

**National Commission for Protection of Child Rights (NCPCR)
Government of India
New Delhi**

NATIONAL CONSULTATION ON HIV/AIDS – RIGHTS AND ENTITLEMENTS OF CHILDREN

OCTOBER 27, 2010

Vigyan Bhavan Annexe (Hall 'C'), New Delhi

AGENDA

Time	Session	Presentations
10:30-11:15	Welcome Address & Introduction	Mr. Lov Verma, Member Secretary, NCPCR
	Opening Remarks	Honorable Chairperson NCPCR: Prof. Shantha Sinha
11:15-1:00 (15 min per state)	<p style="text-align: center;">FIRST SESSION</p> <p style="text-align: center;">Presentation of State specific Interventions for Children living with HIV/AIDS.</p> <p style="text-align: center;">Review of Compliance of Public Hearing Directives.</p>	<p style="text-align: center;">Chaired by Mr. Lov Verma</p> <p>1)Mr. R.R. Jannu, Project Director, Karnataka State AIDS Prevention Society</p> <p>2)Dr. R V Chandravadan IAS, Project Director, Andhra Pradesh State AIDS Control Society</p> <p>3)Dr Aiswarya, Joint Director (Basic Services Division), Tamil Nadu State AIDS Control Society; District Collector, Villupuram, Tamilnadu</p> <p>4)Dr Anant Hazarey, Maharashtra State AIDS Control Society</p> <p>5)Dr Pradeep Kumar, Addl. Project Director, Gujarat State AIDS Control Society</p>

1:00-2:00	LUNCH	
2:00-3:30 (15 min each)	SECOND SESSION Rights and Entitlements of Children (Health & Nutrition, Education, Shelter & Care: Barriers & Needs, Community based Care & Advocacy) – Need for a Comprehensive Policy	Chaired by Dr. Veena Shatrugna 1)Mr. Mayank Aggarwal, JD (IEC), National AIDS Control Organisation 2)Dr Veena Shatrugna, Former Director, National Institute of Nutrition, India 3)Ms Akhila Sivadas, Executive Director, Centre for Advocacy and Research 4)Ms Anjali Gopalan, Executive Director, NAZ (I) Foundation, New Delhi 5)Ms Jyothi Kiran, Founder, Milana, Bangalore 6)Dr Preeti Kumar, Associate Professor & Project Director, HIV/AIDS Project, Public Health Foundation of India
3:30-4:45 (15 min each)	THIRD SESSION Rights and Entitlements of Children – Legal	1)Ms Veena Johari, Advocate 2)Mr. Sarath Chandra, Member-Secretary, National Legal Services Authority 3)Mr. Raman Chawla, Lawyers Collective 4)Ms Kajal Bhardwaj, Lawyer
4:45-5:00	Vote of Thanks	Mr. Lov Verma, Member-Secretary, NCPCR
5:00	Tea	

Concept Note

1. Introduction

Constitution of India (COI) guarantees right to education, food, non-discrimination, nutrition, protection from exploitation and harm to children in India. India is one of the signatories of the United Nations Convention on the Rights of the Child (1989)¹, and in accordance with the convention's guidelines, the Indian government has adopted a rights based approach to deal with issues related to children.

The National Commission for Protection of Child Rights (NCPCR) was constituted in March 2007 under the Commission for Protection of Child Rights Act, 2005, to ensure the enforcement of child rights and the implementation of policies and programmes needed for the welfare of children². In accordance with its mandate, NCPCR adopted various mechanisms such as field visits, consultations and conferences, constitution of working groups to formulate or improvise laws and policies to perform its functions. Among the many mechanisms adopted by the Commission, public hearings have been observed to be the most citizen input-oriented mechanism. One of the issues being addressed through this mechanism has been rights and entitlements of children in the HIV/AIDS context. The situation of child rights and entitlements in India in the HIV/AIDS context has been consistently alarming despite of State policies and programs for services to children.

NCPCR holds public hearings which include meetings with state and district officials, officials from concerned departments, and consultations with NGOs, community based and other civil society organizations in order to address denial of rights, the systemic failure in service delivery and the lack of institutional capacities. NCPCR has held a series of public hearings on a wide-ranging list of issues pertaining to child rights across the country.

2. Rights and Entitlements of Children living with HIV/AIDS

Orphan and vulnerable children, infected/affected by HIV/AIDS, are being grossly denied their fundamental entitlements such as education, nutrition, leisure, safe and secure environment, housing, property rights, shelter, legal aid, medication (pediatric dosage) and/or treatment (ART as well as for Opportunistic Infections). Two emerging challenges are the issues of *child-headed households* and understanding the effectiveness of *community foster care*. Significant issues such as recognition of guardianship of caregivers (de facto guardianship), implementation of an Adoption law and Foster Care model, presence of updated data of children living with HIV, law on child sexual abuse, advocacy, awareness and redressal mechanisms, and an increased inter-sectoral convergence among all the government and non-government organizations and stakeholders need to be addressed to win the fight against this epidemic.

3. Addressing the Issue of Rights and Entitlement for Children in HIV/AIDS context

In efforts to addressing the issues of children in HIV/AIDS context, six public hearings have been held by NCPCR for orphan and vulnerable children infected/affected by HIV/AIDS in Tamil Nadu (Chennai), Karnataka (Bangalore), Maharashtra (Mumbai), Andhra Pradesh (Hyderabad), Manipur (Imphal), and Delhi (where West Bengal, Orissa, Gujarat, Nagaland and Uttar Pradesh also participated), involving the participation of ten states.

The public hearings have shown the challenges faced by children to live a life with dignity and the responses of various State governments in provisioning of services – in terms of health care, psycho-

¹ <http://www.unicef.org/crc/>

² <http://ncpcr.gov.in/>

social support, nutritional support through ICDS, mid day meal schemes, PDS and other programs, education facilities, free transportation, access to institutional as well as non-institutional support and so on. Further, efforts of the State have been focused largely on prevention of HIV/AIDS amongst adults and minimal on prevention of pediatric HIV and adequate provisioning of care and protection to those children affected and infected by HIV/AIDS

It has been found that combating HIV/AIDS is a multi-sectoral issue, and involves simultaneous efforts by institutions and organizations working at different levels of governance. In order to avoid fragmented response towards a larger issue, strong leadership, co-ordination and tracking of outcomes by a central authority and system is required. The reality of the theoretical guidelines offers a huge gap between the on-paper policies and their on-ground implementation.

Towards this, a National Consultation on 'HIV/AIDS – Child Rights and Entitlements' is being organized by NCPCR to address the aforementioned issues and find comprehensive national policy solutions with the participation of all the stakeholders. The consultation will also focus on lessons learnt from public hearing and follow up efforts of the State Governments since the hearings.

4. Expected Participants for the Consultation

1. Concerned officials of Department of Women and Child Development/ Social Justice/ Health and Family Welfare/ School Education/ Rural Development/ Food and Civil Supply/ Panchayati Raj/ District Collectors of select states;
2. Project Director, National Rural Health Mission (NRHM)/ State AIDS Control Society/ Sarva Shiksha Abhiyan (SSA)/State Legal Aid Services Authority;
3. Selected NGO Representatives, academics, activists who have been involved in the field of child rights and specifically working with children on rights and entitlements in the context of HIV/AIDS.

5. Expected Outcomes of the Consultation

1. Review of the public hearing follow up by NCPCR
2. Review of existing laws, systems, institutions and policies of states regarding child rights and entitlements in the context of HIV/AIDS
3. Sharing of best practices by states and NGOs
4. Increase interdepartmental as well as inter-sectoral convergence to ensure implementation of programmes, policies and schemes meant for children living in the context of HIV/AIDS
5. Firm up the policies relating to children living in the context of HIV/AIDS

Minutes –

Introduction

The meeting was initiated by Mr. Lov Verma, Member-Secretary, NCPCR, with a welcome address. He gave a brief yet informative background of the public hearings held by NCPCR to address the issue of Rights and Entitlements of orphan and vulnerable children infected and affected by HIV/AIDS. The address was followed by a round of introduction of the participants.

Dr Shantha Sinha, Chairperson, NCPCR, in her opening remarks, emphasized the role played by the mechanism of public hearing in bringing out instances of children infected and affected by HIV/AIDS who wanted to live and were brave enough to address a large audience. She indicated that the fight against the epidemic of HIV/AIDS is not secretive anymore and Positive People's Networks function in the open to ensure that State interventions reach the people and the children living with HIV/AIDS. Dr Sinha also pointed out the donor-centric approach adopted by organizations. She said that it was unfair if support was withdrawn from certain projects and programmes due to lack of funds after children were given hope and aspirations of a better future. The need for an institutionalized response was also highlighted by her – "what if the same officer is not there?"

First Session

Presentation of State specific Interventions for Children living with HIV/AIDS and Review of Compliance of Public Hearing Directives

Dr Naina Rani, Deputy Director, PPTCT/NRHM Integration, Karnataka State AIDS Prevention Society

Data on ART, Link ART, Community Care Centres (CCCs), and children registered on ART was shared with the group along with the new initiatives and treatment facilities such as Early Infant Diagnosis (EID) and Strengthening Provider Initiated Testing (SPRIT). It was informed that support of Rs 1 crore has been provided by the Karnataka Government for children living with HIV/AIDS for the present financial year. The CABA (Children Affected By HIV/AIDS) Care Program, pilot project, is being developed and implemented in Belgaum and Bagalkot districts. There are four exclusive CCCs for the CABA model catering to the needs of 200 children living with HIV/AIDS and Foster Care Units are being developed. The role of Link Workers and District level Networks in providing support to children and their families living with HIV/AIDS was presented.

In terms of challenges, Dr Naina indicated the magnitude of the need of services as well as diversity and urgency of needs of children to provide timely relief. An action-taken report regarding the cases of children to be addressed on a priority basis was also submitted to NCPCR after a reminder was made. The Commission was informed that Sneha Care, an institution providing residential care to children living with HIV/AIDS, shall receive the FIT Institution status in 30 days time as a result of the Karnataka public hearing directive.

Dr R V Chandravadan, Project Director, Andhra Pradesh State AIDS Control Society

Dr Chandravadan presented the data on positive children registered and on ART. Strategic response by the State – constitution of institutional mechanisms, piloting of CABA in East Godavari and Krishna districts, child friendly ART centres, treatment of malnutrition among HIV affected children – and several other mainstreaming efforts were discussed along with the outcome, progress and success of these initiatives, for instance, double ration to children, light work employment to PLHIV, ration cards and pensions to families etc. He declared that Sahara cards, a precursor to the Smart cards, to 36,000 children and people living with HIV, are being issued. He named malnutrition among children, lack of livelihood options for bedridden single parents, and high levels of stigma and discrimination as major challenges in Andhra Pradesh and made recommendations such as specific policy for children, separate budget allocation for child specific programs etc.

Dr Veena Shatrugna proposed that a consultation should be held to formulate diet plans for children living with HIV. While the wide range of initiatives presented was appreciated, questions were raised as to why these services are not reaching children and they are moving from Andhra to other States. Concern was raised by Lawyers Collective regarding reservation for children living with HIV under the Right to Education (RTE) Act and whether the denial of admission on the basis of HIV status would lead to de-recognition of the school. It was informed that it would. An action-taken report of the Andhra Pradesh public hearing has been submitted to NCPCR after a reminder was made at the Consultation.

Dr Aiswarya, Joint Director (Basic Services Division), Tamil Nadu State AIDS Control Society

Dr Aiswarya revealed to the group that Tamil Nadu is no longer a high prevalence State and from the past four years has become a medium prevalence State. She mentioned that there is a Tamil Nadu Trust for Children Affected by HIV/AIDS (TNTCAA) with the objectives to provide educational, nutritional, medical and socio-economic assistance. Disbursement of funds to single and double orphan children takes place through the trust fund. The compliance of Chennai public hearing directives was also discussed and it was pointed out that all 8 District Collectors were present during the Chennai hearing, have accorded top priority and have personally addressed the grievances.

The Chairperson, NCPCR, asked about the grievance redressal mechanisms and it was informed that the ART Centres have drop boxes wherein complaints are dropped and the serious ones go up to the State Grievance Redressal Committee convened by the Principal Secretary, Health. Tamil Nadu also has legal aid clinics where cases are dealt with. ART Centres also have the provision of directing complaints to the legal aid centres where disputes and grievances, mostly involving property, are redressed. Noori, from SIP Shelter Home, pointed out that while houses have been constructed in districts such as Villupuram, Chennai still faces a problem when it comes to construction of houses and shelter homes. FHI responded to the presentation by mentioning that the points relating to stigma and discrimination, legal assistance and institutional care were missed out. Dr Aiswarya brought to notice that TNSACS is funding 6 care homes and is addressing stigma and discrimination through the Positive People's Networks.

Dr Anant Hazarey, Regional Coordinator (ART) Maharashtra State AIDS Control Society

An action-taken report of the Maharashtra public hearing was presented and the status of 16 cases as well as the implementation of NCPCR directives was discussed. Dr Hazarey presented the data and State specific interventions for children as well as the operational guidelines for the CABA program as being implemented in the districts of Sangli and Nagpur. A brief presentation about the CHAHA Programme, as implemented in Maharashtra, was also given.

Dr Pradeep Kumar, Addl. Project Director, Gujarat State AIDS Control Society

Action-taken report and the present status of children who deposed from Gujarat in the Delhi public hearing was presented by Dr Kumar. Implementation of various innovative schemes for children living with HIV was presented and discussed. An updated public hearing action-taken report was submitted to the Commission post the presentation.

Second Session

Rights and Entitlements of Children (Health & Nutrition, Education, Shelter & Care: Barriers & Needs, Community based Care & Advocacy) – Need for a Comprehensive Policy {Chaired by Dr Veena Shatrugna}

Mr. Mayank Aggarwal, Joint Director (IEC), NACO

An overview of the epidemic in India was presented with child-specific data. Care, Support and Treatment Initiatives for children living with HIV/AIDS were also presented such as educational, nutritional, travel and vocational initiatives. The new initiatives under National Pediatric AIDS Initiative were discussed – Pediatric First Line, Alternative First Line and Second Line ART, Strengthening of Provider Initiated Testing in Pediatrics (SPRIT), Pilot scheme on Children affected by AIDS (CABA), and Launch of Early Infant Diagnosis (EID) from 6 weeks of birth. Mr. Mayank called the need for continued medical care and optimum nutritional requirements of children as challenges.

Ms Veena Johari pointed out that the issues of shelter and care, and maintenance have not been covered by NACO. Ms Anjali Gopalan expressed her disapproval over the fact that no long term care option was being made available to orphan and vulnerable children. She revealed that the funding for Community Care Centres (CCCs) has also been stopped. Dr Veena Shatrugna mentioned that NACO was one of the first organizations to be constituted for addressing the aforesaid issues and it is unfair if after so many years it wants to piggyback on other departments and schemes (such as ICDS) to address the important issue of nutrition; instead of providing powders good food should be provided to these children. Ms Padma from Alliance suggested that rather than linking children to schemes, food security for them should be ensured

Dr Babu from NACO clarified that due to improper functioning of the CCCs an audit had to be conducted and therefore the funding has been stopped temporarily. He also declared that NACO would consider having a consultation with experts regarding the nutritional guidelines for children living with HIV/AIDS. Ms Ivonne Cameroni, from UNICEF, pointed out that the issues of confidentiality and disclosure have not been addressed by either NACO or Ministry of Women and Child Development and stated that the CCCs are temporary and medical solutions to the problem of children and HIV.

Dr Veena Shatrugna, Deputy Director (Retired), National Institute of Nutrition, Hyderabad

She emphasized the fact that children in India have a double burden because of malnutrition and HIV and thus the food problem needs to be addressed especially for children living with HIV. HIV has struck India at a time when 50% of our children are undernourished; proneness to TB has also increased. Experts and organizations in India should follow the WHO guidelines on Nutrition requirements of PLHIV; NACO should look at these guidelines, have a consultation on food for children and make it a part of Right to Food. Ideal meal plan for children living with HIV/AIDS was discussed clearing many widespread misconceptions about dietary requirements of children. Noori, from SIP Shelter Home in Chennai, revealed that the powders provided to children are made in Punjab and by the time they reach Chennai they are 4 months old and spoilt. Instead, she suggested, children should be provided with fish, rice, oil, etc. to provide holistic nutrition.

Ms Akhila Sivadas, Executive Director, Centre for Advocacy and Research (CFAR)

She declared that stigma and discrimination had been at its peak from 2005 to 2007 and the major villain in this regard was the health care provider. She suggested that NCPCR should play the role of the complaint redressal organization, have its redressal mechanisms in place, have a jury, complaint section, visit States, follow up on implementation and grill the erring duty bearers to ensure redressal.

Ms Anjali Gopalan, Executive Director, Naz (I) Foundation

She emphasized the need for “continuum of care” – shelter, institutional and community-based; it was pointed out that when an NGO is derecognized for funding for lack of transparency, children have nowhere to go and it negatively impacts their well-being. It was highlighted that if the Government feels that the institutions are not providing the best care to children, it should take up the responsibility to do so or set up effective monitoring mechanisms to oversee the functioning of shelter homes. Discontinuing funds to existing services/programmes for children is not the solution to address the issue.

Ms Jyothi Kiran, Founder, Milana, Bangalore

Milana is a family support network of people living with HIV/AIDS and gives special attention to women and children; it primarily works through counseling and peer support. Milana has initiated a child support group called 'Chiguru' (sapling) where children living with HIV come together and discuss their issues with each other. The network has set an example for others to follow in terms of its community based care and advocacy; as a result of the Karnataka public hearing and the advocacy carried out by the network a child and his mother received legal aid and now have access to widow pension and their property. Similarly the issue of CWC membership is also being addressed by Milana; other issues involve promoting a foster care model, media advocacy, nutrition and universal access to treatment. Ms Jyothi informed that Milana also plans to launch a CABA forum bringing all children under one umbrella.

Vital gaps in the policies for children living with HIV were pointed out involving issues relating to special protection, nutrition, CWCs etc. and a consultation including child participation was suggested to address the policy gaps and develop a more comprehensive policy framework.

Dr Preeti Kumar, Associate Professor & Project Director, HIV/AIDS Project, Public Health Foundation of India

Data on the estimate of the problem of HIV in India was shared along with the different routes of transmission. The impact of HIV on mothers and children was discussed – social exclusion, exploitation, loss of home/property, job, education, child abuse etc. Dr Preeti communicated the current interventions through NACP III, namely Early Infant Diagnosis, PPTCT, Pediatric HIV/AIDS Initiative, and the CABA program. Gaps in the coverage were presented along with the challenges being faced and role of the key players such as NACO, policy makers, donors etc.

Third Session

Rights and Entitlements of Children – Legal

Ms Veena Johari, Advocate

Rights and entitlements of children were presented along with the problems faced by them in terms of livelihood, health, education, protection etc. Further the rights of children which are mostly being violated were discussed and the enforcement of those rights by various Government departments was shared.

Mr. Sarath Chandra, Member-Secretary, National Legal Services Authority (NALSA)

He reiterated the point that decisions should be taken in the best interest of the child. As per the Legal Services Authority Act, children are entitled to free legal services. However children do not come to

access the services, the services should reach out to them. NALSA is starting a nation-wide project, conducting training of trainers, to create a network of paralegals and assist in providing legal aid.

Mr. Raman Chawla, Lawyers Collective

The framework of the HIV/AIDS Bill was presented highlighting its substantive provisions (such as prohibition of discrimination, consent & confidentiality, access to treatment etc.), grievance redressal, and implementation. The process of drafting the Bill started in May 2002 and it is one of the few bills in India which has been drafted after various consultations; however it has been with the Health Ministry since March 2010. The Bill provides for legal redressal in private sector (school or hospital) which was till now outside its purview and if it is passed in its present form everything – access to treatment, tests, treatment of opportunistic infections etc. – will be free of cost.

Regarding the property issue, any one (child or the family) can submit the papers to the CWC and it will take care of the property rights; also, the guardianship of older siblings with respect to orphan children will be recognized and there is a provision of living will by parents infected by HIV. However the Bill does not talk about the guardianship of other care givers such as grandparents, aunts, uncles, etc. and the organizations working in this area should submit letters regarding this issue to the Standing Committee. De facto guardianship is one of the 12 provisions still pending.

Ms Kajal Bhardwaj, Independent Lawyer

The cons of Free Trade Agreements of India with Japan and the European Union were revealed; it was divulged that the medicines in India are set to become more expensive as a result of these Agreements which have taken place without any consultation with NACO and the SACS. She also brought to light the fact that a group of positive people protesting peacefully outside Udyog Bhawan were lathi charged, thereby questioning the extent of police sensitization.

Ms Lakshmi, from ActionAid Hyderabad, spoke about the consequences of the public hearing held by NCPCR in Andhra Pradesh and submitted a list of recommendations to the Chairperson, NCPCR regarding CCCs, NGO funding, treatment & nutrition services, child-headed households, CWCs, and implementation of NCPCR directives. This was followed by a vote of thanks by Mr. Verma, who expressed his gratitude to the participants for contributing richly to the Consultation.