



'Policy Framework for Children and AIDS' India

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Ministry of Women
and Child Development



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HIV/AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights – of the care, love and affection of their parents; of their teachers and other role models; of education and options for the future; of protection against exploitation and abuse. The world must act now, urgently and decisively, to ensure the next generation of children is AIDS-free¹.

¹ A Call to Action: Children, the missing face of AIDS. UNICEF, UNAIDS 2005

1. Introduction

Children² affected by HIV/AIDS include a relatively small number of children who are HIV-positive and a far larger number who are not infected but whose parents are living with, or have died of AIDS. In addition, there is an even larger group of adolescents³ who are at a heightened risk of HIV infection because they engage in unsafe behaviour or live in communities which are vulnerable to HIV.

The Government of India is committed to preventing HIV-infections and mitigating the medical impact of the virus on the lives of those already infected. It has already provided a detailed vision of how it proposes to do so in the National AIDS Control Programme 2007–2012 (NACP III). However, there is a need for a simple yet comprehensive Policy covering a broader agenda, spanning both the medical and socioeconomic dimensions of the epidemic as it affects children.

The Policy Framework adopts a rights based approach. It takes into account recent changes in the global understanding of the adverse impacts of HIV/AIDS on children, and of the best ways to address them. It is cognisant of advances in medical science.

The first priority of this Policy is to prevent HIV infection, in order to ensure an AIDS-free generation. In addition to prompt diagnosis, the focus will also be to ensure access to treatment to prolong life. Treatment of parents is vital to maintain family cohesion and protect the best interests of children. And where families are affected by HIV/AIDS, the imperative is to ensure

they are not excluded from the same services and opportunities as others. For families affected by HIV/AIDS the Policy will seek to ensure their inclusion and access to social services and opportunities.

NACP III focuses on ensuring that HIV-positive children receive medical treatment and after-care, access to schooling, adequate nutrition and a safe environment. However this Policy Framework seeks to broaden the focus to address the needs of the overwhelming majority of children affected by HIV/AIDS in recognition of the fact that the virus is seen to have a profound and permanent effect on their lives.

The Policy Framework also recognises the futility of trying to differentiate between children in distress, and affirms the need for a universal approach in addressing the needs of all children subjected to social exclusion⁴, neglect and abuse, including those affected by HIV/AIDS.

This implies that these children and adolescents are provided with equitable access to social services and opportunities, without in any way compromising on the need to ensure prevention of infection among adolescents most at risk.

The Policy on children and HIV/AIDS seeks to broaden the partners to implement the vision, the guidelines and the interventions proposed herein.

The Policy provides a mandate and a framework for government departments working at all levels of governance for the welfare of children

² Children are defined in this document as those who are less than 18 years old. More definitions and concepts are contained in the Annexes.

³ Adolescents - age group 10-19 years

⁴ Social exclusion also results from gender, caste, economic status, disabilities.

to collaborate and also establishes a mechanism to coordinate the efforts of civil society and NGOs and the private sector, non profit and for profit in the achievement of its aims and objectives.

India has a unique opportunity to use her strengths – low prevalence, concentrated epidemic, rapidly increasing ART coverage, strong government structures and family safety nets,

growing recognition and advocacy for human rights and a robust media – to free the next generation from the burden of AIDS.

This Policy Framework provides guidance to each ministry for undertaking detailed planning of programme activities in order to scale up interventions. Operational guidelines have been developed to guide such programming and scale up.

2. Children and HIV/AIDS

The number of people living with HIV/AIDS in India is estimated to be 2.0 - 3.1 million, giving a national adult prevalence of 0.36 percent. According to national estimates women account for almost 39 percent of all HIV infections.

It is estimated that 70,000 children below the age of 15 are infected with HIV in India and 21,000 children are infected every year through mother to child transmission⁵. A small proportion are also infected by unsafe injections and infected blood transfusions, a preventable cause which continues in resource limited countries. Nearly half of reported AIDS cases are in the 15–29 age group⁶.

⁷Based on antenatal prevalence (ANC), six states in India have been identified as high prevalence states (having more than 1.0 percent HIV

prevalence in general population), three states as moderate prevalence states (concentrated epidemic with more than 5% HIV prevalence in high risk population) and the rest as low prevalence states. However, on the basis of vulnerability factors such as migration, size of the population and weak health infrastructure, the low prevalence states/UTs have been further classified as “Highly Vulnerable” and “Vulnerable” states.

2.1 Heterogeneity of HIV Epidemic

The epidemic in India is very heterogeneous with diverse modes of infection, particularly in southern and western states, namely, Tamil Nadu, Karnataka, Andhra Pradesh, Maharashtra and two north eastern states, namely, Nagaland and Manipur. Even within states, there is a wide

Table 1: Categories of States

High Prevalence	Moderate Prevalence	Low Prevalence	
		Highly Vulnerable	Vulnerable
Tamil Nadu Andhra Pradesh Maharashtra Karnataka Nagaland Manipur	Gujarat Goa Pondicherry	Assam Bihar Delhi Himachal Pradesh Kerala Madhya Pradesh Punjab Rajasthan Uttar Pradesh West Bengal Chhattisgarh Jharkhand Orissa Uttaranchal	Arunachal Pradesh Haryana J & K Meghalaya Mizoram Sikkim Tripura A & N Islands Chandigarh D & N Haveli Daman & Diu Lakshadweep

⁵ Updated NACO estimates, 2007

⁶ NACO 2006

⁷ National AIDS Control Programme 2007–2012, Chapter 2

variance in HIV prevalence between and within districts as evidenced by data from HIV sentinel surveillance centres and Integrated Counselling and Testing Centres (ICTCs). The epidemic in India is largely driven by sub epidemics among sex workers, injecting drug users and men who have sex with men. HIV infection prevalence among high risk groups as per the data in 2006 is around 10% in FSW, MSM and IDUs.

2.2. Categories of Districts

Based on the HIV surveillance data, epidemiological profile, risk and vulnerability, NACO has classified the 611 districts in the country into four categories viz. A, B, C and D, many of them located within the so called low prevalence states. For further details on categories of districts and state-wise break-up please see Annex 4.

Table 2: Category of Districts

	Category of Districts	
1.	More than 1% ANC/PPTCT prevalence in district in any time in any of the sites in the last 3 years	A
2.	Less than 1% ANC/PPTCT prevalence in all the sites during last 3 years associated with more than 5% prevalence in any HRG group (STD/CSW/MSM/IDU)	B
3.	Less than 1% in ANC prevalence in all sites during last 3 years with less than 5% in all STD clinic attendees or any HRG with known hot spots (migrants, truckers, large aggregation of factory workers, tourist etc)	C
4.	Less than 1% in ANC prevalence in all sites during last 3 years with less than 5% in all STD clinic attendees or any HRG or No or poor HIV data with no known hot spots/unknown	D

2.3. Adolescents at risk and vulnerable to HIV infection

Adolescents are at risk of HIV infection from unprotected sex with multiple partners, or with a partner who has multiple partners, and through injecting drug use and blood transfusions. These situations are most likely to arise among children who are vulnerable to abuse or trafficking, or who are denied information and engage in risky sexual experimentation.

2.4. HIV infection in young children

HIV disease in children affects their immature immune system at a very early stage in perinatally acquired infection. These children experience rapid progression to severe symptomatic disease. As a consequence of HIV infection, severe nutritional and immune deficiencies occur in children leading to higher mortality in children less than five years old. 40 percent of HIV-positive children under 18 months in clinics experience developmental delays. Cumulative mortality is 33% in first 12 months, 50% by 24 months and 60% by 36 months.

Early diagnosis for confirmation of infection in children under 18 months exposed to HIV through vertical transmission is the cornerstone of treatment, care and support interventions. Providing adequate nutrition and micronutrients at early stages improves immune status, delaying disease progression and mortality. Simultaneously children should be followed up with regular CD4 estimations and clinical evaluations to establish eligibility for antiretroviral therapy. Children on ART combined with appropriate nutritional supplementation respond rapidly, ensuring normal development⁸.

2.5. Social exclusion, impact of HIV on children

The single most adverse impact of HIV/AIDS is stigma and discrimination which is weakening social support systems, intensifying vulnerability and impacting on the economic status of those affected.

While economic deprivation has resulted in children withdrawing from school to care for sick parents or earn additional income, social discrimination has resulted in the denial of basic services to affected children, especially health and education services⁹. Discrimination enhances the vulnerability of children to disease and also subjects them to other forms of exploitation.

Another study conducted by UNDP¹⁰ showed that more than a third of the sample of

HIV-affected households were headed by widows. The study further shows that in such households there is a higher school absenteeism among children and boys are being withdrawn from school to earn income for the family. Conversely the study found that many widows who had no source of income and were denied parental and marital property were resorting to sex work in order to support their children.

The above situation necessitates a systemic response to ensure social inclusion and access to services by HIV/AIDS affected persons to allow them to realise their full potential and to lead healthy and productive lives.

The challenges facing children in the context of HIV/AIDS in India are illustrated in Table 3:

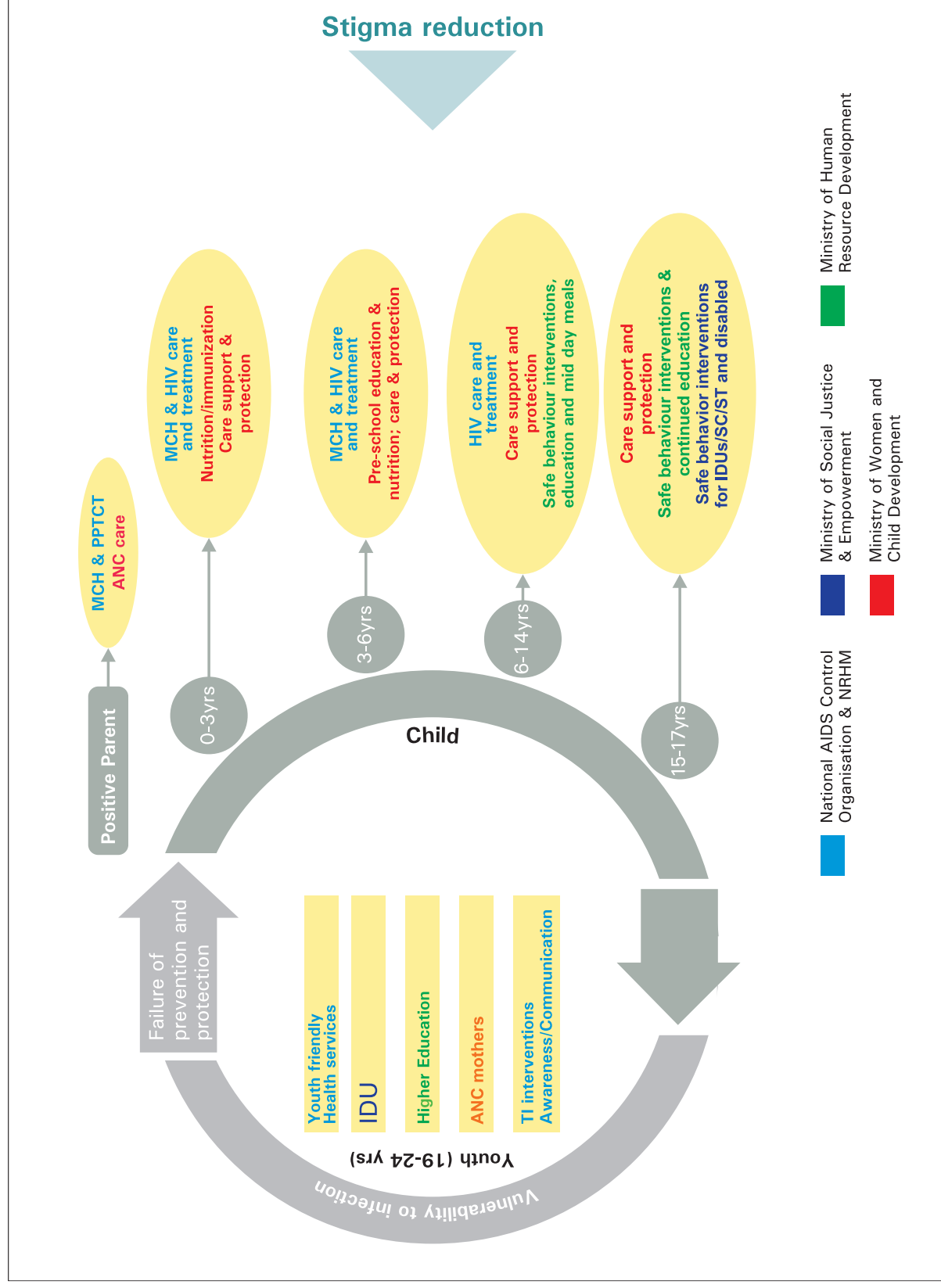
Table 3:

Target population	Adolescents vulnerable to infection	HIV-positive pregnant women	HIV-positive children	Children orphaned or affected by HIV/AIDS
Impact	Biologically and behaviourally most at risk of infection	Can infect new born children before, during or after birth	Likely to die within two years unless diagnosed & treated Social impacts as for affected children →	Parental illness often leads to poverty and disintegration of family Stigma often leads to exclusion from family and community support, and from public services and entitlements
Actions	Life-skills education in schools Targeted interventions with high-risk groups and out of school adolescents	Diagnose (VCT and ANC) PPTCT	Paediatric ART Early diagnosis and treatment Help parents and children cope with medical and psychosocial issues Address social impacts →	Diagnose and treat parents Ensure access to standard services and entitlements for all children – including those affected by HIV/AIDS Redress the rights of those excluded, and refer for additional services where required.

⁹ 'Barriers to services for children of HIV positive parents, UNICEF, 2007.

¹⁰ Socio-Economic Impact of HIV and AIDS in India, NACO, NCAER and UNDP 2006; www.undp.org.in; www.ncaer.org.

Desirable action to meet the challenges is diagrammatically described in Figure 1:



3. Scope of the Policy

3.1. The Policy framework

- provides rights-based programming guidance to MOHFW (NACO & NRHM), MWCD, MHRD and MSJE to develop and implement programmes for children and AIDS in a coordinated manner;
- forms the basis of implementation by all donor agencies, international NGOs and civil society organisations, private foundations, and other like stakeholders/partners, working in the area of children and AIDS under the leadership of Government;
- complement Policy guidance in NACP III and the GOI 11th Five Year Plan on issues concerned with children.

The Policy Framework¹¹ focuses on

- Pregnant HIV infected women.
- Children including adolescents who are vulnerable to HIV infection.
- Children who are HIV infected.
- Children who have a parent (or two) who has died from AIDS related conditions.
- Children who have a parent (or two) who is HIV infected.

3.2. Guiding principles

This Policy reaffirms

- The unifying principle of the “Three Ones”, i.e. one strategic action framework, one national HIV/AIDS coordinating authority and one national system for monitoring and evaluation;
- India’s commitment to achieving the Millennium Development Goals, particularly

Goal 6 – halting and beginning to reverse the HIV epidemic by 2015;

- India’s commitment to the UN Convention on the Rights of the Child, acceded to in 1992;
- The SAARC Regional Framework for programming for children affected by HIV/AIDS (2007, in draft);
- The National AIDS Control Programme 2007–2012 (NACP III)

The SAARC regional framework for programming for children affected by HIV/AIDS, provides that children affected by HIV/AIDS¹²

- Have the same rights as other children – specifically to the care of their parents and extended families, to health, education, legal services, social security, and protection against abuse and neglect;
- Effectively pose no risk of infection to others, and as such should have access to the same social service facilities and providers, including schools, hospitals, health clinics and welfare services as other children.

The Government further acknowledges its duty to implement the provisions of the UN CRC for all children, including those who are affected by HIV/AIDS, which provides for the Right

- To information and material aimed at the promotion of social, spiritual and to moral wellbeing, physical and mental health (art. 17)
- To health (art. 24) and to preventive health care, sex education and family planning education and services (art. 24 (f))
- Not to be separated from parents (art. 9) and to be protected from violence (art. 19)
- To social security and social insurance

¹¹ While the framework focuses on children, it does recognize that children grow up in families and communities and interventions need to take place in that context.

¹² This subsection is drawn from the SAARC Regional Framework for programming for children affected by HIV/AIDS, and will evolve in line with that document.

- (art. 26) and to special protection and assistance by the state (art. 20)
- To education and leisure (arts. 28 and 31)
 - To be protected from economic and sexual exploitation and abuse, and from illicit use of narcotic drugs (arts. 32, 33, 34 and 36)
 - To be protected from abduction, sale and trafficking as well as torture or other cruel, inhuman or degrading treatment or punishment (arts. 35 and 37)
 - To physical and psychological recovery and social reintegration (art. 39)

The design and implementation of interventions will be guided by

- The views and best interests of children, as expressed by them, including children living with or otherwise affected by HIV/AIDS, and with the active involvement, of PLHA;
- The unique needs of children of different ages and genders, within different socioeconomic and cultural settings, and facing any threats to their rights or prospects including illness and exclusion for reasons other than HIV/AIDS;
- The need for an enabling environment, free of stigma and discrimination, in which prevention, treatment and mitigation activities will succeed and the rights of all children – including those affected by HIV/AIDS – will be met;
- The representation, strengthening and active involvement of civil society;
- Equity and universal access to services and entitlements by all children, including those living with HIV or otherwise affected by HIV/AIDS;
- Efficiency and accountability through evidence-based programming, monitoring and evaluation of impact and the sharing of information among all stakeholders;
- Coordinated action across sectoral, institutional and geographic boundaries;
- Prioritisation of those communities where children are most vulnerable to HIV infection, or to the medical and socioeconomic impacts of HIV/AIDS.

The rights of children in the context of HIV/AIDS

will be met by ensuring access by children, parents, communities and public service providers to accurate and timely information so they can:

- Protect themselves and their new born children from HIV infection;
- Understand and defend their rights and entitlements;
- Overcome the fears and misconceptions which underpin stigma and discrimination.

3.3. Overall Goal

India will provide a sustainable and integrated system of HIV prevention, counselling, testing, treatment, care and support to ensure that children who are vulnerable to HIV-infection or who are HIV-positive or otherwise affected by HIV/AIDS enjoy the same benefits and opportunities as all other children to develop their full potential.

3.4. Strategic Objectives

- To create a non stigmatising environment, enabling access by children and young people to prevention services including complete information and skills to protect themselves from and reduce their vulnerability to HIV infection;
- To identify HIV-infected parents and children early, and to provide high quality treatment and support to prolong and maintain the quality of life, and to ensure they are able to fulfil their potential and responsibilities;
- To ensure that affected children – whether HIV positive or not – are not excluded from or treated differentially by service providers in the public and private sector;
- To eliminate stigma and discrimination by overcoming myths and misconceptions in relation to HIV/AIDS, and by implementing regulatory and legal measures to address discrimination wherever it occurs.
- To ensure social protection measures are in place to prevent and redress violations of their rights and entitlements.

4. Strategies, Objectives and Targets

Strategies to implement this Policy must employ a life-cycle approach while keeping elimination of stigma and discrimination central to the formulation, implementation and monitoring of all policies, programmes and activities. Evidence-based strategies based on the Global Campaign¹³ are as follows:

- Primary prevention– to reduce and eliminate HIV infection among adolescents by encouraging behaviour change and linking to services.
- Prevention of parent to child transmission – to reduce vertical transmission of HIV from mother to child before, during or after birth, ensuring access for care and treatment of mothers and follow up care of mothers and infants;
- Paediatric AIDS treatment – to diagnose and treat new-born children, ensure drug adherence and provide assessment based nutritional supplementation;
- Protection and care of children and families affected by AIDS – to ensure that children who have been orphaned by AIDS, have a parent who is HIV-positive, or are HIV-positive themselves, have equal access to family and alternate care and services without discrimination and on par with other children in their communities.

Objectives and Targets¹⁴

4.1. Primary Prevention among adolescents

4.1.1. Global goal

By 2010, reduce percentage of young people living with HIV by 25 percent globally

4.1.2. NACP III goals

The overall outcomes envisaged under NACP III for young people are reduction of risk behaviour, especially among young people, and reduction in rate of HIV infection among young people.

4.1.3. Programme Targets

- 152,000 secondary and senior secondary schools having at least two trained teachers as a resource for implementing the Adolescent Education Programme.
- 25 million students to be reached through the Adolescent Education Programme.
- 70 million young people not in the school system including vulnerable youth, street children, children of CSWs, children in institutions and child labourers will be reached by HIV prevention skills education programmes and related services.
- 100 percent coverage of all high-risk groups including CSWs, IDUs and MSM.

4.2. Prevention of parent to child transmission

4.2.1. Global goal

- By 2010 offer appropriate services to 80 percent of women in need.

4.2.2. NACP III goals

- To scale up PPTCT services through public-private partnerships, extend the services up to the level of CHCs as part of the ICT centres to be established to prevent vertical

¹³ A call to action: Children, the missing face of AIDS. UNICEF, UNAIDS, 2005

¹⁴ The following sections present targets from the Global Campaign ; the National HIV/AIDS Control Programme, Phase III (NACP III) 2007-2012; and the Integrated Child Protection Scheme (ICPS) of the Ministry of Women and Child Development, AEP Framework and various schemes of the MSJE, within each of these strategic categories

transmission of HIV in an annual cohort of 70,000 HIV positive pregnant women throughout the country.

4.2.3. Programme targets

- 7.5 million pregnant women covered through PPTCT counselling and testing services;
- 75,600 HIV infected mother baby pairs to receive prophylaxis ART.

4.3. Paediatric AIDS treatment

4.3.1. Global Goal

- By 2010, provide either antiretroviral treatment or cotrimoxazole, or both, to 80 percent of children in need.

4.3.2. NACP III Goals

- All children eligible for treatment have access to treatment

4.3.3. Programme Targets

- 40,000 children receiving ART.

4.4. Protection and care of children affected by HIV/AIDS

4.4.1. Global Goal

- By 2010, reach 80 percent of children most in need

4.4.2. NACP III Goal

- To achieve highest quality of life¹⁵ for HIV affected children and their families and ensuring that they are not excluded from or treated differently within public services which are available to all children in their communities.

4.4.3. ICPS Goals

- All children (including children affected by HIV/AIDS) have access to basic services (health, education, nutrition and treatment for AIDS);
- Upholding the rights of children in difficult circumstances;
- Securing for all children (including children affected by HIV/AIDS) all legal and social protection measures to prevent and redress all forms of abuse, neglect and exploitation.

4.4.4. Programme Targets

- Number of children (including children affected by HIV/AIDS) linked to child welfare scheme;
- In the short term, to reach out to the maximum number of infected children, provide them with treatment and care and support services.
- In the long term, to achieve the highest quality of life for all children, including those who are HIV infected or otherwise affected, through a comprehensive set of basic health and education and social protection services¹⁶.

4.5. Reduction of stigma and discrimination

4.5.1. NACP III Goal

- To prevent and redress stigma and discrimination at all levels

4.5.2. Programme targets

- Each ministry has a written Policy on prevention of stigma and redressal of discrimination.

¹⁵ Quality of life should be interpreted in the context of local conditions – the intention is not to provide benefits to affected children or families that are not available to their neighbours.

¹⁶ This package constitutes nutrition, education, social security and medical support for children and livelihood support for families. In the long run this will be taken up by MWCD, MSJE and MHRD as their responsibility.

- Percentage increase in PLHA accessing social and community services and educational services without discrimination (NACP III)
- Increase in the number of reported instances of stigma and discrimination
- Effective response and redressal mechanisms in place for cases of discrimination on the basis of disease status.

4.6. Strategic Responses

Table 4 categorises the indicated actions according to service type and classification. Note that the concepts of universal and targeted interventions; mainstream or HIV/AIDS-specific interventions; and supply - or demand-driven services are discussed in Annex 1.

Table 4:

Objective for the child	Method	Service type	HIV/AIDS specific?	Supply-or demand-driven?
Primary prevention	Behaviour development and modification	Universal, information	Yes	Supply
Overcome stigma	Overcome myths & misconceptions	Universal, information	Yes	Supply
Overcome discrimination	Awareness of children's rights & entitlements	Universal, information	No	Supply
Screening & referral	VCT	Targeted service	Yes	Demand
Family support - medical	Parental ART, PPTCT	Targeted service	Yes	Supply
Family support - social/ medical	Counselling	Targeted service	No	Demand
Diagnosis and Treatment of AIDS	Paediatric ART	Targeted service	Yes	Supply
Family support - social	Facilitate access to services	Universal access	No	Demand
Alternative care	Family based care and Institutional care	Universal access	No	Demand
Enforce rights	Legal intervention	Universal access	No	Demand
Address discrimination	Redressal mechanism	Universal access	No	Demand

5. Mandate and Responsibilities of Government Bodies

An integrated, universal response to children and HIV/AIDS calls for inter-ministerial and inter-sectoral collaboration among many actors, inside and outside of government. However, it is essential that government assume leadership of this process and accept responsibility for the results, through four key ministries:

- Ministry of Health and Family Welfare, through the National AIDS Control Organisation and National Rural Health Mission;
- Ministry of Women and Child Development;
- Ministry of Human Resource Development; and
- Ministry of Social Justice and Empowerment.

The following section proposes key actions for each of these ministries. The actions are designed to fit into existing schemes rather than create new ones. Each Ministry is expected to mobilise additional resources for addressing the gaps in capacity and infrastructure required for the implementation of the key actions listed below.

Detailed operational guidelines have been developed in each of the following areas to inform programme design and implementation.

5.1. Ministry of Health and Family Welfare (MOHFW)

5.1.1. NRHM

This Ministry has a major role to play in mainstreaming HIV/AIDS health services beyond specific clinical interventions. These include removal of stigma and discrimination in all public health-care facilities, scaling up access to PPTCT services, establishing youth-friendly services, and outreach for HIV prevention and treatment of AIDS.

The community-based workers proposed under the NRHM (National Rural Health Mission) namely ASHA and the ANMs are important links between the programme and communities to ensure early diagnosis of HIV, adherence to treatment, and care for affected families and their children.

Key actions include

- Strengthen existing public health infrastructure to scale up access to youth-friendly health services;
- Integrate prevention, care, support and treatment with NRHM initiatives through RCH;
- Expanding access to institutional deliveries for increasing uptake of ARV prophylaxis as part of PPTCT services, family planning and abortion services, STD treatment, health education such as nutrition, breast feeding, alcohol, drug abuse etc.;
- Treatment of TB and opportunistic infections through TB control programmes.
- Treatment of opportunistic infections through public health infrastructure located as close to the community as possible;
- Institute procedures to prevent stigma and redress discrimination in healthcare settings by raising awareness, knowledge and empathy, and by enforcing hospital infection control and disciplinary action;
- Leverage utilisation of existing schemes and programmes to remove financial barriers and ensure social security in order to remove financial barriers and provide social security to children affected by HIV/AIDS;
- Ensure supply of and access to condoms to young people at high risk through

innovative distribution systems and promote dual use of condoms;

- Ensure access to safe blood;
- Train all health care providers in public health facilities at all levels on HIV prevention and against stigma and discrimination;
- Strengthen data management and review performance at state and district levels;
- Strengthen district health societies to oversee the implementation by DAPCU
- Expedite the processing of the HIV/AIDS Bill and utilize existing policies and laws to protect children against stigma and discrimination.

The key interventions for operationalizing the above are capacity building of service providers, building of an enabling environment, and the implementation of monitoring systems. The monitoring system will incorporate HIV data such as the use of condoms during last sex among 15–19 year olds, and the proportion of young people aged 10-19 who are HIV positive;

5.1.2. National AIDS Control Organisation (NACO)

NACO launched the third phase of National AIDS Control Programme in July 2007. The overall goal of NACP III is to halt and reverse the epidemic in India over the next five years by integrating programmes for prevention, care, support and treatment.

The specific objectives of NACP III are to reduce the incidence of new infections by:

- Sixty percent in high prevalence states to reverse the epidemic; and
- Forty per cent in the vulnerable states so as to stabilize the epidemic.

Three key focus areas within NACP III which relate directly to children are prevention of HIV infection among high-risk populations and adolescents; prevention of parent-to-

child transmission; and treatment of AIDS. These activities will be implemented by SACS and DAPCU in priority districts based on level of epidemic.

Prevention among high risk groups and in communities vulnerable to HIV infection will be implemented by civil society. Rural prevention programmes will introduce a new cadre of workers called link workers who will support mapping, mobilise communities and implement interpersonal communication activities for behaviour change.

PPTCT services will be provided by existing medical and paramedical personnel of MCH clinics and will be supported by counsellors and laboratory technicians and provided with additional infrastructure where necessary.

Paediatric AIDS treatment will be provided by early diagnosis of exposed children through PCR tests, treatment using fixed-dose paediatric formulations at district level ART centres, assessment based nutritional supplementation supported by front-line health and ICDS workers to strengthen home based care and referral.

NACO will also provide overall policy leadership and technical support to other ministries and ensure coordination of implementation at national, state and district level.

Progress will be monitored by tracking key indicators laid out in the policy and managed by the strategic information management unit at NACO. NACP III will provide approximately Rs 1,800 crores for PPTCT, prevention and treatment.

Key actions include

- Scale up and intensify prevention among the most at-risk and vulnerable groups with a focus on adolescent groups;
- Scale up PPTCT service delivery points

within public and private health care systems based on population coverage targets;

- Increase diagnosis of HIV-exposed children and scale up treatment of HIV-positive children including nutritional supplementation where necessary;
- Provide overall policy and technical leadership to ensure coordination of action among the four key ministries with mandate on children and AIDS;
- Support ministries to develop specific policies and programmes to prevent and redress stigma and discrimination;
- Advocate for the enactment of the HIV/AIDS Bill, increase communication campaigns (ie: with a specific “do not stigmatise.....it is a violation of human rights” message), and provide quality control to prevent the inadvertent use of stigmatising messages.

5.2. Ministry of Women and Child Development (MWCD)

The two flagship programmes of the MWCD are the Integrated Child Development Service (ICDS) and the recently introduced Integrated Child Protection Scheme (ICPS). These schemes are ideally placed to reach families not covered by NACO programmes and to complement the efforts of State AIDS Control Societies (SACS). In order to fully complement the services offered by NACO and the SACS, the ICDS and ICPS recognise that:

- children who are HIV-positive or otherwise affected by HIV/AIDS effectively pose no risk to others and are entitled to the same protection, and to inclusion in the same public services, as other children; and
- singling out children affected by HIV/AIDS for special protection services is both stigmatising and unnecessary. HIV positive children need medication but, once their condition is stabilised, they can function just

like any other child, as long as they are not subject to stigma and discrimination.

5.3.1. Integrated Child Development Scheme (ICDS)

This 30-year-old scheme for child development is India’s response to the challenge of providing pre-school education and breaking the vicious cycle of malnutrition, morbidity, reduced learning capacity and mortality.

The backbone of this scheme is made up of community-based anganwadi workers, who belong to the communities they serve. The package of services they provide includes supplementary nutrition; non-formal pre-school education; immunisation; health check-up; referral services; nutrition and health education; iron and folic supplementation; and health and hygiene education among adolescents.

Three services – immunisation, health check-up and referral – are delivered through public health infrastructure such as health sub-centres and primary and community health centres under the Ministry of Health and Family Welfare. Anganwadi workers can also identify persistently ill mothers and new born children, and refer such cases for appropriate follow up.

Nutrition and Health Education (NHE) for mothers is a key element of the work of the anganwadi worker. If provided with the right information on infant and young child feeding, and the nutritional and health needs of an HIV-positive mother and child, they can also ensure that an infected child receives pre-ART home-based care and refer for appropriate HIV care.

Anganwadi workers must be sensitised and sensitise others on the right of children who are HIV-positive or otherwise affected by HIV/AIDS to confidentiality, and to inclusion in all public services and community events.

Train and develop skills of anganwadi workers with special focus in high prevalence districts for ensuring nutrition and health of children infected

by HIV and create an enabling environmental within centres to ensure easy access to HIV affected families. Further in order to monitor the implementation of this critical intervention develop appropriate reporting formats and include in the MPR.

5.3.2. Integrated Child Protection Scheme (ICPS)

This new scheme envisages setting up a nationwide child protection mechanism. Child protection refers to the protection of children from any form of neglect, abuse and exploitation. The scheme aims to give effect to statutory provisions under the Juvenile Justice (Care and Protection) Act 2000 by combining preventive and ameliorative steps to safeguard children in difficult circumstances. Children affected by HIV/AIDS are recognised as a category of children in difficult circumstances.

The ICPS is being implemented through Child Protection Units at state and district levels, and through existing Child Welfare Committees. These bodies will be equipped to deal effectively with cases of discrimination or abuse arising from any cause, including HIV/AIDS.

In addition, out-of-family care of children will be subject to regulatory, quality control and monitoring mechanisms, which must include appropriate safeguards to prevent the exclusion of children affected by HIV/AIDS, while providing suitable treatment and support for those who are HIV-positive. Such measures must be incorporated into minimum standards of care in child-care institutions.

Specifically for children affected by HIV/AIDS, including infected children, the district child protection units will provide legal aid that includes support for the preparation of wills and transfer of property, access to legal support and redressal for specific legal issues, especially for orphans, sensitise family, local governance structures and village committee members to address rights and entitlements of children,

succession planning for children, information dissemination on legal rights of the family and children. The scheme will strengthen alternate forms of family based care like foster care and adoption and ensure that the stay in a child-care institution is as short as possible and that they are not discriminated against. Sanctions should be implemented against institutions that violate the national policy on stigma and discrimination.

Some of the programmes, which will fall within the purview of this scheme like Integrated Street Children Scheme and Child Line, can facilitate strengthening HIV prevention strategies for vulnerable children in urban sites.

Rs 2,000 crores has been approved for ICPS of which Rs 85 crores has been released for the first year of the 11th five-year plan.

Key actions include

- Build capacity of family and community to prevent and respond to abuse, neglect and exploitation of children to ensure that children are able to stay within family care.
- Strengthen systems and competence of staff of ICPS and ICDS on HIV related issues to deliver inclusive child welfare (including growth monitoring, provision of supplementary nutrition and referral for treatment) and protection services including sponsorships, child care in institutions, foster care & adoption, access to short stay home, care and protection services for all orphans and abandoned children including children affected by AIDS.
- Provision of social protection/economic strengthening will include sponsorship and cash transfer, redressal of cases of discrimination including care, protection, treatment, development and rehabilitation of children.
- Provision of legal and redressal support will include birth registration, support for preparation of will and transfer of property, access to legal support and

redressal for specific legal issues especially for orphans.

- Provision of alternative care services will include identification of children in need of alternative care, identification of potential care givers, ensuring quality of care for children and communities through effective monitoring, supporting family-based care with home visits and specific strategies for infected child.
- Advocacy campaigns to ensure birth registration, sensitise families and communities of child rights and their role as duty bearers, remove barriers to accessing services in order to ensure legal inheritance and access to public services
- Ensure access (prevent exclusion) to adequate supplement nutrition to meet calorie needs and to correct or prevent malnutrition at anganwadi centres
- Endorse, introduce and enforce minimum standards of care in childcare institutions and any other formal/informal care systems for children
- Develop a specific policy on stigma and discrimination

5.3. Ministry of Human Resource Development (MHRD)

As the ministry responsible for education, the MHRD has a key role to play both in terms of prevention of infection among adolescents, and also by ensuring that children are not excluded from educational institutions because they are HIV-positive or otherwise affected by HIV/AIDS.

The National Policy on Education 1986 provides that, up to a given level, all children irrespective of caste, creed, location or sex, have access to education of a comparable quality. The policy states that it is not only necessary to provide equal opportunities for access but also for

success. It further states that awareness of the inherent equality of all people will be promoted through the core curriculum, in order to remove prejudices and complexes transmitted through the social environment and the accident of birth¹⁷.

From 1995-2003 NACO spearheaded the school HIV education programme across the country. Following a programme review and secondary assessment of HIV prevention programmes in schools (2003-04) the leadership of the programme was shifted from NACO to MHRD, Department of Education, and redesigned as adolescent education programme (AEP). The AEP is a comprehensive life-skills based HIV prevention programme, designed as an early intervention to reach vulnerable adolescents. The HIV prevention programme is set within a broader life-skills programme that addresses a range of issues relevant to the development of adolescents.

The programme was scaled up by the Ministry of Human Resources Development in collaboration with National AIDS Control Organisation (NACO) in 2005 to reach all students in secondary and senior secondary schools across the country and is being implemented at state level by state education departments.

Key actions include

- Integrate life skills based HIV prevention education into the school curriculum, teacher training (pre-service and in-service) adult education schemes, distance education and open schooling programmes
- Include co curricular activities to complement the curriculum based HIV prevention education in the short and medium term.
- Reinforce teachers training to build non discriminatory attitudes and to cope with issues of children living with HIV.
- Build and sustain a resource for HIV prevention life skills based education in

17 National Policy on Education 1986, www.ugc.nic.in/policy

Secondary and higher secondary schools educational institutions to function as mentors and first line counsellors;

- Build capacities of children to be peer educators (child to child approach), including red ribbon clubs, reduce stigma and discrimination in the community and to ensure complete knowledge and skills to protect themselves from HIV infection;
- Ensure all children affected by HIV are able to eventually realize their right to education and are supported to complete their education. There should be no discrimination for admission and retention.
- Formulate inclusion of policy to ensure non discrimination of children affected by HIV/AIDS and to that all adolescents receive life skills based HIV prevention education within education policy.

5.4. Ministry of Social Justice and Empowerment (MSJE)

NACP III sets up linkages with district level organisations and departments to enable People Living with HIV most in need to access social welfare schemes and benefits for the poor that are available in each state.

The MSJE through its social welfare programmes and special schemes for SC/STs and the disabled, must not be denied to and must ensure inclusion of PLHA families. Some of the support areas which will benefit affected families include facilitating access to medical treatment

and helping them to remain productive through livelihood and employment opportunities.

Through its de-addiction programme, MSJE will enhance prevention among injecting drug users. This includes supporting the collection of disaggregated data by age and gender as part of any monitoring and evaluation.

MSJE will also support various awareness and skills building sessions on drugs and HIV/AIDS for special vulnerable groups including hard-to-reach populations and child drug users as part of their outreach and peer education programmes.

Key actions include:

- Ensure HIV prevention education is accessible to those most at risk of infection such as injecting drug users attending MSJE de-addiction centres, with a special focus on children and young people;
- Ensure that harm-reduction programmes are implemented across all MSJE supported de-addiction centres as per need.
- Ensure access to income generation and welfare schemes by HIV-positive and otherwise affected persons, especially widows and children;
- Develop life-skills materials on HIV prevention for children who are disabled or in schools for SC/ST communities and enhance capacities within these institutes to work on HIV related issues with special and vulnerable groups.

6. Management and Coordination

Table 5

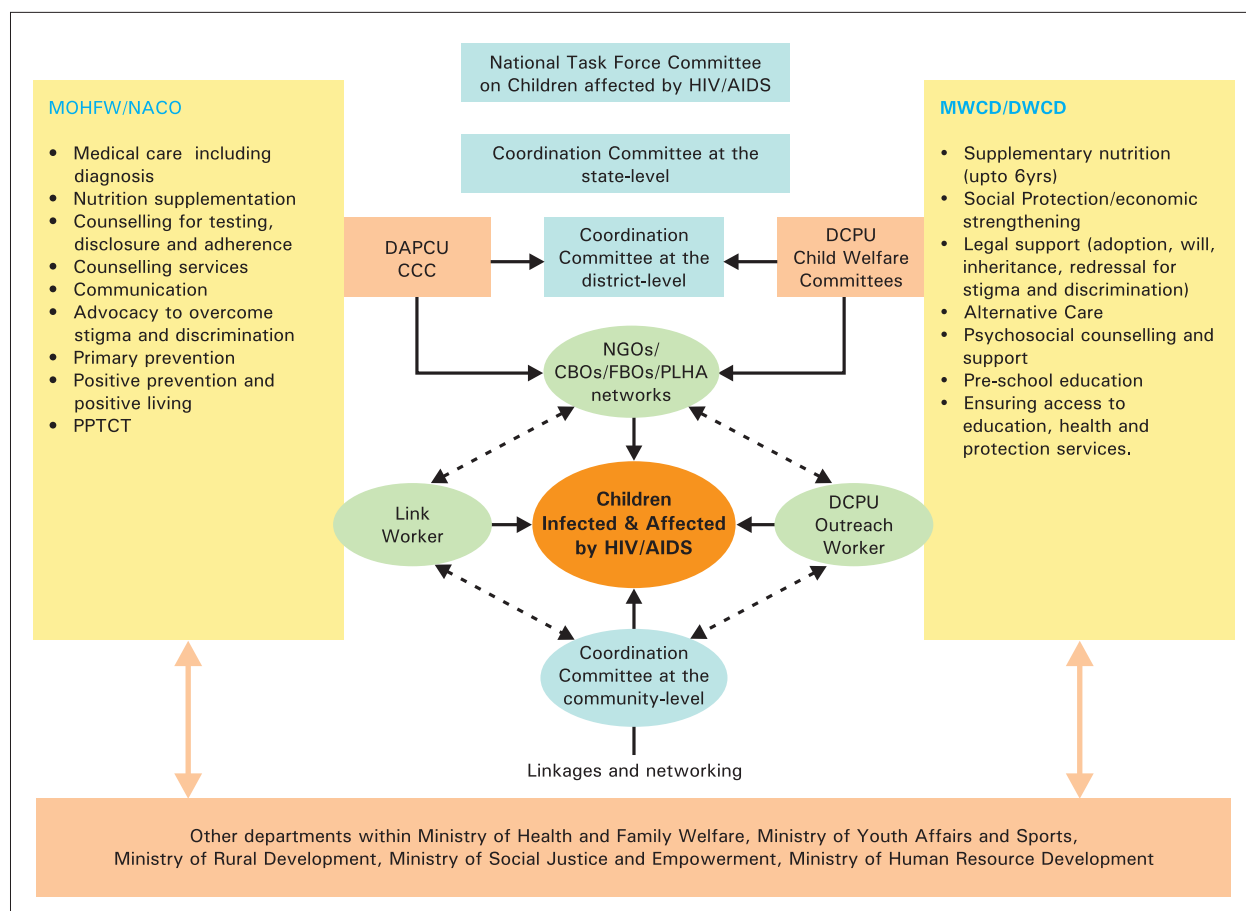
Coordination Committee	Members	Key Function
National Task Force Committee on Children affected by HIV/AIDS	DG, NACO as chair Members: MOHFW, MWCD, MHRD, MSJE, UNICEF, UNFPA, WHO, Civil society organisations, International NGOs and foundations, PLHA network	Review programmes and policies on children infected and affected by HIV/AIDS Develop national operational guidelines for implementing programmes for children infected and affected by HIV/AIDS Provide technical assistance for implementing programmes for children infected and affected by HIV/AIDS Third party concurrent monitoring
Coordination Committee at the state-level	Chief Secretary as chair Members: MOHFW: Health Secretary; DWCD: Secretary/Director (Child Welfare), Director (Child Protection); SACS: Project Director/ Joint Director (Communication); Joint Director (Care and Support); Asst. Director (Mainstreaming), NGO Coordinator; Director Education; Secretary Social Welfare; Director Social Welfare; Programme Managers/Officers of UN agencies, state-level NGOs, CBOs, FBOs and PLHA networks	Coordinate implementation of the programme as per the operational guidelines and with reference to the minimum standards of care and protection set at the national level Review redressal mechanisms to facilitate joint and speedy interventions
Coordination Committee at the district-level	District Collector as the chair Members: DCPU: Programme Officer (Child Protection), SJPU, and CWC; District Programme Officer (HIV/AIDS), Additional Supervisors for NGO and Care & Support, DAPCU; Child Development Project Officer (CDPO) of Integrated Child Development Service (ICDS); District Education Officer; Chief Medical Officer, District Health Centres; District Welfare Officer; Programme Managers/Officers of UN agencies, state-level NGOs, CBOs, FBOs and PLHA networks	Coordinate integration of HIV/AIDS including stigma and discrimination into the training programmes for district officials of different departments Coordinate implementation of the programme within the framework of the operational guidelines and minimum standards of care for children as defined by MWCD Joint review of programmes for infected and affected children Coordination of redressal mechanism for denial of services to children

6.1. At district level

NRHM, NACO and MWCD are committed to decentralise the planning, implementation and monitoring of programmes for TB, RCH, HIV

prevention and care, and social protection for children and women. Implementation of policy on children and AIDS will fully utilise processes laid out in these programmes and strengthen horizontal linkages and synergy as shown in Figure 2:

Figure 2:



7. Summary of Action Priorities

In the context of HIV/AIDS, the hierarchy of needs is as follows:

7.1. Prevent new HIV infections among new born children, adolescents and adults

HIV infection not only threatens the life of an individual but has serious social, economic and psychological implications for their entire family. While HIV may be incurable, it is completely preventable. In the context of the epidemic, there is no greater priority than protecting new born children from infection, and empowering young people to protect themselves from infection as they move into adulthood and parenthood.

7.2. Diagnose and treat new born children, adolescents and parents who are already infected

Antiretroviral therapy offers a future to HIV-infected children and adults – but these drugs are of no help to people who do not know they are HIV-positive. In the case of new born children early diagnosis is essential to effective treatment but, once diagnosed, most HIV-positive children can lead normal lives. In the case of parents, failure to diagnose HIV infection is disastrous not only for them but for their children, partners and extended families. The challenge posed by HIV/AIDS comes not from those who know they are HIV-positive, but from those who do not.

7.3. Overcome stigma and discrimination

Stigma is both a cause and an effect of the epidemic. It inhibits people from protecting themselves, and from seeking testing and treatment. Stigma leads to exclusion from essential services and within the family and community. Stigma is the root of the psychosocial distress associated with AIDS. To effectively address stigma requires:

- Implementing an informational campaign, targeting public service providers first (teachers, doctors, anganwadi workers etc.) to make them aware of the rights and entitlements of affected children, and to overcome myths and misconceptions which lead to stigma and discrimination. This should be supported by a review of regulation and legislation, to detect and respond to discrimination;
- Implementing an informational campaign targeting the broad population, including people who are HIV-positive, making them aware of everyone's rights and entitlements to public services – including those affected by HIV/AIDS – and helping them to overcome myths and misconceptions which lead to stigma and discrimination. This must be supported by an awareness of who they can turn to if they are excluded or discriminated against for any reason, including HIV/AIDS.
- Implementing and/or strengthening mechanisms to intervene in cases of discrimination or exclusion, to redress the rights of children to the services from which they have been excluded, and to refer them to additional specialised services if required.

Annex 1: Definitions and Concepts

Children are people who have not yet turned 18 years of age¹⁸.

Children affected by HIV/AIDS include those who are HIV-positive, those who have been orphaned by AIDS, and those who are living in a household which is affected by HIV/AIDS – usually because their parent is HIV-positive¹⁹.

Vulnerable children, in India, are usually understood to be young people who are particularly vulnerable to HIV-infection – for example juvenile commercial sex workers. They are not “affected” unless they also have a positive parent, or are orphaned by AIDS. The term “vulnerable children” is also used to describe children at risk of abuse, neglect, discrimination or other violations of their rights, for example in the phrase “orphans and vulnerable children” which usually, but not always, refers to children whose rights are at risk because of their association with HIV/AIDS. The ambiguity of this word suggests caution in its use.

Various contextual and structural factors can lead to increased risk of HIV infection. These could be high population mobility, geographical and economic disparities, illiteracy, lack of preventive knowledge and skills, gender roles, high risk sexual behaviours (initiation of sexual activity at younger ages, engaging in sexual intercourse without using a condom).

Children and HIV/AIDS includes children who are not “affected” but who are at heightened risk of being infected, and/or whose parents are at heightened risk of infection (for example commercial sex workers or injecting drug users). Actions for “children and AIDS” include prevention and mitigation, whereas “children affected by HIV/AIDS” focuses on mitigation.

The impacts of HIV/AIDS on children arise from two sources – medical and social. The two factors are highly inter-related (social factors impact on medical prognosis and vice versa) but can also function independently (eg: it is not necessary to be ill to be stigmatised, or inevitable that one will be stigmatised even if one is ill)²⁰.

Mitigation of the impact of HIV/AIDS on children refers to reducing or overcoming the threats to children’s wellbeing which arise from HIV/AIDS. Mitigation activities can address the cause of those threats (eg: by overcoming stigma or treating a child’s HIV-positive parents) or the effect on the child (eg: intervening with schools that turn them away).

Treatment, in the context of HIV/AIDS, means medical treatment which is appropriate to the condition of an HIV-positive person – for example antibiotic prophylaxis (cotrimoxazole) and antiretroviral therapy (ART) to prolong and improve the quality of life and to reduce

¹⁸ Eg: UN Convention on the Rights of the Child

¹⁹ eg: SAARC Regional Framework for programming for children affected by HIV/AIDS (2007, draft). Note the phrase “infected and affected” is illogical, since “infected” children are a sub-set of “affected” children. It is like saying “girls and children”.

²⁰ These impacts are primarily modified by: awareness of sero-status by the infected person (eg: determines medical prognosis); awareness of sero-status by others (eg: leads to stigma and discrimination); relationship of the child to the infected person (eg: dependent, sibling, self) family status (eg: economic strength, family ties, social standing). Impacts are further modified by a range of environmental variables, discussed below, and result in a cascade of medical, social, economic and psychological outcomes, with short- and long-term implications for the child.

the risk of transmission – particularly vertical transmission from mother to child. Treatment is seen as a sub-set of mitigation, since it mitigates the medical impact on an HIV-positive person, and mitigates the socio-economic impact of their illness on the family.

Prevention means encouraging behaviour change to reduce the risk of HIV infection. One focus of prevention activities focuses on risk-taking populations, such as commercial sex workers, injecting drug users, and men who have sex with men. Adolescent prevention refers to behaviour change among young people, principally the adoption of safe practices, by deferring sexual debut or by using condoms, not using infected needles. Prevention also refers to the use of antiretroviral drugs and other techniques to reduce the risk of an HIV-positive mother infecting her newborn baby. In India the term “prevention of parent-to-child transmission” (PPTCT) is used.

Stigma, in the context of HIV/AIDS, refers to a negative attitude towards those who are (or are believed to be) HIV-positive. Stigma is believed to originate in part from fear of infection, and in part through moral judgement of those infected. Self-stigma refers to negative attitudes held by an HIV-positive person toward themselves, although the term is also used in place of self-discrimination, described below.

Discrimination means behaving differently toward certain people because of assumptions about them – usually (but not always) in a negative sense. Discrimination in the context of HIV/AIDS means excluding, ignoring, mistreating or exploiting those who are (or are believed to be) HIV-positive. Self-discrimination (or self-stigma) means excluding oneself from services, generally for fear of disclosing one's status, and/or being rejected or mistreated.

Rights-based vs needs-based programming

means responding to children's rights, which are primarily defined by the UN Convention on the Rights of the Child. This approach is based on legal obligations by parents (“primary duty bearers”) and governments (“state parties”) to protect and fulfil specific children's rights, as opposed to a needs-based or “welfare approach” which is based on moral obligations arising from socio-cultural imperatives such as religious values and traditional practices.

Targeted vs universal (or systemic) interventions.

Targeted interventions identify a specific group of people as the recipients of a service, while universal or systemic interventions aim to provide that service to everybody. Many medical interventions are targeted – attempting to locate and treat people who need that treatment – while public awareness interventions are generally universal, attempting to get a message to all people in a given area.

Supply-driven vs demand-driven services. Supply-driven services attempt to locate beneficiaries to “deliver” a particular service, and are measured by how many services are supplied (eg: as a proportion of the number estimated to need that service). Demand-driven services attempt to persuade people to come forward and “demand” a service, and are measured by the number of people who ask for the service²¹.

Mainstream vs HIV/AIDS specific. A school or anganwadi centre is “mainstream”, while an ART or VCT centre is HIV/AIDS specific. However, it is possible to have HIV/AIDS specific services within a mainstream institution – for example voluntary testing in an antenatal clinic, or preventive (life-skills) education in a school. It is also possible (although nearly always undesirable²²) to have mainstream services within an HIV/AIDS specific institution – for

21 Note that targeted interventions can be supply-driven (eg: PPTCT activities, which attempt to locate HIV-positive mothers and deliver services to them) or demand-driven (eg: VCT, which tries to stimulate a demand for people to come forward for testing). Universal interventions can also be supply-driven (eg: adolescent prevention activities) or demand-driven (schooling in India attempts to get all children to present themselves for schooling).

22 See section on principles for a discussion of the merits of mainstream and specific services, separation and integration of affected children from others.

example offering regular school classes in an institution for children orphaned by AIDS.

Public awareness. In the context of HIV/AIDS, this term is often understood to mean awareness of the modes of HIV-transmission. Unfortunately this limited understanding does little to overcome stigma, and may actually encourage it. An understanding of how HIV is not transmitted, the effectiveness of ART, and particularly of children's rights, are central to overcoming stigma, and this information must reach the suppliers and consumers of the service, and both affected and unaffected families²³.

Redressal and referral. Raised public awareness of children's rights and entitlements is meaningless unless it is coupled with a redressal mechanism for those who are discriminated against despite raised public awareness. It is essential that this mechanism is accessible and effective, which implies it must be "mainstream" – not specific to HIV/AIDS – or else few people will avail themselves of the service²⁴.

Psychosocial support. This term refers to the support a child needs for effective socialisation and psychological wellbeing. In practice, this support comes from a child's parents, siblings,

extended family, neighbours, teachers and other peers, mentors and role-models. HIV/AIDS can threaten this support system, both by exposing the child to stigma (often from the very people who should be supporting them) and leading to the disintegration of the family²⁵.

Counselling can mean providing information and advice to help people make informed decisions (information) or helping people to deal with emotional problems (therapy)²⁶.

Environmental variables

It is widely acknowledged that there is no "right way" to respond to children and AIDS. Practices which work in one country or region sometimes fail or do not perform optimally in another. If we had the answers, we would be doing better at overcoming the problems. Work is ongoing to understand the factors which influence success in different settings, and the following variables feature in the debate:

High/low HIV-prevalence²⁷ India is firmly in the low-prevalence category, with a national adult sero-prevalence approximately half of that of North America or Eastern Europe. Statistically,

23 Many people who can recite the modes of transmission are unaware that HIV is not particularly infectious, that most children with positive parents are not HIV-positive themselves, and that there is practically no chance that a child with a positive parent will infect another child (see panel on accidental exposure). Many are not aware that ART is extremely effective for both adults and children, and that PPTCT can reduce vertical transmission to almost zero. And many who are highly trained in all aspects of HIV/AIDS are unaware of children's rights – for example the right of all children, including those affected by HIV/AIDS, to remain with their parents, to receive quality education and health-care services, and to be consulted on matters which affect them – and of the government's responsibility to help parents fulfil their duties to their own children.

24 In any event, such a mechanism is central to the protection of the rights of all children, as has been acknowledged by the MWCD in the design of their Integrated Child Protection Scheme. From a system perspective, a redressal and referral (R&R) mechanism performs the same screening function for the social manifestations of HIV/AIDS as VCT centres perform for the medical manifestations. Thus the demand for testing (created by prevention campaigns) finds its outlet in VCT centres, which either resolve the issue (with a negative diagnosis) or refer the case for further services (treatment). Similarly the demand for redressal (created by anti-stigma and children's rights campaigns) is channelled through an R&R mechanism which either resolves it (by establishing that there is no violation of rights) or refers the case for appropriate intervention (eg: facilitating re-admission to school, or to a counselling centre for advice and support). The relationship is depicted graphically in Table X

25 The first step to ensure the psychosocial wellbeing of a child is to preserve the psychosocial support structure, which begins by treating HIV-positive parents so they are able to raise and provide for their children. The second step is to overcome the stigma which causes discrimination and distress – which must be done by reaching out to those who stigmatise, rather than focusing on their victims. If the medical and social implications of HIV/AIDS are addressed, it is highly unlikely that any further intervention will be required, but see "counselling" below.

26 In the context of HIV/AIDS, "counselling" could be used to describe the sharing of information with people being tested for HIV infection, advising a nurse that there's no risk to her if she bandages the wound of an HIV-positive child, or reassuring an HIV-positive mother that she can live to raise her children – and do a better job than an orphanage. Counselling children traumatised by AIDS-related death or stigma is widely advocated and practised, although with ART available to all who know they are HIV-positive it may be better to keep parents alive than to comfort their orphans, and it may be more productive to "counsel" those who are doing the stigmatising, and not only their victims.

27 UNAIDS provides definitions of "low-level" and concentrated epidemics but, in practical terms, a 5% national adult sero-prevalence is sometimes used as the benchmark of a high-prevalence country eg: the UNICEF-led Progress Report proposal, described in "Self-assessment of programmatic effort on children and aids in five countries of Central America", 2005.

children in the high-prevalence region of Southern Africa are several hundred times more likely to be affected by the epidemic than their counterparts in India²⁸. While low prevalence countries always have clusters of higher prevalence, it is important to recognise that the (so-called) high-prevalence communities in India are actually low-prevalence in global terms, and that even in these areas there is a far greater chance that a child's rights will be threatened by some other disease or form of exclusion than by HIV/AIDS.

Access to ART. The advent of antiretroviral therapy has transformed AIDS from a terminal illness to a treatable chronic condition. The latest research²⁹ shows the great majority of adults and children respond well to ART, achieving sub-detectable viral loads within a matter of months, which means they can lead normal lives and are less likely to infect others. The roll-out of ART even in resource-poor countries, thanks to PEPFAR and the GFATM, obliges programmers to reconsider their priorities. ART has significant implications for prevention activities, overcoming a major constraint to voluntary counselling and testing, and it shifts the entire paradigm of mitigation programming, as described throughout this document³⁰.

Diagnosis. While numerical estimates relating to HIV/AIDS do not generally differentiate between those who know they are HIV-positive and those who do not, the programming implications for these two groups are fundamentally different. In India, nearly everyone who knows they are HIV-positive already has access to ART³¹, which means the priority is to diagnose those who do not know their status. But while diagnosis opens the door to effective treatment, it also opens

the door to stigma and discrimination. Stigma is acknowledged as a major disincentive to voluntary testing, which means that stigma must be addressed both as a means to expand testing, and to mitigate the impact of the virus on those who are affected.

Access to public services and family support.

Social "safety nets" – both public and private – are the most important asset in responding to the impact of HIV/AIDS on children, but may also be compromised by both the medical and socio-economic impacts of the virus. Public service infrastructure (health care centres, schools, food security programmes, cash transfer schemes etc.) and family and community support systems vary widely between countries and regions, both in terms of accessibility (eg: lack of infrastructure, high cost, discrimination) and capacity (eg: limitations imposed by poverty, socio-cultural practices, stigma). India is stronger than many countries in terms of schooling and health care, but may be weaker in terms of social welfare services and children's rights protection³².

Other risk factors. One factor which is rarely mentioned in the literature is the prevalence of other illnesses or social exclusionary factors in HIV-affected communities. In societies where serious illness and discrimination are commonplace, it will be much less useful to focus attention on a minority of children affected by HIV/AIDS than in a community where these children outnumber or are worse-off than other kids. In addition, it will be much harder to mount an effective response specifically for children affected by HIV/AIDS in a community where public and private safety nets are already straining to cope with children who are malnourished,

28 Global Partners Forum discussion paper on the impact of HIV/AIDS on children in lower prevalence countries, 2006.

29 Eg: abstracts for the Toronto World AIDS Conference 2006.

30 The paradigm shift can be summarised as follows: Before the advent of ART death was a certainty, and mitigation meant preparing to die from AIDS while minimising the many negative impacts on children. Now, with ART, survival – at least for those who know their status, and at least until their children grow up – is a near certainty, and mitigation means preparing, literally, for "living with HIV/AIDS". The effect is to narrow the focus of programming to two issues – making sure all HIV-positive parents know their status (and thus can access ART) and overcoming HIV/AIDS related stigma. Success in these two areas will not only mitigate the impact of the epidemic on children, it must inevitably bring the epidemic to an end.

31 NACP III

32 Index of programming effort exercise in six high-prevalence states of India, UNICEF 2006 (unpublished), and Study on child abuse 2007, Ministry of Women and Child Development, Government of India, April 2007

out-of-school, exploited or separated from their parents for any reason.

Stigma. Just as AIDS is the medical manifestation of HIV, so stigma is the social manifestation of the virus. But, while ART has the potential to overcome most of the medical consequences of HIV infection, there are no proven strategies to overcoming fear and discrimination – even

though these are the key barriers to diagnosis and treatment, and the primary causes of distress for affected children³³. Indeed, there's a very strong possibility that the key intervention for stigma – raising awareness of the modes of HIV-transmission – actually makes it worse! We don't even know the extent to which the perception of stigma differs from reality, but we do know that stigma holds the key to the epidemic³⁴.

³³ Barriers to services for children with HIV-positive parents in five states of India, UNICEF 2007.

³⁴ Indeed, it is difficult to imagine the HIV/AIDS pandemic surviving without stigma. What would stop entire populations from queuing up to be tested; the uninfected negotiating safe sex or clean needles; and the positive being treated? Without parental illness and death, and without stigma and discrimination, "affected children" would simply vanish! With no new born children infected at birth, and very few positive children dying from AIDS, it would take 17 years for the category of "infected child" to disappear. Of course a few parents would not respond to ART and would die, but their situation would be both rare and easily recognised – certainly no more of a threat to children's wellbeing than many other diseases.

Annex 2: Policy Analysis

International Commitments made by India for children and HIV/AIDS

India along with other member states adopted a Declaration of Commitment for HIV/AIDS in the United Nations General Assembly Special Session on HIV/AIDS in 2001. It reflected a global consensus on a framework to achieve the Millennium Development Goal (6) of halting and beginning to reverse the HIV epidemic by 2015. The core indicators agreed upon by the Member states including India in 2001 were:

- By 2005, ensure that 90%, and, by 2010, 95% of youth aged 15–24 have information, education, services and life-skills that enable them to reduce their vulnerability to HIV infection.
- By 2005, reduce HIV prevalence among young people (aged 15 to 24) by 25% in the most affected countries, and by 2010, reduce it by 25% globally.
- By 2005, reduce by 20% and, by 2010, by 50%, the number of babies infected by HIV by ensuring that: 80% of pregnant women in antenatal care receive HIV information, counselling and other prevention services; HIV-infected women and babies receive treatment to reduce mother-to-child transmission; and HIV-infected women receive treatment, including antiretroviral drugs and breast-milk substitutes.
- By 2005 implement national policies and strategies to build and strengthen government, family, and community capacities to provide a supportive environment for orphans and children infected and affected by HIV/AIDS

including by providing appropriate counselling and psychoso-social support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.

India is a signatory of the International Child Rights Convention since 1992. The Government has been proactive in developing legislations and policies to address all form of violation of rights of the children, although the effectiveness of the implementation of these legislations and policies needs to be enhanced to reach the proposed standards. are yet to reach the standards proposed. The fight against HIV/AIDS must include efforts to prevent child protection abuses, which make children particularly vulnerable to the disease. For children orphaned or otherwise made vulnerable by HIV/AIDS, protection of their rights is a key priority³⁵.

General comment of the Committee on the Rights of the Child, 2003 in relation to children affected by HIV/AIDS provides an authoritative guidance to states parties to the CRC in relation to specific rights or specific situations of children. The committee recommends that there is a need to identify measures and good practices to increase the level of implementation by the States of the rights related to prevention of HIV/AIDS and the support, care and protection of children infected and affected by HIV and AIDS³⁶.

³⁵ Unicef Working Draft, June 2005

³⁶ General Comment, Committee on Rights of Child, HIV/AIDS and rights of the child, 2003.

The Policy Environment: Children in India

The **guarantee of equality and non-discrimination under the Indian Constitution**³⁷ implies that children living with HIV are not to be discriminated against in matters concerning them like education, health and other public services. At the same time, the State can institute special measures to mitigate the impact of HIV on affected persons and communities³⁸.

Though couched in negative language, the **right to life and liberty** has been interpreted expansively by the Supreme Court to encompass positive claims including *privacy*³⁹ and *confidentiality*⁴⁰, *health*⁴¹ and medical *treatment*⁴² and *education*⁴³. Government's obligation to ensure access to paediatric treatment for HIV stems from Article 21⁴⁴.

In 2002 Article 21 A⁴⁵ was inserted to give explicit recognition to the right to free and compulsory education for all children between the age of six and fourteen years. Three years later, a **Right to Education Bill**⁴⁶ was introduced in Parliament to give effect to this Constitutional obligation. The Bill sought to secure the enrolment and participation of children aged 6 to 14 years in elementary education. Child Rights activists and social educationists criticised the Bill for failing

to address equity and quality in access to education⁴⁷.

With respect to exploitation of children, the Constitution **forbids trafficking in human beings, begary and other forms of forced labour**⁴⁸. Anti trafficking⁴⁹ and child labour⁵⁰ statutes and a host of penal provisions⁵¹ give effect to this constitutional mandate.

Articles 32 and 226 of the Constitution secure the right to seek redress for non-enforcement and/or violation of constitutional rights. The former allows aggrieved persons to petition the Supreme Court, the latter establishes the right to move the High Court. Further, Courts have the authority to strike down any legislation, policy or executive action, which, in its finding, is contrary to or compromises fundamental rights⁵².

To enable access to justice to the poor and marginalised, Courts have evolved procedures like *Public Interest Litigation* that allow any person with a *bona fide* and sufficient interest in an issue to file a petition to vindicate fundamental and/or statutory rights. This principle assumes immense significance for vulnerable children, who are unable to seek relief on account of legal and other disadvantages. Many landmark decisions on child rights have been borne out of public interest litigations⁵³.

37 Art 12 AND 13 Part III of the Constitution

38 Courts in India have upheld discriminatory actions that are reasonable, that is, where classification is founded on an intelligible differential having a rational nexus with the object sought to be achieved. To illustrate, social cash transfers to families caring for children with HIV/AIDS is seemingly discriminatory; the action may be defensible as eligibility is determined on an intelligible criterion, i.e HIV status of children, which is rationally relatable to the object of the policy, alleviation of impact of HIV.

39 Govind v. State of Madhya Pradesh, AIR 1975 SC1378

40 Mr. X v. Hospital Z (1998) 8 SCC 296

41 State of Punjab v. Mahinder Singh Chawla, AIR 1997 SC 1225

42 Parmanand Katara v. Union of India, AIR 1989 SC 09

43 J.P. Unnikrishnan vs. State of Andhra Pradesh AIR 1993 SC 2178

44 Right to life

45 Article 21 A was incorporated under the 86th Constitution Amendment Act, 2002. It reads "The State shall provide free and compulsory education to all children of the age six to fourteen years in such manner as the State may, by law, determine."

46 Available at <http://education.nic.in/elementary/RighttoEducationBill2005.pdf>

47 <http://timesofindia.indiatimes.com/articleshow/1748745.cms>

48 Article 23, Part III, Constitution of India

49 The Immoral Trafficking (Prevention) Act, 1956

50 The Child Labour (Prohibition and Regulation) Act, 1986

51 See Sections 370 to 374 of the Indian Penal Code, 1860

52 Article 13. However, the expression "law" has been interpreted to exclude non-statutory personal law, i.e. law which is applicable to a persons on the basis of their religion

53 See, Bandhua Mukti Morcha v. Union of India, AIR 1997 SC 2218 and M.C.Mehta v. State of Tamil Nadu, AIR 1997 SC 699 where the Supreme Court issued directions on hazardous work and education, health and welfare of child labour

The Directive Principles⁵⁴, though non-enforceable, are fundamental to governance and law-making in the country⁵⁵. This is evident from the fact that Courts have applied Directive Principles to interpret and accord a wider meaning to citizens' rights and State's obligations.

Directive principles relevant to children include ***directions against abuse of tender age⁵⁶ and exploitation of young persons⁵⁷, for securing work, education, welfare and assistance in situations of debility and destitution⁵⁸, and for the provision of care and education to young children⁵⁹.***

Child related statutes

The Juvenile Justice (Care and Protection of Children) Act, 2000

The Juvenile Justice (Care and Protection of Children) Act 2000 ("JJA") sets out the framework for dealing with children in difficult circumstances including those in conflict with the law. Enacted first time in 1986⁶⁰, the JJA was revamped⁶¹ in 2000 in keeping with international obligations⁶². The Act was recently amended to incorporate additional provisions⁶³.

Though not explicitly mentioned, children affected by HIV are covered as they fit the criteria of *"children suffering from terminal diseases or incurable diseases having no one to support or look after"*⁶⁴.

The Act entrusts the handling of such children to Child Welfare Committees ("CWC"), to be constituted by State Governments for one or more districts⁶⁵. Appointments to the CWC, comprising a Chair Person and four members are made by the State Government and must include a woman and an expert on children's issues⁶⁶. Concerned by inaction on the part of State Governments to establish CWCs, the 2006 Amendments prescribe a one year timeline for completion of this task⁶⁷.

Any concerned person or agency or the child herself may present herself to the CWC⁶⁸. On completion of inquiry about the child⁶⁹, the Committee may either return the child to her parents/guardian/fit person or institution or place the child in government or voluntary homes⁷⁰. The Act and the Rules framed there under set out procedures for establishment, maintenance, monitoring of State run as well as recognition of institutions operated run by NGOs⁷¹.

The JJA ostensibly promotes reintegration of children in their family⁷². In the absence of a

54 Articles 6 to 51, Part IV, Constitution of India

55 Article 37, Part IV, Constitution of India

56 Article 39 (e) – "that the health and strength of workers, men and women, and the tender age of children are not abused and that citizens are not forced by economic necessity to enter avocations unsuited to their age and strength;"

57 Article 39 (f) – "that children are given opportunities and facilities to develop in a healthy manner and in conditions of freedom and dignity and that childhood and youth are protected against exploitation and against moral and material abandonment"

58 Article 41 – "The State shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of underserved want."

59 Article 45 – "The State shall endeavour to provide early childhood care and education for all children until they complete the age of six years."

60 The Juvenile Justice Act, 1986 (No. 53 of 1986)

61 The Juvenile Justice (Care and Protection of Children) Act, 2000 (No. 56 of 2000)

62 The United Nations Convention on the Rights of Child, adopted in 1989 and ratified by the Government of India in 1992

63 The Juvenile Justice (Care and Protection of Children) Amendment Act, 2006 (No. 33 of 2006) (Hereinafter the "2006 Amendments")

64 Section 2(d) (iii)

65 Section 29 (1)

66 Section 29 (2)

67 See Amendment to Section 29, The Juvenile Justice (Care and Protection of Children) Amendment Act, 2006 (No. 33 of 2006)

68 Section 32

69 Section 33 (2)

70 Section 33 (3)

71 Section 34, JJA and Rule 28 under Model Rules. Section 34 (6) of the 2006 amendments prescribes a six month timeline for registration of homes run by non-government organisations.

72 Section 39

natural family, the statute sets out to provide a family like environment to children through **adoption**⁷³, **foster care**⁷⁴ and **sponsorship**⁷⁵. The 2006 amendments attempt to streamline adoption⁷⁶ under the JJA⁷⁷, signalling the government's intent to promote adoption of abandoned children⁷⁸. In a country where adoption itself is not very popular, chances of HIV positive children finding adoptive parents remain bleak.

The Act introduces **foster care**, as a mechanism to provide temporary residence to children, unable to live with their natural family. Unlike adoption, foster care does not involve a legal relationship between the child and the foster family. At any given point, placement with a foster family cannot exceed four months⁷⁹. In the long term, the children can remain in foster care for no longer than five years⁸⁰. Foster families must fulfill certain economic and health standards for selection⁸¹. Incidentally, HIV status has been identified as one of the criterion to determine medical fitness of foster families that in itself is discriminatory⁸².

In recent years, NGOs mobilising a community response to children affected by HIV/AIDS have employed foster care with varying degrees of success. While in coastal *Andhra Pradesh*,

families have come forward to take care of affected children in difficult circumstances such as when the parent is hospitalised or critically ill; in *Tamil Nadu*, the response from the village community has not been encouraging⁸³. Further, children's responses to placement in foster families were mixed; testimonies from *Andhra Pradesh* indicated a preference for foster families over biological relatives whereas in *Tamil Nadu*, affected children expressed apprehension over living with an unknown family⁸⁴. This mixed experience underscores the need for research to identify community and structural factors affecting foster care in general as well as specifically for children affected by HIV.

The government has acknowledged that efforts to reduce children's vulnerability have been weak. Programmes for children in need of care and protection are poorly funded with inadequate or non-existent infrastructure⁸⁵. To strengthen child protection services, the government is proposing to club different projects under a central **Integrated Child Protection Scheme**⁸⁶.

Another significant legislative development is the enactment of ***The Commissions for Protection of Child Rights Act, 2005***⁸⁷. Though approved by the President, the law is still to come into force⁸⁸.

73 Section 41, JJA and Rule 33 of Model Rules.

74 Section 42, JJA and Rule 34 of Model Rules.

75 Section 43, JJA and Rule 35 of Model Rules.

76 Under the new Section 2(aa) of the JJA, adoption is defined to mean "the process through which he adopted child is permanently separated from his biological parents and becomes the legitimate child of his adoptive parents with all the rights, privileges and responsibilities that are attached to the relationship."

77 See Amendments to Section 41. Under the new Section 41(4), the State Government can license one or more Children's Homes to offer abandoned children for adoption, after obtaining approval from the CWC. Further, the new Section 41(6) widens the categories of persons who may adopt to include unmarried persons and couples without biological children.

78 <http://www.hindu.com/2006/08/09/02hdlin.htm>

79 Rule 34(1) Model Rules.

80 Rule 34(2) Model Rules.

81 See Rule 34 (3) Model Rules.

82 Rule 34 (3) (d) Model Rules

83 India HIV/AIDS Alliance, "A situational analysis of child headed households and community foster care in Tamil Nadu and Andhra Pradesh States, India" 2006.

84 Ibid Pgs 39, 40 & 41.

85 A presentation by Joint Secretary, Child Welfare of the Ministry of Women and Child Development, Government of India. Available at <http://wcd.nic.in/statewcd/State%20Secretaries%20Meeting,24-25%20April%202006/ICPS-Lovleen%20Kacker.ppt>

86 The Draft of the policy is available at <http://wcd.nic.in/childprot/drafticps.pdf>

87 Act No. 4 of 2006. The Bill received the President's assent on 20th January 2006. Available at <http://www.wcd.nic.in/>

88 The Act has not been notified by the Union Government as of 15 December 2006.

The Act provides for the establishment of statutory bodies to oversee child rights. At the national level, the Act sets out a **National Commission for Protection of Child Rights** comprising a Chair Person and six members from disciplines of education, child health, juvenile justice, child psychology and law⁸⁹. The Commission's functioning is entrusted to a Member Secretary belonging to the IAS Cadre⁹⁰. The Commission is expected to review, research and examine the status of child rights and advise reforms for the realisation of such rights⁹¹. Within this overarching mandate, the Commission can also inquire and investigate incidents of child rights violation and recommend action including prosecution and grant of relief⁹². State Governments are required to set up Commissions to execute similar powers and functions in their respective States⁹³.

The **National Plan of Action for Children, 2005**⁹⁴ provides strategic direction and a roadmap to achieve goals set out in the National Charter⁹⁵. Four strategic directions outlined in the plan are 1) **Survival**, 2) **Development** 3) **Protection** and, 4) **Participation of children**. The plan of action delineates goals, time bound objectives and programme strategies under various thematic areas. Gender and HIV/AIDS are cross cutting and run through all the strategic themes. At the same time, the document contains a specific section on children affected by HIV/AIDS under strategic direction 3, that is, child protection⁹⁶. Key interventions identified in this context include – (i) prevention of mother to child transmission of HIV, (ii) provision of care and support to children affected by HIV, (iii) provision of free paediatric AIDS treatment to children living with HIV, (iv) ensure equality and non-discrimination

in education, (v) increase awareness of HIV and modes of prevention among adolescents through sexuality education in schools, (vi) protect rights including inheritance and property of AIDS orphans and, (vii) promote community based approaches for integration of affected children.

Proposed action to strengthen instruments to protect rights of children

Education Policy and Right to Education Bill

The National Policy on Education was updated in 1992 to include several key strategies, which have two aims: universal access to education by opening new schools in unserved habitations and improved school environment. There is a lot of stress on the moral and character development of each student within the defined cultural ethos. As long as these remain inflexible, it might be difficult to include life skills education for adolescents in the mainstream education programme. There has to be political will towards changing the attitude of the general community towards sex education for children.

The Right to Education Bill, which is yet to be cleared by the Parliament states that it is the responsibility of the state to provide access to free and compulsory primary education to all children. The relevant clause in the HIV/AIDS context is that, which states that the State shall ensure that economic, social, cultural, linguistic, gender, administrative, location, disability, or other barriers do not prevent children from participating in and completing elementary education⁹⁷. This is fundamental towards making sure that all children affected by HIV/AIDS have equal access to education.

89 Section 3, The Commissions for Protection of Child Rights Act, 2005.

90 Section 11, The Commissions for Protection of Child Rights Act, 2005.

91 Section 13, The Commissions for Protection of Child Rights Act, 2005.

92 Section 14, The Commissions for Protection of Child Rights Act, 2005.

93 Sections 17-24, The Commissions for Protection of Child Rights Act, 2005.

94 <http://www.wcd.nic.in/>

95 National Charter for Children 2003, <http://www.wcd.nic.in/>

96 See Section 16, Children Affected by HIV/AIDS.

97 Chapter 3 Clause 5.

HIV/AIDS Bill, a comprehensive policy

Under the NACP II programme efforts were made to enforce the rights of people living with HIV/AIDS and people vulnerable to infection. A bill to this effect was developed and placed before the parliament; this is yet to become an Act of Parliament.

The bill proposes to prevent and address any form of discrimination⁹⁸, which may result due to HIV for all affected people. It states that the National AIDS authority is responsible for making available counseling protocols for HIV testing and stresses on more elaborate ones for children which includes details on processes to be adopted for obtaining; informed consent from children and how the HIV status is disclosed to the child.

The bill⁹⁹ proposes that every person below the age of 18yrs should have adequate access to HIV related IEC including sexual health information and education. Under the clause (d) related to education it proposes age appropriate information on HIV, prevention, treatment care and support and on stigma and discrimination.

The HIV/AIDS bill also provides specific provision to ensure that children affected by HIV/AIDS are not deprived of their right to health, education and right to property & inheritance.

The new Government strategy NACP III plans advocate for adoption of this bill, the process

towards this needs to be taken up in a more systematic manner so that it becomes law.

Testing counselling and disclosure guidelines for children

The General comment of the Committee on the Rights of the Child(2003) in relation to children affected by HIV/AIDS states clearly that the accessibility of voluntary, confidential HIV-counseling and testing services, with due attention to the evolving capacities of the child, is fundamental to the rights and health of children. These services are critical to children's ability to reduce their risk of acquiring or transmitting HIV, to accessing HIV specific care, treatment and support, and to better plan for their futures.

The WHO/UNAIDS publication on Guidance on provider initiated testing and counseling in health facilities (May 2007), recognises the need to develop legal and policy framework on:

- a) The specific age and /or circumstances in which minors may consent to HIV testing for themselves or for others and
- b) How the assent of and consent for adolescents should best be assessed and obtained.

Family Health International (India), an NGO working on this issue, has produced a Protocol for Child Counselling on HIV testing, disclosure and support which has to some extent filled this gap. This document has to be reviewed with a larger group of stakeholders for wider acceptance.

⁹⁸ 'discrimination' includes any policy, law, practice, custom, tradition, usage, condition or situation which directly or indirectly, expressly, or by effect immediately or over a period of time: 1) imposes burdens, obligations, liabilities, disabilities, or disadvantages or, 2) denies or withholds benefits, opportunities and advantages from or 3) compels forces the adoption of a particular course of action by any person or persons based solely on HIV related causes. (as defined in the Bill).

⁹⁹ Art 24.

Annex 3: Additional information on programming paradigms

Targeted and systemic interventions

There are two ways to help people. One is to find them, or to enable them to find you, and then provide a service to them. The other is to remove the root cause of their problem, or to remove the barriers which prevent them from helping themselves.

The first is a targeted or case-work approach. The second is a systemic intervention.

Targeted interventions tend to be small-scale, needs-driven, flexible, short term and inefficient (ie: the cost per person helped is relatively high). It is this kind of intervention which NGOs do so well.

Systemic intervention tend to be large-scale, rights-driven, inflexible, long term and efficient (the cost per person is relatively low). This is government territory.

When NGOs find themselves running large-scale, long-term, rights-driven programmes – such as those which are needed for children affected by HIV/AIDS – this is a signal that it is time for government to get involved.

Targeted interventions for people affected by HIV/AIDS are difficult, because in high prevalence areas there are so many people needing help, while in low-prevalence areas the intended beneficiaries are scarce and reluctant to be identified.

For this reason, there is a global trend to using systemic, universal interventions

for HIV/AIDS – making sure those affected by the epidemic are catered for in regular health, education and social welfare services.

Civil society organisations continue to play a vital role by identifying and helping people who are excluded from these mainstream services, and by drawing the authorities attention to weaknesses in their systems.

From OVC to ART: shifting the paradigm

A range of programmes were developed during the 1990s to help children affected by HIV/AIDS, who were usually referred to as “orphans and vulnerable children” or OVC. Many of these interventions were based on the premise that their parents would fall ill and die, so causing social, economic and psychological problems for their children.

Typical projects included

- food gardens, micro-lending schemes and nutritional support – to support parents impoverished by AIDS, or feed orphans who were fending for themselves;
- palliative home-based care schemes for bed-ridden, terminally ill parents, so their children were not withdrawn from school to care for them;
- psycho-social support such as counselling and memory books, designed to help children cope with

bereavement and rejection by their relatives;

- hospices for HIV-positive babies and children, whose parents did not have the capacity or will to care for them until they died.

However the roll-out of anti-retroviral therapy (ART) in recent years has shifted this paradigm. ART means that most parents who know they have AIDS are able to raise and provide for their children. It also means that far fewer children are infected at birth, and those who are infected can lead a relatively normal childhood.

As ART reaches more parents, many of the interventions of the OVC era are changing – for example counselling, nutritional support and home-based care are now used to ensure that AIDS-ill people receive and remain on ART, and baby hospices are closing down as the number of infected babies declines, and the prognosis for infected children improves. ART has shifted the paradigm from dying with dignity, to living positively.

In the process, ART is forcing programmers to take a hard look at stigma. Stigma discourages people from shifting their own paradigm through testing and treatment. Even where people with AIDS are in good health, stigma often leads to ostracism by families and communities, and exclusion from public services.

While parents seldom infect their own children with HIV, the stigma attached to the virus is highly contagious, and children with positive parents are often subjected to the same mistreatment since everyone assumes they are also infected.

Programmes in the ART era must focus on stigma, addressing both the manifestations

(exclusion and abuse) and the causes (the myths and misconceptions).

Programming around paradoxes

Programmers working in the field of HIV/AIDS spend their lives confronting paradoxes – truths hidden inside contradictions – including:

- The paradox of sectors: HIV/AIDS is primarily an adult health issue but, paradoxically, it affects the wellbeing of much larger numbers of uninfected children, over a greater span of time. Solutions lie in inter-sectoral collaboration, but government ministries are notoriously bad at talking to each other and to the NGOs who have so far led the response to affected children. Until they do, the solutions to HIV/AIDS will be elusive.
- The paradox of diagnosis: most people who are HIV-positive don't know it, and many who are ill do not realise they have AIDS. They almost certainly need the kind of interventions which were popular before ART appeared – but they won't get them, because nobody knows who they are! Paradoxically, as soon as they are diagnosed, they will have access to ART, which means very few of them will need that kind of intervention!
- The paradox of numbers: the better we become at diagnosing and treating HIV, the worse the problem will appear! As more HIV-positive people receive life-saving drugs, the pool of HIV-positive people will actually increase for a time, since they won't be dying as fast as they become infected. Paradoxically, this is GOOD news, because those who are receiving ART are less likely to infect others, and more able to raise their children and be useful members of society.

- The paradox of stigma: most people who know they are HIV-positive want help, but many are reluctant to come forward for testing and treatment for fear of disclosing their status. Paradoxically, if it wasn't for stigma, many of these people would not have been infected in the first place, because the people who infected them would probably have been tested, counselled and treated, thus reducing the risk that they would pass the virus on.
- The paradox of counselling: many people become ill, and many children become orphans, without needing counselling. Counselling is a feature of many HIV/AIDS interventions because the age-old challenges of illness and death are combined with a painful measure of stigma and exclusion. Paradoxically, counselling doesn't address stigma or exclusion, it simply helps people to deal with the resulting trauma. If there were no stigma, there would be very little demand for counselling.

The risks of accidental HIV infection

Readers of this report are unlikely to share the widespread misconceptions that people can be infected by sharing food, utensils, toilets, clothing, bedding; or by kissing, hugging or even breathing the same air as an HIV-positive person. Transmission can occur only by exposure to the blood, semen, vaginal fluid or mother's milk of an infected person¹⁰⁰.

The US Centres for Disease Control (CDC) investigates every unexplained case of HIV

transmission. They have concluded there is no risk whatever of infection from tears, sweat and saliva, and say there has never been a documented case of HIV transmission due to exposure of a small amount of blood on intact skin. They estimate the risk of transmission from exposure of non-intact skin, or the eye, nose or mouth, to infected blood at less than one in a thousand¹⁰¹. Add this to the extremely low chance of being exposed to infected blood in a low-prevalence setting like India, and there's effectively no risk to anyone outside of a medical setting.

As for nurses and doctors, the most significant risk of accidental HIV infection is through needle-stick injuries (NSIs). However, the CDC estimates that 99.7% of NSIs involving infected blood do not transmit HIV. A review of NSIs over 24 years (1980-2003) in 172 countries involving 22.2 million nurses and doctors found that 18 million occurrences of needle-stick injury produce more than 27,000 hepatitis C infections, but fewer than 500 HIV infections, around the world each year¹⁰².

To give perspective, one could compare the risk of accidental HIV exposure to accidental exposure to cigarette smoke. Lung cancer is at least as deadly as AIDS – of 180,000 people diagnosed with lung cancer in the USA each year, 86% die within five years¹⁰³ while of 440,000 Americans living with AIDS, only 17,000 die each year¹⁰⁴. Accidental HIV infection is extremely rare, and death by no means a certainty, whereas it is estimated 600 people in Britain alone

100 AIDS myths and misunderstandings, AIDS InfoNet, Fact Sheet 158.

102 Exposure to blood – what healthcare personnel need to know. Centres for Disease Control and Prevention, updated July 2003

103 Global country-specific incidence rates of occupational HIV and hepatitis C infections by needlestick injuries. Drain PK and Holmes KK. nt Conf AIDS. 2004 Jul 11-16; 15: abstract no. MoPeC3549

104 <http://www.quit-smoking-stop.com/lung-cancer.html>

105 <http://www.avert.org/statsum.htm>

die each year from lung cancer caused by passive smoking¹⁰⁵.

Simplistic though this analysis may be, it hopefully demonstrates just how absurd it is for both medical and non-medical personnel to use the extremely small risk of accidental HIV infection as a justification for the neglect, abuse or exclusion of children they assume are HIV-positive, let alone those kids who are actually diagnosed with the virus.

Regional action priorities for South Asia¹⁰⁶

According to a synthesis of global and regional research prepared by UNICEF for the recent SAARC Regional Consultation on Children and HIV/AIDS, the following actions are likely to have the greatest positive effect on the largest number of children affected by HIV/AIDS in South Asia:

- **Make sure HIV-positive parents remain alive and productive** – find ways to diagnose more of the people living with HIV, especially parents, and ensure all have access to treatment, and remain on their treatment programmes.
- **Make sure public servants are part of the solution, not part of the problem** – re-educate government service providers, especially doctors, nurses, teachers and local officials, to overcome those myths and misconceptions which sustain stigma and discrimination, and establish and enforce standards of non-discriminatory treatment.
- **Make sure parents raise their own children, rather than getting rid of them** –

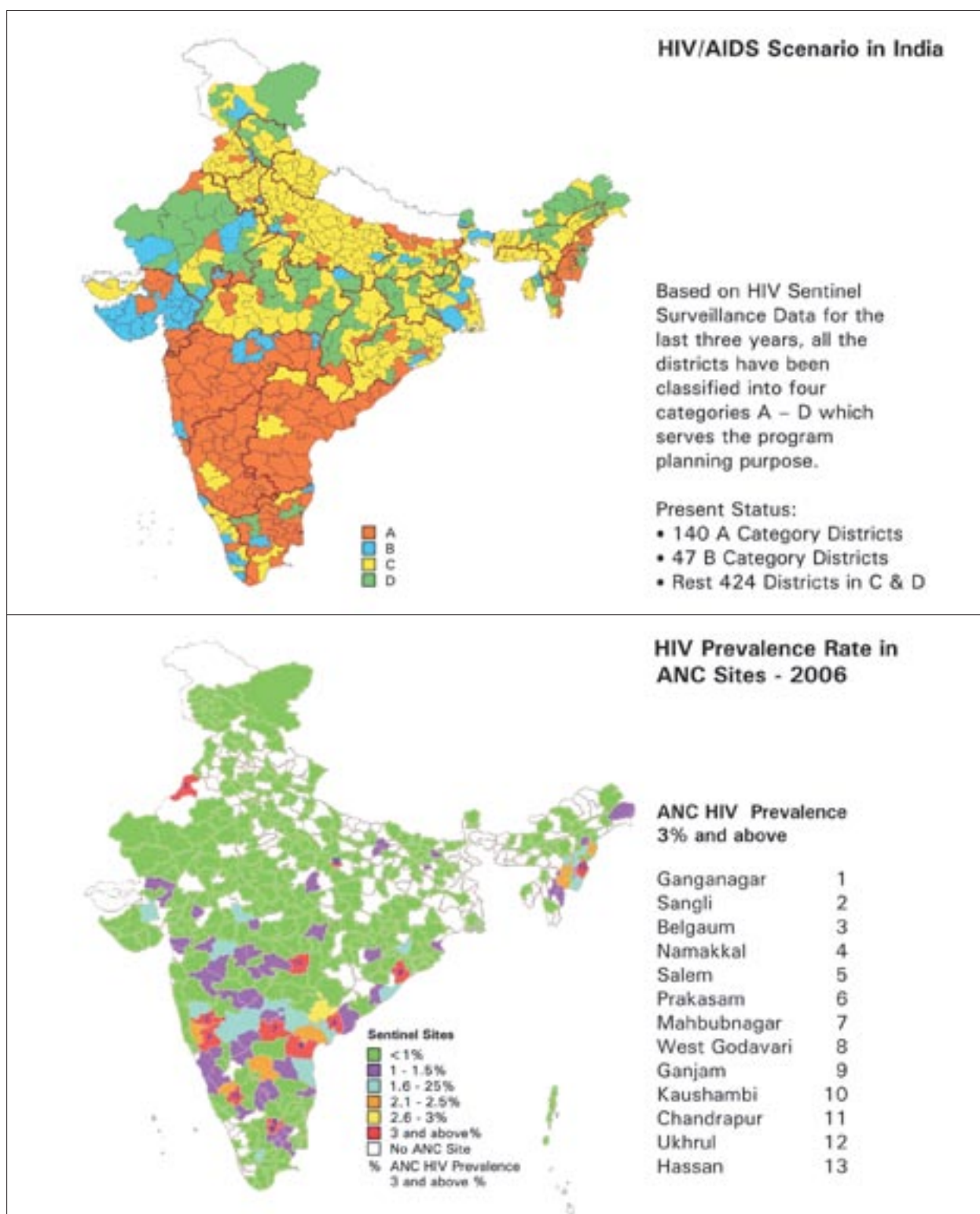
establish/expand/strengthen the nation's capacity for family reconstruction and support, such as nutritional support, home-based care, skills training (parenting and income generation), through all relevant departments and drawing on communities and NGOs.

- **Make sure people don't exclude their own children from vital services** – educate the public on their rights, entitlements, and the services available to help them raise their children effectively, whether or not they are affected by AIDS.
- **Make sure everyone knows the truth about AIDS** – that it's no longer a sentence of death, that children of HIV-positive parents are not usually infected, that infected children won't infect other children, and that HIV affects (and infects) the innocent as well as those engaged in behaviour which society finds abhorrent.
- **Make sure protection failures are detected and corrected** – establish a mechanism (children's advice offices, child protection officers etc.) which is accessible to everyone to give real help to parents who are denied entitlements and children who are neglected or abused, and to refer cases to specialists where necessary.
- **Make sure children in orphanages don't stay long, and are treated well while they are there** – determine and enforce minimum standards of institutional care, including measures to restore children to families as soon as possible (see #3 above) and to ensure their integration in local community life.

¹⁰⁵ Passive Smoking, ASH (UK) January, 2000, cited in Building public awareness about passive smoking hazards. American Cancer Society and International Union Against Cancer, 2003

¹⁰⁶ Children affected by HIV/AIDS in South Asia – a synthesis of current global, regional and national thinking and research, UNICEF Regional Office for South Asia, April 2007

Annex 4



Annex 5: Acronyms

AEP	Adolescent Education Programme	MWCD	Ministry of Women and Child Development
AIDS	Acquired Immuno Deficiency Syndrome	NACO	National AIDS Control Organization
ANC	Ante Natal Clinic	NACP	National AIDS Control Programme
ANM	Auxiliary Nurse Midwife	NCERT	National Council for Education Research and Training
ART	Antiretroviral Therapy	NGO	Non-Governmental Organization
ARV	Anti Retro Viral	NHE	Nutrition and Health Education
ASHA	Accredited Social Health Activist	NRHM	National Rural Health Mission
AWW	Anganwadi Workers	OI	Opportunistic Infections
CBO	Community Based Organization	PHC	Primary Health Centre
CCC	Community Care Centres	PLHA	People Living with HIV/AIDS
CDPO	Child Development Project Officer	PPTCT	Prevention of Parent to Child Transmission
CHC	Community Health Centre	RCH	Reproductive & Child Health
CSW	Commercial Sex Worker	RTI	Reproductive Tract Infection
DAPCU	District AIDS Prevention and Control Unit	SACS	State AIDS Control Society
DCPU	District Child Protection Unit	SAARC	South Asia Association for Regional Cooperation
DFID	UK Department for International Development	SC	Scheduled Caste
FBO	Faith Based Organisations	SCERT	State Council for Education Research and Training
FHI	Family Health International	SHG	Self Help Group
GOI	Government of India	SIE	State Institute of Education
HIV	Human Immuno-deficiency Virus	ST	Scheduled Tribe
HRG	High Risk Group	STD	Sexually Transmitted Disease
ICDS	Integrated Child Development Scheme	STI	Sexually Transmitted Infection
ICPS	Integrated Child Protection Scheme	SW	Sex Worker
ICTC	Integrated Counseling and Testing Centre	TB	Tuberculosis
IDU	Injecting Drug User	TI	Targeted Intervention
MCH	Maternal and Child Health	UNICEF	United Nations Children's Fund
MDG	Millennium Development Goals	USAID	US Agency for International Development
MHRD	Ministry of Human Resource Development	VCTC	Voluntary Counseling & Testing Center
MOHFW	Ministry of Health and Family Welfare		
MSJE	Ministry of Social Justice & Empowerment		
MSM	Men having Sex with Men		



