Breaking Barriers: Building Better Societies for Children with HIV

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ABSTRACT

Children represent the future of our societies, yet HIV/AIDS continues to pose a severe threat to their health, development, and survival. With 2.4 million people living with HIV in India—including approximately 82,000 children under the age of 15—the epidemic continues to impact the nation's youth disproportionately. Globally, a child is infected with HIV every 12 seconds, and one dies from AIDS every 16 seconds, underscoring the urgent need for targeted interventions. In India, young people aged 15–29 bear 31% of the national HIV burden, while alarming data gaps persist for the 10–14 age group. Many children born with HIV go undiagnosed, with half dying before their second birthday due to lack of early detection, limited pediatric ART access, and inadequate healthcare infrastructure. Social stigma, poverty, malnutrition, and the absence of comprehensive policies further compound the problem—especially for orphaned and vulnerable children. Street children, despite facing high-risk environments involving sexual exploitation and drug use, are notably absent from national priority lists. The National AIDS Control Organisation (NACO), under the Government of India, has urged a multi-sectoral response involving 31 ministries to integrate HIV care into broader developmental agendas. Despite progress, significant systemic barriers remain. This paper calls for an integrated, child-centered approach to HIV/AIDS prevention, diagnosis, and care, addressing clinical, social, and policy challenges. Building better societies for children with HIV requires not only medical intervention but also strong family support, community engagement, and inclusive public health strategies that leave no child behind.

Keywords: HIV/AIDS, Children with HIV, HIV education, Stigma and discrimination, Child rights, Sustainable development, Paediatric ART, HIV prevention, Public health, Social inclusion, Human rights, Orphaned and vulnerable children (OVC), India HIV epidemic, Health care access, National AIDS Control Organization (NACO), Global HIV response, Mother-to-child transmission, Youth and HIV prevention, School inclusion, Community support for HIV-positive children

BREAKING BARRIERS: BUILDING BETTER SOCIETIES FOR CHILDREN WITH HIV

Children today are the youth of tomorrow, and HIV significantly impacts this vital generation, with serious consequences for our future, our nations, and the world. HIV/AIDS not only affects health but also economic growth and national morale. In India, people aged 15-29 make up nearly 25% of the population but bear 31% of the AIDS burden. Limited data on adolescents aged 10-14 leaves gaps in understanding and combating infections and deaths within this group, highlighting the high-risk young people face in contracting HIV. According to UNFPA, every 12 seconds someone contracts HIV globally, and every 16 seconds someone dies of AIDS. In India alone, 2.4 million people are infected with HIV [UNICEF, 2020], contributing to the global total of 33 million, including 2 million children under 15. These statistics are a stark reminder of the urgent need to intensify our efforts to eradicate this devastating virus.

India has the third highest burden of HIV in the world with an estimated 25.44 lakh in 2024 with estimated 68000 Children(<15 years of age) however, half of HIV-positive children die undiagnosed before their second birthday. The reasons for the lack of access to treatment of children with HIV/AIDS are manifold and include among others, issues of diagnosis in infants (early diagnosis), lack of clear guidelines for the treatment of children, lack of access to appropriate pediatric ART formulations, inadequate capacity and knowledge of

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service providers in the clinical management of Paediatric HIV/AIDS, lack of surveillance and data in this age group (<15 years), nutrition in young infants, inadequate follow up of infants born to mothers from the PPTCT program and other programmatic issues such as convergence with RCH services and the lack of a minimum package for care and support of children affected and infected with HIV. Enhancement of health care systems' ability to address the health needs of infected children, resulting in effective management of common childhood illnesses and prevention and treatment of opportunistic infections. Children have specific needs for 'growth and development', and of early diagnosis of infection besides needing a-strong family support. Orphaned and vulnerable (OVC) children, both uninfected and infected add to the complexity of the issue in terms of vulnerability, social security, livelihood and poverty.

The National Council on AIDS [NACO] chaired by the Prime Minister of India, then mandates 31 ministries to integrate HIV into their ongoing development activities. Children legally or otherwise aren't considered active agents who are responsible for their behavior and it was only in the late 1990s that people realized something must be done to acknowledge and respond to the fact that a large number of children are getting infected by the deadly virus. Children under 15 make up 13% of new global HIV infections and 17% of deaths every year. Anyone age 13 or younger is counted as a child in US health statistics. In 1992, almost 1,000 children were infected in the US. About 2.4 million people in India are suffering from HIV As per the 2011 Aids report published by the UN. [WHO 2011].

According to the National Aids Control Organisation (NACO), of India's 15.56 lakh PLHIV till 2022 includes approx. 82,000 children (<15 yrs.) while some of them are born infected or become infected each year. No one knows how many street children are at risk of contracting, or have died of, HIV/AIDS. They are not even listed as a vulnerable group, like commercial sex workers and homosexuals. Yet the sexual exploitation and drug abuse that is an inevitable part of their lives, points to a serious problem in urgent need of attention.

History of Hiv/Aids

Acquired Immune Deficiency Syndrome (AIDS) was first discovered and recognized in the United States in 1981. The prevalence of AIDS is escalating all over the world. The occurrence of AIDS is getting higher with every passing minute. The cases of HIV/AIDS are mushrooming all over the world at an alarming rate. AIDS is continuously increasing throughout the world but the rate of increasing differs from one country to another, depending upon the social norms, social customs and sexual practices. The high number and high mobility of sexual partners are the main cause of the spread of AIDS in the country rapidly.

History of Hiv/Aids In India

The first case in India was discovered in 1986 in Tamil Nadu, thereafter in Maharashtra and Manipur. By the year 1990, it had spread to almost half of India and by 1993 all the states and UTs of India had reported cases of HIV/AIDS. NACO estimated that there are 51 lakh HIV cases in India and out of these total cases around 38% are women. In 2005, UNAIDS estimated that there were 5.7 million people of all ages living with HIV /AIDS in India. NACO estimated that there were 5.2 million adults, aged 15-49, living with HIV/AIDS in India. UNAIDS and NACO estimated that HIV/AIDS prevalence among adults in India is 0.9% which is still relatively low in comparison to other countries. India accounts for 75% of HIV/AIDS prevalence in South/South East Asia and 15% of global prevalence. The World Bank, which dealt with HIV/AIDS prevention and treatment in India estimated that India represents 20% of the world's population. The majority of people living with HIV/AIDS in India are from rural areas (57% in 2005). [Youth peer education network]. The United Nations recently estimated that life expectancy gains in India may be lower than anticipated due to the impact of HIV/AIDS.

Acquired Immuno-Deficiency Syndrome is a disabling and fatal disease caused by the human immunodeficiency virus (HIV). It is thought that everyone infected with HIV will eventually develop AIDS; because HIV steadily weakens the immune system of the body. The human body is unable to fight off an infection which is why most people die within three years of the first signs of AIDS appearing.

Acquired: It is not genetically inherited but one gets it from a person who is infected with the HIV virus.

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Immunodeficiency: Weakness or the inadequacy of the body's main defense system to fight external disease-producing germs**.**

Syndrome: It is not just one disease or symptom but a group of diseases or symptoms.

AIDS is a concern caused by a virus. A closer look at the term itself tells us a lot about what AIDS is. AIDS begins from the damage to the immune system, acquired as a result of infection with HIV (Human Immunodeficiency Virus). Many conditions can result in someone being diagnosed, as having AIDS but what links them all is a deficiency or weakness in the immune system. The word syndrome is used to emphasize that AIDS presents itself as a group of signs and symptoms and not a single disease. AIDS can't be diagnosed with the existence of one sign or symptom. All the symptoms of AIDS can be symptoms of other diseases, too. Therefore, a person can't tell whether s/he has AIDS or not unless s/he has been examined at a hospital or health center and his/her blood tested.

The Paediatric ART Program in India

Under the third phase of the National AIDS Control Program (NACP) from 2006-2011, two major initiatives were launched to support children with HIV/AIDS. First, a pediatric fixed-dose combination of antiretroviral drugs became available for infected children. Second, $14 million in funding from the Global Fund for AIDS, Tuberculosis, and Malaria (GFATM) in 2007-08 enabled a five-year program offering a comprehensive package of services, including medical care for opportunistic infections, psychosocial support, supplementary nutrition, and education [Mysore Declaration].In collaboration with the Indian Academy of Pediatrics, NACO developed the Paediatric ART Guidelines, Formulations and Dosing Guide, Protocol for Diagnosis, and an Operational Rollout Plan. Treatment under this program is expected to cost Rs 8,000 per child annually [Global Fund for HIV/AIDS]. Despite efforts to combat HIV, the global number of children living with HIV continues to rise [Beyrer, C. et al.]. Addressing stigma and discrimination requires focusing on the public health impact of HIV criminalization. This approach broadens advocacy to address the public health consequences of neglecting individual rights without compromising civil liberties.

Provisions and Practices

In India, The National Commission for Protection of Child Rights (NCPCR) was set up in March 2007 under the Commission for Protection of Child Rights Act, 2005, an Act of Parliament (December 2005).

The Commission's Mandate is to ensure that all Laws, Policies, Programmes, and Administrative Mechanisms align with the Child Rights perspective as enshrined in the Constitution of India and also the UN Convention on the Rights of the Child. The Commission visualizes a rights-based perspective flowing into National Policies and Programmes, along with nuanced responses at the State, District and Block levels, taking care of the specificities and strengths of each region. The National Commission for Protection of Child Rights (NCPCR) was set up in March 2007 under the Commission for Protection of Child Rights Act, 2005, an Act of Parliament (December 2005). The Commission's Mandate is to ensure that all Laws, Policies, Programmes, and Administrative Mechanisms align with the Child Rights perspective as enshrined in the Constitution of India and also the UN Convention on the Rights of the Child. The Commission visualizes a rights-based perspective flowing into National Policies and Programmes, along with nuanced responses at the State, District and Block levels, taking care of the specificities and strengths of each region [Global Commission on HIV and the Law (2012]. To reach every child, the program emphasizes deep engagement with communities and households, ensuring that on-the-ground experiences shape the support provided by the authorities at all levels. The Commission recognizes the essential role of the State in building strong institutions, respecting local governance, and fostering societal concern for children's well-being. Access to quality, harassment-free education is a right for all children, including those living with HIV [MHRD]. The rights of HIV-positive students and staff in educational settings are protected by several laws, including the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), the Family Educational Rights and Privacy Act (FERPA), and various state laws.

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Mitigation Strategy

A multimedia-driven communication strategy, focusing on youth and a multi sector response, is central to NACP Phase V goals, guided by the HIV/AIDS (Prevention and Control) Act of 2017. This approach emphasizes creating communication materials tailored to epidemiological data and program insights. Social and behavioral change campaigns aim to foster sustained behavior change among high-risk groups and bridge populations, provide information on accessing NACP services, and strengthen an enabling environment by promoting positive societal norms to reduce stigma and discrimination. Prevention programs for adolescents are abundant, helping teens make informed life choices. Prevention can be categorized into three levels:

1. **Primary Prevention**: Reduces the likelihood that adolescents in the program will engage in violent behaviors, as compared to a control group.
2. **Secondary Prevention**: Targets adolescents at increased risk, focusing on preventing the onset and risk of HIV.
3. **Tertiary Prevention**: Aims at adolescents who have already engaged in seriously violent acts [Journal of AIDS].

It is very important to select the appropriate program geared towards the needs of the particular teen and his or her situation. In selecting the right program, look into the characteristics of the program and the youth served. Next, review what the **goals and objectives** of the program are to determine whether the program reaches out to your needs. If there is interventions in the community that work use those as a starting point for treatment. Practically every city must have a prevention and intervention programs in place. Further it is mentioned that:

- The Right to Education (RTE) Act 2010 guarantees education to all children (irrespective of any disability or ailment) in the age group of 6-14 years, this is the first time that a specific provision has been conceived to protect the rights of students with HIV/AIDS. Section 6(4) of the draft law states: "No school shall deny admission or expel any student on the ground of having HIV/AIDS or any other serious ailment."
- The Prohibition of unfair practices in schools Bill 2012- makes refusal of admission or expulsion of students on grounds of having contracted HIV/AIDS a "cognizable offence". Schools denying admission would be liable to pay a monetary penalty and the school principal or any other officer, responsible for the functioning of the institution, would face imprisonment of upto three years or fine or both.[INDIA-TODAY]
- HIV and AIDS awareness program to be integrated in all training program for the teachers & functionaries to enable them to contribute towards spreading awareness regarding HIV issues.
- If possible, undertake program for orphans and vulnerable children affected by HIV and AIDS (OVC) and ensure that they are child-centered, family- and community-focused and rights-based.
- Create an enabling environment that encourages HIV related prevention, care and support activities and reduces stigma and discrimination at individual, community and institutional levels.
- Women have poor access to information and education, which is critical in the context of HIV since behavior change is the key to controlling the epidemic.

In 2000, the global community took an historic step in the United Nations Millennium Declaration by acknowledging the importance of an effective response to HIV/AIDS and by placing it in the context of the broader development agenda. Among the many health targets that were then established in the Millennium Development Goals (MDGs), MDG 6 calls for unprecedented action to halt and begin to reverse the AIDS epidemic.[UNAIDS 2013]. Continued progress was made in mobilizing financial resources for the AIDS response in 2012, although funding still fell short of the global target of US$ 22-24 billion annually. In 2012, approximately US$ 18.9 billion was available for HIV programs in low- and middle-income countries, reflecting a 10% increase from 2011.

India receives only 1% of global HIV funding, despite accounting for 10% of the world's total HIV-positive population [Global Fund to Fight Tuberculosis, AIDS, and Malaria]. The **Global Plan** to eliminate new HIV infections among children while keeping their mothers alive outlines four key programmatic components:

1. Preventing new HIV infections among women of reproductive age.

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2. Helping women living with HIV avoid unintended pregnancies.
3. Ensuring that pregnant women have access to HIV testing and counseling, and that those who test positive receive antiretroviral medicines to prevent transmission during pregnancy, delivery, or breastfeeding.
4. Providing HIV care, treatment, and support for women, children living with HIV, and their families [UNICEF, 2013].

The Global Plan prioritizes scaling up efforts in 22 countries, which collectively account for nearly 90% of pregnant women living with HIV. As of 2021, 81% of pregnant women living with HIV globally received antiretroviral prophylaxis or treatment. Coverage of antiretroviral programs for the prevention of mother-to-child transmission (excluding the less effective single-dose Nevirapine regimen) increased from 57% (51–64%) in 2011 to 62% (57–70%) in 2012 [GARPR, 2012], and further improved by 2022. Sustained progress in scaling up services has brought the world closer to eliminating new HIV infections among children. If this scale-up continues, services could reach 95% of pregnant women living with HIV by 2025, preventing mother-to-child transmission of HIV [Mainstreaming HIV/AIDS]. As a result of these expanded HIV prevention services, the number of newly infected children has drastically reduced. From 2001 to 2012, new HIV infections among children dropped by 52%. Between 2009 and 2012, over 670,000 children were prevented from acquiring HIV due to expanded access to prevention services. To meet the global target of reducing new HIV infections among children by at least 95% by 2025, further acceleration of program expansion is needed.

Treatment Coverage Gaps for Children with HIV

Children living with HIV continue to face significant treatment gaps. In 2012, only 647,000 children under 15 were receiving antiretroviral treatment globally. While the number of children receiving ART increased by 14% from 2011, this pace was slower than the 21% increase seen in adults. In priority countries, only three in 10 children receive HIV treatment. One key factor contributing to this disparity is the limited access to early infant diagnosis in many regions. In three priority countries, less than 5% of infants had access to early HIV diagnostic services, making it difficult to meet the 2025 target of testing 95% of HIV-exposed children.

Children with HIV

Our youth must acquire the right knowledge to prepare for a fulfilling life. Schools should foster a 'working philosophy of life' among students—one supported by meaningful information to guide them through the challenges of learning. Education must be purposeful and deliberate; it requires hard, serious effort. In a country like India, where poverty is widespread and many face significant challenges, it is essential for every child to recognize their social obligations. Each individual must strive to contribute to the betterment of their country, both now and in the future, through balanced development in physical, intellectual, moral, emotional, aesthetic, social, and spiritual dimensions.

The younger generation faces an urgent challenge from the threat of AIDS, which spreads rapidly due to high-risk behaviors, particularly among youth [NACO]. Women are biologically and socially more vulnerable to HIV than men, and the issue is increasingly seen as a sociological one. Solving this problem cannot be the responsibility of teachers, parents, or the community alone; it requires a collective effort. Addressing HIV/AIDS is a major challenge for educators, planners, and the government, but with determination, we can tackle it. If we can translate this vision into reality, no force of terror will succeed, no wars will occur, and peace will prevail on earth.

Looking Further

More than 1.75 billion people, or one in every five individuals worldwide, are adolescents aged 10 to 24 years, making this age group particularly vulnerable to HIV/AIDS. While HIV prevalence is decreasing in many industrialized nations, the decline in many developing countries, particularly among adolescents, has been inconsistent. In countries like India, where over 22.8% of the population is between 10 to 19 years old, HIV poses a significant threat both in terms of incidence and prevalence. Despite the prominence of young adults in the HIV epidemic, research on prevention for adolescents has been limited. Adolescence (ages 10–19) is a critical period of both physical and psychological development. Among 109 countries reporting results in mid-

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term reviews, nearly all identified the elimination of new HIV infections among children and the reduction of AIDS-related maternal deaths as national priorities. An updated analysis of progress toward reducing new child infections by 90% between 2009 and 2015 shows that significant effort and innovation will be needed to achieve this target, particularly in the 21 priority countries of sub-Saharan Africa. Since adolescents make up a large portion of the reproductive age group, they will play a crucial role in shaping the future growth of India's population and economy. Therefore, investing in their well-being through financial resources, research, and policies is essential. To reach every child, efforts must penetrate deeper into communities, with support from all levels of authority and key community leaders [P. Orner].

The purpose of education is to nurture the inherent dignity of every individual. Globally, an estimated 35.3 million people were living with HIV in 2012, with an increase in the number of people receiving life-saving antiretroviral therapy. There were 2.3 million new HIV infections globally in 2012, a 33% decline from 3.4 million in 2001. Likewise, AIDS-related deaths have also decreased, with 1.6 million AIDS deaths in 2012, down from 2.3 million in 2005. In 2009, India had an estimated 2.39 million people living with HIV, with women comprising 36% and children 4.4%. By 2021, this number had risen to 38.4 million globally, with 36.7 million adults and 1.7 million children under 15. Among these, 54% were women and girls. The AIDS response has advanced the right to health, gender equality, human rights, employment, and social protection. It has also addressed entrenched social norms, exclusion, and legal barriers that hinder health and development, and its investment approach is increasingly being adopted to accelerate global health and development gains.

HIV is not just a medical condition but a social disease, and its management requires a comprehensive approach that includes physical, psychological, spiritual, and social support, alongside active community mobilization and participation. Teachers, in particular, should reconsider their relationships with children affected or infected by HIV. By empathizing and putting themselves in the students' shoes, educators can better understand their emotions and needs. Today, let us reexamine our responsibilities toward these children and ensure that every child has access to education and the opportunity to grow up healthy.

The present paper explores the role of society in supporting the education of children with HIV/AIDS.

- Recognize that children with HIV/AIDS are part of an evolving concept and should not face exclusion due to stigma.
- Emphasize that HIV/AIDS should not be considered an environmental or attitudinal barrier that prevents children from full and effective participation in society on an equal basis with others.
- Highlight the importance of integrating disability issues, including those related to HIV/AIDS, as part of sustainable development strategies.
- Affirm that discrimination against any person based on HIV-positive status violates the inherent dignity and worth of the individual.
- Promote and protect the human rights of children with HIV/AIDS, ensuring they are supported to thrive and participate fully in society.

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