dham Trust, Pune	Nitesh Davande
Dilasa, Sangli	Fr. Sabu Mathew
Armed Forces Medical College [AFMC], Pune	Dr. A.K.Jindal
Muktaa Charitable Foundation, Pune	Dr. Rupa Agarwal Shweta Chawan
RTM SAP MANDAL, Amravati	Dr. Raghunath Wadekar
Manavya, Pune	Ujwala Lawate Sonali Ghadage Siddhi Raste
Prayas, Pune	Dr Vinay Kulkarni Dr Sanjeevani Kulkarni Dr Ritu Parchura
CFAR, Pune	Anand Bakhade Pankaj Bedi
Sangram, Sangli	Sushila Kunde Sunita More
NMP+	Vaishali Naik Yuvraj Shinde Manoj Pardeshi.
Social Development Education Trust, Parbhani	Suryakant Kulkarni
Vimala Sadan, Aurangabad	Sr. Sheeba Paul
Gramin Samaj Mukti Trust, Yavatmal	Praful Uke
Terre Des Homes, Pune	Sampat Mandave
Women & Child Development, Pune	P. N. Waghmare Lahade Vidya

LIST OF PARTICIPANTS FROM MUMBAI:

ORGANIZATION	PARTICIPANT/S
Prerana	Priti Patkar Saumya Bahuguna
ACT	Alita Ram Sharmila Amar
Chirag	Dr Anitha Chetiar Anna Fernandes Vaneeta D'Souza Krishnakant Prasad
St. Catherines Home	Sr. Shanti Remedioes
Lawyers Collective	Nitu Sanadhya
Oasis	Vasu Vitthal Accumma
Individual	Sarita Shankaran Dr Sharad Agarkhedle
MSF	Asmaa Valiyakath Mariana Garcia
Save the Children	Ipshita Das
World Vision	Heather Ferriera
IMCARES	Sonali Gaekwad Beryl Coutinho
Community Development Initiative	Jovita Lemos
Our Children	Kalpana Gaekwad
NTP + Thane	Bharti Sonawane. Harshala Salvi Jude Emmanuel
IAPA	Laxmi Nair
Courtyard Attorneys	Veena Johari
Tata Institute of Social Sciences	Shivranjani Shweta Bajaj
Plan India	Devdatta Deshpande
Child Welfare Committee, Mankhurd	Adv. Indumati Jagtap
Mumbai State AIDS Control Society	Dr. Swapnali Patil

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