# Care for children affected by HIV/AIDS

#### What is in this guide?

This guide looks at ways of supporting children affected by HIV/AIDS. It covers children whose parents are ill or have died as well as children living with HIV/AIDS.

#### It has the following sections:

- 1. Introduction
- 2. Important principles
- 3. Community child care committees
- 4. Children whose parents are ill
- 5. Children who are orphaned
- 6. Children who are living with HIV/AIDS

# This web site also contains the following guides on HIV/AIDS

Important things to know about HIV/AIDS

Introduction to community projects on HIV/AIDS

How to run HIV/AIDS prevention and education projects and campaigns

How to care for people living with HIV/AIDS and their families

How to care for children affected by HIV/AIDS

How to coordinate local community projects on HIV/AIDS

How to develop a municipal AIDS strategy

#### Introduction

The fact that there is a stigma around HIV/AIDS that prevents people from being open increases the isolation of people in families affected by HIV/AIDS. Not only do they have to deal with their own grief and emotional suffering but also this is made worse by the way that the community treats them.



The greatest impact of HIV is on young people. The same generation whose parents are ill now are likely to be the ones who will themselves be ill in later years. In their childhood, they get little emotional and material support and they often have to start playing roles that are usually expected from adults. In many families, they play the adult role of maintaining the house and sometimes even trying to provide an income. Most of them play some nursing role and directly look after the parents who are ill. Older children also play the parent role to their younger siblings.

When parents die, very small children are often taken in by relatives. The survival of older children is often neglected and they are more vulnerable. In many cases, older children drop out of school to look after younger siblings. When they are not provided for by relatives, some end up living on the streets or barely surviving in very impoverished homes.

There are three categories of children who need special care:

Children whose parents are ill Children whose parents have died Children with HIV/AIDS

Most of the affected children (and the people who care for them) do not get the grants they have a right to get. See page 24 for foster, care dependency and child support grants. The main reason for this is ignorance, lack of access and lack of the right documents.

#### 2. Important principles

#### Target all children in need

There are many different models of community childcare projects. The main principle should be that all children in need should be identified and supported in some way. A project that deals with children affected by HIV/AIDS should be integrated in other efforts to help children in need.

This will also help to deal with the stigma and secrecy surrounding HIV/AIDS. If all children who have ill parents are supported, it will be easier for children to ask for help than if a project only helps children whose parents are ill with AIDS.

#### Keep children in their communities

Children should be supported in ways that help them to stay part of their community and family. For example, the common old-fashioned idea that children who are orphaned should be put in institutions like orphanages is no longer popular.

Orphanages are expensive and are not very healthy places for children to grow up. It is much better to keep the children in the communities they come from and to make sure that they get adult supervision and support in a familiar environment.

Adoption is also not easy to organise, especially for older children. It is even difficult to find adoptive parents for babies if there is a chance that they may be HIV positive.

It is not good to separate children from their siblings when they have lost their parents. It is much better to keep them as close to their natural support groups as possible. If there are other members of the family who can take in children this is often better than fostering them out to different families or letting different families adopt different children.

#### Coordinate services and use volunteers

Support must be well coordinated and reach down to the ground. This means that all services and organisations should work together to identify children in need and to make sure they get the right help. Welfare and health workers should work with churches and schools to identify children whose parents are ill or have died.

At a local community level, volunteers should be used to visit families, help child headed families and monitor foster care and other projects.

#### 2. Community childcare committees

Community childcare committees are an option that has been used very successfully in different countries. A group of adults work together to take responsibility for organising support for vulnerable children in an area. Childcare committees can be set up by social workers, the community can elect volunteers or they can be appointed by various organisations. It is important that they have community support and some official status so that they can be effective.

The volunteers usually come from different organisations and religious groups. They find out children in need and try to ensure that they are either linked to welfare services or that members of their family look after their needs.

The community childcare committees can also take responsibility for helping all children in need to get access to social workers and to child support or foster grants. They should also take responsibility that all births and deaths are registered so that children can get IDs and therefore access to social grants when they need them.

Community childcare committees can also help to screen foster parents and to monitor them to make sure that they treat children properly. Children in need are very vulnerable to exploitation and abuse. Some people take in foster children just to get the foster grants.

Community childcare committees should be linked to social workers from the government Welfare Department or the Child Welfare Society. They should get some training and report regularly to professional supervisors to ensure that they are doing their work properly.

#### 3. Children whose parents are ill

In many families, children become the main caregivers for people who are ill with AIDS. Older children also often play the parenting role for younger ones. Home-

based care and childcare volunteers should target these children for training and support. Here are some of the things that should be done:

Educate children about HIV/AIDS and teach them basic methods for washing and looking after patients.

Make sure they are in school and are able to survive – get food parcels and clothes to them. Help them to get access to grants and to things like parent's bank accounts. Talk to them about their fears and answer their questions.

Make sure they are registered with Home Affairs and apply for ID books.

Invite older children to family support group meetings

Make sure the ill parents make memory boxes and have all their documents in order

Talk about the future and help make arrangements to look after the children after their parents death – most children are terrified by the uncertainty of what will happen to them when their parents die.

#### 4. Children who are orphaned

Children who have lost one or both parents need a lot of support. They have to deal with grief as well as survival. Most orphaned children are supported by relatives. They are usually older women and are often unemployed or on pension. The family will become poorer and will need food and financial support.

A large number of orphans stay on alone in the family home when their parents die. Older children look after young ones and try to find ways to survive. Thousands of children are living in desperate poverty in these child-headed homes. Many of them drop out of school and some turn to sex work or crime to survive.

Some children are taken in as foster children whilst others go to orphanages or other institutions. In this section, we look at the different options and the role child care committees can play.

#### Child-headed homes and care by relatives

We must find ways to support children who are looked after by relatives or by older siblings in child-headed homes. Community child-care committees are best to reach and support these children. Here are some of the things that community child care volunteers should do:

Make sure that they get the government grants they are entitled to receive and help them get access

Make sure they get food parcels and benefit from poverty relief programmes

Try to keep children in school as long as possible and work with schools to organise support for children who cannot afford books, fees or clothing.

A volunteer should visit the family at least once a week to check that children are coping, going to school and eating.

Check that children are healthy and help them get healthcare, vaccinations and medicine when needed.

Support children who are HIV positive and get them into medical and other support programmes.

Work with churches and welfare organisations to collect clothes, bedding and building materials

Help children get documents like death certificates and IDs

Counsel children to help them deal with their feelings of loss and grief.

Be an adult they can trust and come to with their problems

#### Foster care

Foster care is provided by a family that takes in orphaned and other vulnerable children and looks after them. They do not adopt them and the state remains responsible for the welfare of the children. A court has to officially appoint foster parents – this is usually organised by social workers. Foster care parents receive a grant for doing the work and should use it to provide material and emotional support for the children and to ensure that they attend school. (see page 23/4 on grants)

If foster parents do not fulfill these obligations, the children will be moved to another family. Foster care is better than orphanages because it provides a family life for children. It is still not always an ideal situation and many children in foster care can be neglected or even abused and exploited.

It is important for foster parents to be trained and monitored by social workers. Childcare committees should also visit foster families and talk to the children to check that they are receiving proper care.

#### **Group housing**

In some communities group housing has been provided for children. This means that a number of different children who are orphaned will live in a house or homestead with one adult to look after them. These adults are often older women who no longer have their own children to look after. This option has been tried on farms and in rural villages where orphans have become a big problem and the traditional leader or farmer has taken responsibility for setting aside a house for this purpose.

#### Adoption

When you adopt a child it is a formal legal process and the child becomes yours. You have full responsibility for the child and the law treats the child as it would treat your own biological child. There are no special grants for adopted children and they family will only qualify to get the child support grant if they are poor.

#### **Orphanages**

There are very few orphanages available for the thousands of orphans who need care. Orphanages are a very expensive way of looking after children since the building, staff and services are costly. Orphanages are also not very good for children since they are impersonal and often there is too little contact with adults. Many children are abused by older children in orphanages. Families are the best place for children to grow up. When that is impossible it is better to get one adult to look after a small group of children than to put a children in an institution.

Some orphanages use a house parent system and instead of one large orphanage, they have a number of smaller houses in one place. Each house will have 5 -10 children with one adult to act as their "parent".

#### 5. Children living with HIV/AIDS

Children living with HIV/AIDS will have special needs that are different from those of adults. They are not able to get access and help themselves in the same way. Usually they depend on their mother or another caregiver. If they are very young, they will not understand the disease and the steps they have to take to stay healthy and to protect other people.

Most children with HIV/AIDS get the disease from their parents who can become ill or die when the child is very young. Home-based care and childcare volunteers should make sure that children with HIV/AIDS are properly supported.

It is best for children to be looked after by those they know and make them feel safe. If possible, children with HIV/AIDS should be left in the care of their families and relatives. In some areas, there are hospices or homes for children who are ill or dying. Social workers should work with clinics, home—based care and childcare volunteers to identify children who would be better off in hospices. Most ill children are too small to care for themselves in any way. The caregiver has to be the main target for support and training to make sure the child receives proper care.

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# Global Estimates of the HIV/AIDS epidemic, as of end 2002.

	Total	5 Million
People newly infected with HIV in 2002	Adults	4.2 Million
	Women	2 Million
	Children 15 years	800,000
	Total	42 Million
	Adults	38.6 Million
Number of people living with HIV/AIDS in 2002	Women	19.2 Million
	Children <15 years	3.2 Million
	Total 3.1 Million	
AIDS deaths in 2002	Adults	2.5 Million
ATES deaths in 2002	Women	1.2 Million
	Children <15 years	610,000
	Total	21.8 Million
Total no. of AIDS deaths since the beginning of the epidemic until the end of 2001	Adults	17.5 Million
epidemic until the end of 2001	Women	9 Million
	Children <15 years	4.3 Million
Total no. of AIDS orphans\$ since the beginning of the	Total	14 Million
epidemic until the end of 2001		

# The number of adults\* and children infected with HIV during 2002

Region	Total of newly infected Adults & Children with HIV
Sub Saharan Africa	3.5 Million
Asia and the Pacific	970 000
Eastern Europe & Central Asia	250, 000
Latin America and the Carribean	210, 000
The Middle East and North  Africa	83, 000
High-income countries	75, 500

# Regional HIV/AIDS statistics, December 2002.

Region	Epidemic started	Adults and children living infected with HIV/AIDS	Adult prevalence rate*	Percent of HIV- positive adults who are women	Main mode(s) of transmission# for adults living with HIV/AIDS
Sub Saharan Africa	Late '70's - Early 80's	29.4 Million	8.8%	58%	Heterosexual sex
North Africa and the Middle east	Late '80's	550,000	0.3%	55%	Heterosexual, IDU
South and South East Asia	Late '80's	6.0 Million	0.6%	36%	Heterosexual, IDU
East Asia and Pacific	Late '80's	1.2 Million	0.1%	24%	IDU, Hetero, MSM
Latin America	Late '70's early 80's	1.5 Million	0.6%	30%	MSM, IDU, Hetero
Caribbean	Late '70's - Early 80's	440,000	2.4%	50%	Hetero, MSM

Total		42 Million	1.2%	50%	
Australia and New Zealand	Late '70's - Early '80's	15,000	0.1%	7%	MSM
North America	Late 70's - Early 80's	980,000	0.6%	20%	MSM, IDU, Hetero
Western Europe	Late '70's - Early '80's	570,000	0.3%	25%	MSM, IDU
Eastern Europe & Central Asia	Early '90's	1.2 Million	0.6%	27%	IDU

#### **Notes**

- \* The proportion of adults (15 to 49 years of age) living with HIV/AIDS in 2001, using 2001 population numbers.
- # MSM (sexual transmission among men who have sex with men), IDU (transmission through injecting drug use), Hetero (Heterosexual transmission).
- \$ Defined as children who lost one or both parents to AIDS when they where under the age of 15 .

These figures are estimates at the end of 2002, published by UNAIDS in the 'AIDS Epidemic Update', December 2002 and UNAIDS ' Report on the global HIV/AIDS Epidemic', July 2002.

These estimates include all people with HIV infection, whether or not they have developed symptoms of AIDS, alive at the end of 2002.

For each of these countries, the 1999 prevalence rate published by UNAIDS was applied to the country's 2001 adult population to produce estimates given in the table. The estimates are given in rounded numbers. However, unrounded numbers were used in the calculation of rates and regional totals, so there may be minor discrepancies between the regional/global totals and the sum of country figures.

Adults in this report are defined as men and women aged 15-49. This age range captures those in their most sexually active years. While the risk of HIV infection continues beyond the age of 50, the fast majority of people with substantial risk behaviour are likely to have become

infected by this age. Since population structures differ greatly from one country to another, especially for children and the upper adult ages, the restriction of 'adults' to 15-49 has the advantage of making different populations more comparable.

For further information, see our web pages

- Global HIV and AIDS epidemic
- AIDS around the world
- AIDS in Africa
- AIDS in India, China, AIDS in Thailand



# INDIA AND HIV/AIDS - STATISTICS

India has a population of one billion, around half of whom are adults in the sexually active age group, with a large number below this age group. The first AIDS case in India was detected in 1986, and since then, HIV infection has been reported in all States and Union Territories.

The spread of HIV in India has been diverse, with much of India having a low rate of infection and the epidemic being most extreme in the southern States. 96% of the total number of nationally reported AIDS cases were found in 10 of the 28 States and 7 Union Territories, the worst being Maharashtra in the west, Tamil Nadu and Pondicherry in the south, and Manipur in the north-east.

In Maharashtra and Tamil Nadu the infections are mostly due to heterosexual contact, while infections are mainly found amongst injecting drug users (IDU) and their sexual partners in Manipur

#### Estimated numbers of adults and children living with HIV/AIDS, end 2001

Adults	3970000
Women	1500000
Children	170000
Adult HIV prevalence estimate	0.7%

These estimates above are based on previously published estimates for 1997 and 1999 and on recent trends in HIV/AIDS surveillance in various populations. Adults are defined as men and women aged 15 to 49. These estimates include all those with HIV infection, whether or not they have developed symptoms of AIDS.

## AIDS data on December, 2002

AIDS cases in India	Cumulative
Males	32161
Females	10786
Total	42947

The statistics for AIDS cases may be a poor guide to the severity of the epidemic, as in many situations a patient will die without HIV having been diagnosed, and the cause of death attributed to an opportunistic infection, such as tuberculosis or PCP.

Transmission Categories	Number of cases	%
Sexual	36201	84.29
Perinatal	1119	2.61
Blood and blood products	1282	2.99
Injecting drug users	1232	2.87
Not known	3113	7.25
Total	42947	100

Age group	Male	Female	Total
0 - 14	1018	624	1642
15 - 29	10427	5011	15438
30-44	18132	4507	22639
=>45	2584	644	3228
Total	32161	10786	42947

State/Union Territory	AIDS cases
Andhra Pradesh	2350
Assam	149
Arunachal Pradesh	0
A & N Islands	24
Bihar	146
Chandigarh (UT)	650
Delhi	720
Daman & Diu	1
Dadra & Nagar Haveli	0
Goa	124
Gujarat	2029
Haryana	247
Himachal & Kashmir	2
Karnataka	1575
Kerala	267
Lakshadweep	0
Madhya Pradesh	941
Maharashtra	9106
Orissa	82
Nagaland	298
Manipur	1238
Mizoram	34
Meghalaya	8
Pondicherry	157
Punjab	227
Rajasthan	616
Sikkim	6 .
Tamil Nadu	18276
Tripura	5
Uttar Pradesh	804
West Bengal	930

	267
Mumbai MC	1563

HIV estimates, 2001

The prevalence rates below are taken from data collected during screening of women attending antenatal clinics, meaning that these prevalence rates are only relevant to sexually active women.

State/Union Territory	HIV Prevalence (%)
Andhra Pardesh	1.50
Assam	0
Arunachal Pradesh	0
A & N Islands	0.16
Bihar	0.13
Chandigarh (UT)	0
Delhi	0.13
Daman & Diu	0.25
Dadra & Nagar Haveli	0.25
Goa	0.50
Gujarat	0.50
Haryana	0.51
Himachal Pradesh	0.13
Jammu & Kashmir	0.25
Jharkhand	0.08
Karnataka	1.13
Kerala	0.08
Lakshadweep	-
Madhya Pardesh	0.25
Maharashtra & Mumbai	1.75
Orissa	0.25
Nagaland	1.25

Manipur	1.75
Mizoram	0.33
Meghalaya	0
Pondicherry	0.25
Punjab	0.40
Rajasthan	0
Sikkim	0
Tamil nadu	1.13
Tripura	0.25
Uttar Pradesh	0
Uttranchal	0
West Bengal	0.13

Some areas report an HIV prevalence rate of 0 in antenatal clinics. This does not necessarily mean that there is no HIV in the area, as some of them report the presence of the virus at STD clinics and amongst injecting drug users.

#### Sources:

UNAIDS Epidemiological factsheet, 2002 Update.

NACO HIV and AIDS Surveillance in India, 31/12/2002



#### HIV/AIDS great threat to child rights

Cape Town 27 May 2003 Sapa

One of the greatest threats to the realisation of child rights in South Africa and in sub-Saharan Africa is the HIV/Aids pandemic, the University of Cape Town's Children's Institute said on Tuesday.

"The illness and death of adults as a result of HIV/Aids has a profound impact on the survival, development and protection of children in South Africa," the institute said.

According to a report released by the university's Centre for Actuarial Research, about 6,5 million South Africans are estimated to be HIV-positive, including 3,2 million women of childbearing age (15 to 49).

For each man between the ages of 15 and 24 who is infected with HIV, 4 young women are infected.

It says that about 75 percent of HIV-infected people in South Africa are in stages one and two of the disease's progression, therefore they have not yet developed symptoms and many do not know their status.

Between January and December last year 89,000 children were infected with the virus as a result of being born to an HIV-positive mother. This figure is around 7,5 percent of the total number of babies born during this period.

The institute warned that without access to health care services that could prevent the transmission of HIV/Aids from mother to child, the cumulative number of HIV-infected children in South Africa would continue to grow.

"Without access to the necessary basic health care services and support, most of these children will require repeated and prolonged hospital admissions - placing a massive burden on health facilities - and will die before their 5th birthday.

"Improved health service delivery to HIV-positive children is urgently needed as part of a comprehensive national treatment plan," it said.

Last year alone, about 150,000 children lost a mother to Aids.

The institute said that without any major new health interventions, close to two million children would lose a mother by 2010, and this would mainly be due to Aids.

Children in South Africa faced many vulnerabilities before their caregiver died. These included children having to look after the sick adult, not being able to attend school, and a loss of earnings as the adult was not able to work.

"The Children's Institute therefore supports the call for urgently improved and accessible poverty alleviation mechanisms as part of a comprehensive package of care and support for all children in South Africa."

The institute said that in heavily HIV-affected communities - the majority of which were poor - the impact of HIV/Aids was felt collectively, placing an enormous strain on community structures and formal and informal support systems.

Households that previously supported one another, through the sharing of resources and responsibility for care, were now unable to do so as household members fell ill or died as a result of HIV/Aids.

"As increasing numbers of households are affected by illness and death, it is inevitable that informal networks of inter-household support -often referred to as the "social safety net" - will be weakened," it said.

"This has an impact on all children, not just those directly affected by HIV/Aids."

The institute said the provision of antiretrovirals in the public sector was a crucial step towards decreasing the number of children who would be made vulnerable as a result of HIV/Aids.

It warned that the stage of the pandemic in South Africa this year was such that the country was 12 years away from experiencing the peak in the number of orphans.

"We currently face an equally large and more immediate service need that is often neglected: supporting the large numbers of children currently living with, and often caring for, terminally ill adults and other children.

"Well-grounded strategies and interventions put in place now will lay the foundation for a response that can grow with the size of the orphan population and should strive to appropriately address the needs of children currently living with sick adults," it said.

Child Protection Week, which aims among other things to highlight the plight of abused children, is currently being observed in South Africa.

Volume 5, Number 1, Fall/Winter 1999

# HIV/AIDS and Children's Rights

BANGALORE

Today, the majority of all new HIV infections occur among children and young people under 25 years of age, the people who were born and who have grown up during the AIDS epidemic. The epidemic is straining resources in already impoverished communities and creating new obstacles to the realization of children's rights to survival, development, and protection. The failure to ensure children's rights creates opportunities for HIV infection; at the same time, HIV/AIDS creates opportunities for the violation of children's rights. Advances in the realization of children's rights, including the implementation of the United Nations Convention on the Rights of the Child (UNCRC), are necessary to stem the growth of the AIDS epidemic.

We reproduce a fact sheet produced by the Interagency Coalition on AIDS and Development (ICAD) that summarizes available information on HIV/AIDS and children, and discusses the effect of HIV/AIDS on children's rights. The fact sheet also provides information about other, essential resources on HIV/AIDS and children.

# A Universal Framework for Children's Rights

The United Nations Convention on the Rights of the Child (UNCRC) was unanimously adopted by the General Assembly of the United Nations on 20 November 1989. The Convention has since been ratified by 191 member states of the United Nations and has entered into force as an international treaty. Only the United States and Somalia have not yet ratified it. This near- universal ratification establishes the UNCRC as the global standard for children's rights. The UNCRC covers the cultural, social, economic, and political rights of children and is guided in interpretation and implementation by four principles: non-discrimination; the best interest of the child; the maximum survival and development of the child; and consideration of children's opinions and views in matters that affect them. The rights defined in the Convention are indivisible and form a comprehensive framework for use in

determining children's best interests.

The United Nations
Convention on the Rights of
the Child has been ratified by
191 member states of the
United Nations. Only the
United States and Somalia
have not yet ratified it.

# Defining Children in the Context of Their Rights

The UNCRC defines children "as every human being below the age of 18 years unless, under the law applicable to the child, majority is obtained earlier." Unfortunately, most epidemiological data collection for HIV uses 14 as the cut-off age for children and labels all people above this age as adults. To avoid discriminating against any portion of the global population of children, all persons under the age of 18 should be counted and referred to as children. This means that until all-inclusive data on children becomes available, references and statistics that count children between the ages of 15 and 18 together with adults should be clearly identified as being inclusive of children.

#### Children Infected with HIV

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), children and young adults (ie, persons under 25 years of age) accounted for over one-third of the 33 million people living with HIV in 1998. As well, the majority of all new HIV infections in that year came from this population. Four million children under the age of 15 contracted HIV since the epidemic began, most of whom (about 90 percent) became infected from their mothers during pregnancy, labour, birth, or breastfeeding. In 1998 alone, it is estimated that there were 590,000 new infections among children under the age of 15, and 2.5 million new infections among children and youth in the 15-24 age group. Combined, this translates into 8500 new infections among children and young people every day.

## **Children Orphaned Due to AIDS**

Children who became orphans due to the death of one or both parents from HIV/AIDS are a rapidly growing population in urgent need of attention. By the year 2010, the number of orphaned children is

expected to reach 40 million. Current estimates from UNAIDS reveal that by 1997 a total of 8.2 million children under age 15 had lost their mothers since the beginning of the epidemic, and that in 1997 there were 6.2 million children alive who had been orphaned by HIV/AIDS. Ninety percent of these children were in sub-Saharan Africa. The need for homes and guardians for large numbers of orphans is impacting entire communities and regions of the world. A study by the Zambian Ministry of Health indicated that 40 percent of all households have one or more orphans. In Zimbabwe, eight percent of all children under the age of 15 have lost their mothers to AIDS.

#### Children Affected by HIV/AIDS

Children are affected by HIV/AIDS not only through infection or the loss of a parent. For example, many children experience a premature end to their childhood as they are required to become heads of households, drop out of school, work, raise younger siblings, and care for parents and other family members sick from AIDS. Furthermore, children experience greater poverty as a result of the loss due to AIDS of adult wage earners, farmers, and other skilled and contributing household members. These losses affect all of the children in a household and, where infection rates are high, entire communities. Without adequate care and support, children experience losses in health, nutrition, education, affection, security, and protection. They suffer emotionally from rejection, discrimination, fear, loneliness, and depression.

## The Effect of HIV/AIDS on Children's Rights

The realization of the survival and developmental rights of children, as defined in the UNCRC, are affected in obvious ways as family and community resources become strained and overburdened by HIV/AIDS. Accomplishments in child survival that were made over the past two decades are endangered. If the AIDS epidemic is not contained, the mortality rates of infants in some countries could increase by 75 percent, and those of children under five years of age by 100 percent (UNAIDS). In the absence of caring adults to protect them, and as they struggle to survive, children who experience increased poverty, abandonment, rejection or discrimination, or an added burden of responsibility for themselves and other family members, are at increased risk for abuse and exploitation. Children's rights are ignored as family property is taken, siblings are separated, the children suffer physical and sexual abuse, or the children become homeless. Girls marry at very young ages in order to have a home. Children join the 100 million children estimated to be living and working on the streets of the world (UNAIDS) or the more than one million children annually

who are sexually exploited for the first time (1996 World Congress Against Sexual Exploitation of Children).

# The Effect of Implementing the UNCRC on the AIDS Epidemic

Actions that support the protection of children's rights and the implementation of the UNCRC are synonymous with those that reduce the likelihood of infection with HIV. When their rights to survival, development, protection, and participation are realized, children are less likely to find themselves in situations involving a high risk of HIV infection. Protecting children from situations where they are known to be at risk of sexual abuse and exploitation, and where intravenous drug use is common, directly reduces their risk of infection. Healthy physical and emotional growth and development, access to information about their rights and about sexual health, and a voice in making decisions that affect them - all among the rights of children - are vital steps that, if begun in childhood, enable people throughout their lives to protect themselves from HIV. Lasting solutions for the next generation must address both protection from HIV and protection of children's rights.

# The Impact of HIV and AIDS on Children, Families and Communities: Risks and Realities of Childhood during the HIV Epidemic Miriam Lyons

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#### Introduction

While recent scientific efforts have resulted in a series of discoveries and advances in understanding and controlling the virus that causes AIDS, this progress has had limited impact on the majority of HIV infected people and populations living in developing countries. The social and economic conditions that nurture the spread of the virus have to be confronted as essential elements in local and global efforts to stem its spread and create effective solutions to halt the epidemic. The current demographics of the epidemic illustrate that this is particularly true of the conditions of human life during childhood.

HIV has found a wealth of opportunities to thrive among tragic human conditions fueled by poverty, abuse, violence, prejudice and ignorance. Social and economic circumstances contribute to vulnerability to HIV infection and intensify its impact, while HIV/AIDS generates and amplifies the very conditions that enable the epidemic to thrive. Just as the virus depletes the human body of its natural defenses, it can also deplete families and communities of the assets and social structures necessary for successful prevention and provision of care and treatment for persons living with HIV/AIDS. This is demonstrated by the estimated 30 million people living with HIV/AIDS, mostly in developing countries. Over 2 million people are expected to die from HIV related illnesses this year adding to nearly 12 million deaths attributed so far to the epidemic. The impact of HIV/AIDS extends beyond those living with the virus, as each infection produces consequences which affect the lives of the family, friends and communities surrounding an infected person. The overall impact of the epidemic encompasses effects on the lives of multiples of the millions of people living with HIV/AIDS or of those who have died. Those most affected by HIV/AIDS are children.

#### The First Generation

#### Growing up with the HIV Epidemic

Children and young adults currently between the ages of 15 and 24 were born and grew up as the first generation to experience childhood during the HIV/AIDS epidemic. Today it is among this same population of 15 - 24 year olds that new HIV infections are concentrated. According to recent United Nations estimates, more than 50% of the 16,000 new HIV infections which occur daily are within this age group. An additional 10% of new infections occur among children under age 15. Since the virus was first identified in 1981, more than 3 million children have been born HIV positive and the mothers of over 8 million children have died from AIDS. By the year 2010 it is predicted that as many as 40 million children in developing countries will have lost one or both parents to HIV/AIDS. In some countries this is equivalent to one in every 4 to 6 children. The



effects of HIV and AIDS on children who are orphaned, or in families where parents are living with the virus, not only include these calculable loses, but also the immeasurable effects of altered roles and relationships within families. Clearly HIV infection has its greatest impact on the young.

#### Childhood: Rights and Goals

Although "childhood" might differ for every human being and numerous interpretations of the concept exist, common to all is a period in the early years of human life marked by rapid growth and development. During the years of physical growth in which a child matures towards adulthood, the child is also developing psychologically and in ways that define intellectual, social, spiritual and emotional characteristics. The circumstances or conditions in which this growth takes place can limit or enhance development. Physical and emotional well being and social and intellectual development can be permanently limited for a person deprived of the opportunities and time to grow and develop successfully during their childhood.

The most universally accepted statements with regard to children and childhood can be found in the U.N. Convention on the Rights of the Child (UNCRC). Having been ratified by all but two member nations of the United Nations, this international covenant can rightfully be utilised as a guide for ensuring universally accepted goals for childhood. The individual articles of the UN Convention on the Rights of the Child address rights related to survival, protection, development and participation that enable a child, a person under age 18, to achieve the goals of childhood successfully. It confirms, as did the Universal Declaration of Human Rights, "that childhood is entitled to special care and assistance.": this care and assistance being designed to promote and provide for, among other things, the "full and harmonious development of his or her personality" and "that the child be fully prepared to live an individual life in society." To this end the UNCRC declares that "The family, as the fundamental group of society and the natural environment for growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities in the community."

# Social and Economic Contexts: Vulnerability to HIV Infection and AIDS

Children are affected by HIV/AIDS in ways that can diminish their childhoods and as a result limit choices and opportunities for successful survival throughout their lives. Circumstances of an individual's life and their social context in family and community during childhood can increase the probability they will one day be exposed to, and infected by, HIV. In order to develop appropriate means of enabling and protecting people, either as children or as adults, against infection and the effects of HIV/AIDS, adequate and judicious attention needs to be given to the rights and realities of childhood.

#### **Children First**

HIV and AIDS are brutal escalators of other cruelties which children endure. In today's world the majority of people living in poverty are women and children. Three quarters of the 24,000 daily deaths (more than 8 million every year) related to hunger are among those under the age of five (The Hunger Project). One hundred and twenty million children between the ages of 5 and 14 work in conditions that are hazardous to healthy growth and development (ILO). Estimates suggest that as many as 100 million children worldwide are homeless or spend most of their time surviving on the streets (UNICEF). Massive populations of families with children are displaced and often separated because of conflict and natural disasters. According to the United Nations Expert Report on the Impact of Armed Conflict on Children, prepared by Graça Machel, more than half of the near 60 million people displaced by war are children with millions separated from

their families. Millions more have been injured, disabled, orphaned and died in armed conflict. Children are used as soldiers and forced to kill; raped by soldiers or made to watch their mothers and sisters raped and their families murdered. Added to these, children are victimised and trafficked as commodities for sale in local and global sexual prostitution and pornography industries. Estimates are that at any time, as many as one million children are involved in the commercial sexual exploitation arena every day. (ECPAT, World Congress Against Commercial Sexual Exploitation of Children). Countless others are physically, sexually and psychologically abused in what should be the secure confines of their homes and neighborhoods.

The roles that children fill as poor, hungry, exploited and abused human beings increase their vulnerability to HIV infection. This can occur directly through those activities known to be associated with transmission, or indirectly as occurs when earlier harm turns children into vulnerable adults. For example those with have a history of childhood physical or sexual abuse have also been found in adolescence or adulthood to be more likely than non-abused peers to engage in behaviors that place them at high risk of HIV infection..

#### Poverty, a Leading Promoter of HIV and AIDS

Poverty is clearly a factor in the spread and impact of HIV/AIDS. The struggle to survive everyday overshadows attention and concern about a virus that does not demonstrate any immediate harm. HIV/AIDS is a distant threat until it has a visible presence manifested by illness and death. Poverty, in depriving people of access to health facilities, schools and media also limits their access to information and education on HIV/AIDS. Poverty pushes families, often unaware of the risks, to send children into the work force or to hand them over to recruiters promising jobs in a distant place where, unprotected, they might be forced into a childhood of harsh labor or sexual abuse. When HIV/AIDS appears in an already impoverished household there are limited means for response, the mortality rate is high, the impact is severe and the pressures and pain of poverty increase. As increasing numbers of infected young adults are unable to contribute to their communities through their work as parents, teachers, laborers, drivers, farmers, etc., entire economic and social structures of communities suffer and demands for services increase with fewer able people to provide them.

The vast majority, over 90%, of all people infected with HIV since the beginning of the epidemic are from the developing world. In sub-Saharan Africa where two-thirds of the world's infections have occurred, more than 7.4% of the population between the ages of 15 and 49 is estimated to be infected with HIV. In Zimbabwe infection rates are estimated to be in the region of 20% while in Botswana adult infections are thought to be approaching 25 - 30% of the population. In India although the overall infection rate is still less than 1% of the population, this amounts to between 3 and 5 million people, most of whom are untested and unaware of their infection status. Antenatal testing among those with access to health facilities provides some staggering statistics: in Haiti the national rate is over 8%, while in some areas of Southern Africa local HIV infection rates among pregnant women of 30 - 60% have been reported.

#### Losses for Children that Last a Lifetime

While the majority of the 2.3 million predicted HIV/AIDS related deaths this year will occur in developing countries, this is also where 87% of the world's 2 billion children will be trying to grow up. Although life-saving drug regimens have dramatically decreased mother-to-child transmission of HIV and have kept mothers well and alive longer in the industrialised world, poverty and the lack of necessary social and medical infrastructure and services make them inaccessible in those places where they are most needed. Many women who know that they have tested positive for HIV may have no choice but to breast feed their babies when clean water and formula are unobtainable, even though they risk transmitting infection to their babies. Without access to health care or a nutritious diet, infected infants often die before they are two or three years old.

For children who survive longer, for uninfected children whose parents or guardians are incapacitated by HIV/AIDS, and for those who are orphaned, childhood can be dramatically shortened in other ways.

The illness or death of parents or guardians because of HIV/AIDS can rob a child of the emotional and physical support that defines and sustains childhood. It leaves a void where parents and guardians once provided love, protection, care and support. Since HIV is often (but by no means always) transmitted to sexual partners, children are more likely to lose both parents to HIV/AIDS. Someone is needed to step into parental roles so that children can survive and develop into healthy and productive adults. Grandparents, aunts, uncles or other caring adults frequently assume responsibilities that enable children to remain in their homes or take them into their own families and households. However, where the infection rate is high or harsh social or economic conditions exist, adults may be unable to assume the additional responsibilities of these families and children affected by HIV/AIDS. Other barriers grow out of ignorance and social attitudes. Fear of discrimination leads to families keeping secret the knowledge of HIV infection and AIDS within the household rather than seeking help. Others seek help but are rejected or abandoned, even by family members, when they reveal the nature of the illness. Fear, discrimination. ignorance, and social stigma associated with HIV/AIDS, in addition to overwhelming demands on caring adults, leave children isolated with their grief and suffering while they watch parents and other loved ones die and their families languish.

#### Children in Adult Roles: Working to Maintain Home and Family

In the absence of capable adult caretakers, children themselves take on responsibilities for the survival of the family and home. Undeniably children in most families share duties even when parents are healthy. In economically disadvantaged communities, a child's contribution is often necessary for the survival of the household. But in numerous HIV/AIDS affected households children have not simply increased the amount of work that they do but have also assumed decision-making and responsibilities that transform roles within families and households. Children assume adult roles as heads of household because there are no alternatives. They care for parents and younger siblings who are sick and dying from HIV/AIDS. They take charge of the care and running of the home for themselves and their siblings. They work long hours doing household tasks, supervising younger children and engaging in income-generating work in order to support the family. Many quit school and jeopardise their own health and developmental needs to take on roles as parent, nurse and provider.

#### Failing to Meet the Goals of Childhood

In many families and communities the environment for healthy growth and well-being has been devastated by HIV/AIDS. Instead of receiving special care and assistance, childhood is spent providing care and assistance. Children become decision-makers, responsible for the social and economic future of the family, and fill these roles without the physical and emotional protection, guidance and support that, as children, they deserve. They may act like adults, but it cannot be forgotten that these "heads of households" are children, but children whose childhood has been impoverished by HIV/AIDS. In such households, all children are affected. The care that older siblings can provide for younger children is likely to be inadequate because of the increased poverty of the household and the lack of maturity and experience of the caretaker, leading to poor health, hygiene and nutrition; absence from school, and developmental delays. The loss of material, emotional and developmental support from an adult exposes children to the distress which results from lack of affection, insecurity, fear, loneliness, grief or despair. It limits the possibility of a successful childhood which, in turn, affects the future as adults.

#### Children Treated Like Children: For Better or Worse

In this world where some children are fortunate enough to be loved and nurtured in ways that respect their rights as children and are supported in ways that enable them to become independent, competent, adults while others are treated as little more than property or tools to be used for the benefit and satisfaction of adults, the idea of "treating a child like a child" has contradictory meanings.

#### **Vulnerabilities of Childhood**

Even when adults intervene and take responsibility for children who are left without parents or guardians because of HIV/AIDS, it cannot always be assumed that children benefit. The limitations that adult society places on them because of their assumed immaturity (while often to their advantage) can also leave children powerless and defenseless. Precisely because they are children, in most societies, children have no direct right to own or control property, nor to take responsibility for important decisions concerning their own future. While the right to participate in such decisions is confirmed in the UN Convention on the Rights of the Child this is often ignored. As a result of the sickness or death of parents or guardians, children are often made to leave the place that they have always known as "home" and sometimes are separated from their closest remaining family members, their siblings. They are dependent on the abilities and attitudes of adults who are given ownership or control over their property and decision making about their future life. Separated from close family members, without a secure home, the vulnerabilities of childhood can take on new dimensions.

Since the need for caretakers of infants and very young children is obvious and immediate as a matter of basic survival, they are taken into the homes of family members, placed with foster parents or quardians or in group homes or larger institutions. However, the needs of older children (approximately 8 to 18 years of age) can be more easily under-served, overlooked or underestimated, since the risks to their survival are less apparent. Even under good conditions, where resources and caring adults are available, it is not easy for a child who has lost everything to recover and adjust. Some are offered a home with caring adults but nonetheless resist being absorbed into new families and homes because of fear and distress. For the majority, counseling and psychological support services are unavailable. Some react with behavior which provokes rejection. Others run away. Where infection rates are high within a family or community, even the most loving guardians must focus their energy on the survival of those households where large numbers of children have been taken in and need care and support. Although these guardians or foster parents work hard to furnish a caring substitute home and family for children, there are often limits to how much care and support they are actually able to provide. Children may be unable to go to school because there is no money to pay for books and fees or because they experience rejection or discrimination. Some must leave school to help care for younger children or to earn an income to help support the household. Fear and frustration lead children to run away in search of a better life often only to join the growing numbers of homeless and exploited children.

#### The Value of a Child

The experience of older children who have lost their homes or families to HIV/AIDS related illness and death is insufficiently documented. However, in a world where millions of children are neglected, exploited and abused everyday it is reasonable to assume that these children can become easy prey to adults who are unconcerned with the child's best interest. Some adults might take children into their households to serve an ulterior purpose. Children are easy to intimidate and control. Children can provide extra income or free labor and can be treated like property or servants, kept from school and given inferior food and care. Millions of children suffer neglect and physical and sexual abuse. In the absence of alternatives, more and younger girls

marry early. Boys and girls trade abusive situations for the streets where life and survival are even more difficult. The risk of HIV infection rapidly increases as children are exposed to drug use and engage in unprotected sex (willingly or coerced), exacerbated by the increased susceptibility to infection of bodies which are still in the process of physical development and maturation.

#### **Balancing Empowerment and Protection**

The empowerment of children, essential in reversing pervasive inequality between adults and children, needs to be balanced with the necessary protection and guidance to which children have a right as part of safe and healthy development. However, adult authority can result in decisions which are misquided or unrealistic.

Judgements about children based upon adult wishes rather than reality can lead to decisions that do not serve a child's best interest. For instance, in many societies, prevailing attitudes support the idea that children should be "protected" from information pertaining to sex in order to preserve "childhood innocence". Such attitudes are inconsistent with the realities of life for millions of vulnerable children and therefore deprive them of opportunities to understand the risks and dangers they may face. One result of this is that children are inadequately taught about sexuality and STD's(including HIV/AIDS) before sexual experiences begin. The factors which make it necessary to provide such education is a problem many adults prefer to ignore. Children left powerless through the denial of sex education are also rendered powerless to protect themselves from infection in those situations which they are able to control.

# WOMEN, THE GIRL CHILD AND HIV/AIDS

# Sheila Dinotshe Tlou

#### Introduction

I feel it is appropriate that a woman from Sub-Saharan Africa, where millions of people are infected with and affected by HIV/AIDS, should critically examine some of the sociocultural dimensions of the epidemic.

It is even appropriate because I come from the Southern African Development Community (SADC), the region where more than three quarters of the member countries have the highest number of HIV and AIDS cases in the world per capita. SADC has only 1% of the world's population, but nearly 40% of the world's HIV infections are in the region, and the majority of them are young women.

### Talking was good: the time for Action is Now

The Platform for Action, resulting from the Fourth World Conference on Women and the Programme of Action, adopted at the International Conference on Population and Development, call for a holistic life cycle approach to women's health care with emphasis on increased allocation of resources for the provision of affordable health care, health promotion and disease prevention, and prevention and treatment of sexually transmitted diseases and HIV/AIDS.

The call was again made at the 43rd Session of the Commission on the Status of Women when member states resolved to ensure greater protection of women from HIV infection, including access to female controlled methods, access to affordable antiretroviral therapy for people living with HIV and AIDS, eradication of gender based violence and harmful practices such as female genital mutilation. Southern African Development Community (SADC) sponsored a resolution on women, the girl child and HIV/AIDS which called upon Governments, NGOs, civil society and the international community to speed up efforts to prevent and reduce the horrible impact of HIV/AIDS on women and girl children in developing countries.

The twenty-third Special Session of the General Assembly entitled "Women 2000: gender equality development and peace for the twenty first century" noted some positive, but very slow, signs in the fight against HIV/AIDS and member states further resolved to intensify efforts to protect women of all ages from HIV infection and other sexually transmitted infections, including access to female controlled methods, voluntary and confidential HIV testing and counselling, and development of vaccines.

In short, the 'talk and talk' about the gender aspects of HIV/AIDS has been with us for a considerable length of time. The question one needs to ask is: why is there so

little or inadequate action when it comes to implementing these gender sensitive resolutions?

In my paper I attempt to answer this question by looking at some of the factors behind the non-implementation of these noble resolutions.

### Youth: our window of hope

The special vulnerability of girls and young women to HIV/AIDS has been documented in many studies and discussed at the various United Nations fora. While most states agree that young people have the right to develop their capacities, to access a range of services and opportunities, to live, learn and earn a safe and supportive environment, and to participate in decisions and actions that affect them, one finds that social institutions such as schools, NGO's, the media, the private sector, and the governments are doing very little to support these rights. For example, access to information relating to sexual health is still a controversial issue despite extensive research showing that school-based life skills education empowers youth and does not increase their sexual activity (Kirby et al., 1994).

From my observations, backed by 10 years of experience teenagers who are "kept in the dark" about matters of sexuality are at a much greater risk than those who are provided with information because when they do decide to engage in sex, it is likely to be unsafe sex which immediately results in a pregnancy and/or a sexually transmitted disease. Their ignorance and lack of planning guarantees that they cannot negotiate safer sex let alone carry a condom or even know how to use it.

# Girls, women and poverty

In most countries, the legal systems and cultural norms reinforce gender inequality by giving men control over productive resources such as land, through marriage laws that subordinate wives to their husbands, and inheritance customs that make males the principal beneficiaries of family property. This is still happening despite the fact that most of these countries have ratified the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW). Such resolutions have far reaching consequences for the rights of women, the achievement of national development, and the transmission of HIV. Furthermore, Structural Adjustment policies seem to have worsened the levels of poverty in many countries rather than improving their economic situations. As usual, women and girls have been the most affected by some of the strategies employed. The continuing retrenchments and lack of employment opportunities have resulted in women and girls resorting to both direct and indirect commercial sex work for survival, placing them at risk for HIV infection. The appropriate question to ask is: To what extent do governments have linkages between programmes targeting HIV/AIDS at community level to those targeting economic empowerment of women? Poverty eradication among women requires gendered dimensions by dismantling the institutions and ideologies that maintain women's subordination in all spheres of their lives. Economic empowerment and poverty reduction cannot be accomplished through antipoverty programmes alone, but through a democratic environment and changes in economic structures giving access for all to resources and opportunities that enhance their quality of life.

For women living with HIV and AIDS, a gendered approach ensures that they have access to food, sanitation, education, housing and health care, including the provision of antiretroviral drugs. Our governments seem to hide under the cloak of "drugs are too expensive" to the point where very little is being done to procure them, but these are the same governments that spend millions of dollars on military equipment and on armed conflicts. In my own continent, Africa, about one eighth of the military budget of most countries would be enough to provide free antiretroviral drugs to all citizens living with HIV and AIDS, yet it is the drug companies that seem to be getting an unequal share of the blame for exploiting the situation. Whatever happened to state accountability to its citizens?

#### Political will and commitment

There is still a wide gap between the acknowledgement of HIV/AIDS as a problem and what any one political leader does about it, and the resources to be allocated for such programmes and activities. What we need are leaders who can:

- (a) create supportive socio-political and legal frameworks for gender equality.
- (b) ensure gender-sensitive programming which educates for use of and provides both male and female-controlled methods of HIV prevention.
- (c) transform their societies into 'noble societies' which have programmes for the **life-long empowerment** of women and girl children against HIV/AIDS. One such 'noble society' is Botswana which can serve as an example of good governance, political will and commitment to a human rights approach to HIV/AIDS. Some of the national programmes in place include:
  - Free schooling with meals provided
  - Free health care for Tuberculosis and STI clients, persons under 18 and those over 60; the rest pay P2-00 or US 40 cents
  - o Universal National Old Age (over 65) pension of P110-00 a month
  - Social welfare programme for the destitute
  - Community home based care programme which includes:
    - (a) food basket for nutrition supplementation
    - (b) supplies and equipment such as gloves, adult diapers, detergent, bedpans, wheel chairs, etc.
  - A transportation allowance of P100-00 for volunteer caregivers
  - o An orphan programme with supplies and allowances for caregivers

An MTCT of HIV programme (AZT and infant formula) for HIV positive pregnant women.

#### Working with men

Until recently, men have been the almost invisible part of the solution to the HIV/AIDS epidemic even though it was obvious that their socialisation and subsequent behaviours determine how and to whom the virus is transmitted (Panos, 1998). Men, especially African men, tended to be all tarnished with one long brush that painted them as being irresponsible, violent, predatory and fast transmitting the virus. Such labels are very stereotypical, do not facilitate male involvement, and ignore the fact that there are a lot of good, caring, responsible, loving, and very gender-sensitive men in Africa, and they are in the majority. It is only now, after last year's (2000) World AIDS Day theme, that many stakeholders realise that the qualities of these good men can be tapped and used to role model appropriate behaviours for the "not so good" ones who have wrong perceptions of masculinity.

Civil Society needs to be involved not just as actors but as researchers, decision makers, planners, and designers of programmes on HIV/AIDS prevention and reduction of its impact. Most government programmes fail because they lack community-based experience and expertise, for example: programmes on prevention of mother to child transmission of HIV in Botswana initially had serious problems because they failed to recognise the important role of the community in women's decisions to go for HIV testing, to take antiretroviral drugs, and to exclusively breastfeed or use infant formula (Tlou, S.D., 2000).

**Older persons** are important stakeholders because they are increasingly taking on unrecognised, unappreciated, and unremunerated social and economic responsibilities of caring for the sick and for children orphaned by HIV/AIDS at the expense of their own health (Tlou, S.D., 1999). Therefore, HIV/AIDS interventions, including information, education and support, should also target them.

## What other steps do we need to take?

Based on the above observations, I would like to reiterate the following recommendations for a global response:

- 1. We need to emphasise a human rights approach to the HIV/AIDS epidemic which entrenches the principle that governments should be accountable to their people. Each time a woman is unable to negotiate safer sex, it is a violation of her civil rights because it indicates her lack of autonomy to decide on matters relating to her sexual and reproductive health and such a situation cannot continue.
- 2. There has to be political commitment at the highest level to reform sociocultural and legal systems to empower women and girls for HIV/AIDS prevention and alleviation of its impact. Heads of state should not just talk about HIV and

AIDS, they should rely less on donors and actually allocate at least 10 percent of their budgets for HIV/AIDS programmes.

- 3. HIV/AIDS is a complex epidemic which requires multipronged solutions. No "single fix" can ever be effective, therefore, I call upon the international community and the relevant United Nations agencies to intensify their support of national efforts against HIV/AIDS prevention for women and girls, especially in the worst hit regions of Africa. Africa needs a sustained, substantial support from the global community or it will be unable to keep pace with the epidemic.
- 4. Research on gender and HIV/AIDS issues should inform and drive policy, therefore, there should be for for interaction between researchers, policy makers, and implementers of programmes. The value of policy oriented research and evidence-based practice on HIV/AIDS cannot be overemphasised.
- 5. Men are not the problem but part of the solution, they are also vulnerable to HIV/AIDS and should be involved in all national and international activities relating to prevention, impact alleviation, and care of people living with HIV and AIDS.
- 6. Lastly, allow me to speak as an African woman who has lived most of her life in Africa: My fellow Africans, HIV/AIDS challenges us to take responsibility for our own destiny. No one can do it for us. We can solicit and gain the support of the international community, but in the ultimate we have to be the movers and shakers to rid our continent of this scourge. Let us all make efforts to fulfil the obligations of the Universal Declaration on Human Rights and the Africa Charter of Human Rights for "the other half" of our populations, namely the girls and the women.

# Street Children - Whose Challenge? - Ezekiel Kevin Annan



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A new millennium has dawned for another look to be taken on the subject of street children. An encyclopedia has not been written about this all important subject but only little have been done in practice to curb this menace. Street children's vulnerability is rapidly becoming targeted and expanding the web of social cankers. The onus now lies on all child-workers, governments, NGO's and other stakeholders and opinion leaders to consolidate a cohesive force to combat the much talked about subject. For the purpose of an approach to solve the problem, this piece of writing is intended to assess the situation to enable an indepth understanding and to strategically find a way out.

A child, according to the UN convention for the rights of the child, is anybody below the age of 18 years. This suggests that any single individual below 18 years is a child and should be dependent in his/her parents for development. However, this has not been so in a lot of countries for generation. Definitions of street children have varied from person to person, and from country to country depending on the kind of the perceptual lenses in which street children are see in their new environment. From my own view, the street child is any single individual below the age of 18 years, who is living independently on the street at his home to make ends meet, due to lack of parental care and societal neglect.

It is a choice of necessity. Streetism, could be a predominant source to breed and ignite a heterogeneous whole of social cankers in our world, if society does not go beyond paying lip-services to this threatening predicament. The children on the street are vulnerable to numerous risks including HIV/AIDS due to their nearly universal involvement in "survival sex" (prostitution). The danger has been disclosed in studies that show that frequency of sexual relations within the group of street children also implies that one HIV positive street child could pass the disease to a larger proportion of street children.

Streetism is a danger that undermines the potentials and developments of children. Certain negative values, behaviors and attitudinal changes from the already positive living priority formed at their tender age under the supervision of their parents. It is a liability to society in this era, when they are found without a true home for warmth, and without love and care for a sense of belonging. They are spotted at street corners, both during the day and the night struggling for survival by whatever means possible. Drug addiction, child labour and violence are other key products of streetism which adds to the crime wave and disturbs the peace of the globe.

Children do not deserve the right to be abandoned on the street. The street is void of parental care, protection, love warmth and safety and cannot be a home. "Street children" have become stigmatized by society; ironically their name suggests they were begotten by streets. Truthfully, we forget that these children on the streets are victims of circumstances. These children do not desire to leave their homes and live on the streets where their lives are constantly in danger. They are yearning for the help of all and to get back into sound and secure society.

It is the society that has neglected them and left them to their fate. Their desire is that, they also have that right to complete with equals of the schools but not to compete with equals of similar fate on the streets. They desire to get back home where Daddies and Mummies shout to them for breakfast, lunch and dinner but not where the order of the day is "the survival of the fittest." They are not strong enough of this task.

Some young girls are sexually abused and others are also enticed into nasty relationships in exchange for meals, little presents and shelter. If society fails to act promptly to save these kids, there will follow serious results ranging from HIV infections to other perilous circumstances soon in this hopeful century. Every single individual owes a service to the street child. If we dare make a mistake in handling their issues, if we allow them to "swim their own swim", if we dare say "each one for himself and God for us all" in their case, we will be found digging graves for ourselves. There are indications that, the future of the world, especially the developing countries, is black when pragmatic and drastic measures are not taken to rectify this social diversity of our ways. The unseen will be seen.

Written by: Ezekiel Kevin-Annam

#### **Reader Comments**

#### not neo

#### All childrens

are the concerns and responsibility of all the earths peoples.

Mans greatest act of menace, seperate and conquer.

Even children with legal addresses and parents or guardians are sometimes still "street children". Where there is no love given or found where it should come from then the "streets" are just outside the doors. The places where "twisted minds" or adults lurk.

Nourishment from the heart is not always as readily available as they pretend it to be, where parents have no time or do not know how to spend time with the children. Pre-pre-school..

#### Ivy

#### Inspiring....

Your article has made me think why I'm in this cosy house while someone like my age, is out in the cold out alone being abused by others?? It's not fair. The parents or the guardian has responsibilities and they shouldn't let their children out in the cold out alone. Parents lack of responsibilities is causing problems for the child and the child have to suffer even though she/he didn't do anything to deserve any of it. Sometimes the child might run away and end up as a street boy/girl. The government should be helping people living on the street. I will never survive on the street for days. Those street children eat restaurant's leftovers from the garbage. This has nothing to do with survival with the fittest, like you said. No children under 18 yrs.old will survive out in the streets. Street Children might no even go to school, because they're either afraid other children will make fun of them, or they don't have money to go to school,it just makes it harder for them to find proper jobs, sometimes leading them to prostitution. They're flushing their future down the toilet. People always say "children is our future" but how can they be the future if they're living in the streets?? It doesn't make sense. If children is our future, we got to take ACTION!! lol, I just want to say that you wrote a great article on street childrens and well, keep up the good work!

#### nadinea

I agree 100%with what you have said. "Street kids" are like all the other children around the world. They are not different from you and me. they should be respected and have equal rights and be HELPED!

There are loads of children around the world ,found in each and every country, which do not have shelter, food nor proper education. The is only a limit to when a child(under the age of 18) could live without food water or shelter. streetism is danger fr all youths. Many kids die around the world because of streetism.

Children living on streets die became of sickness, poor health , AIDS/HIV. Without proper shelter adolescents are exposed to the harsh weather .With no way to see a doctor you get sicker and sicker until your body can't take it no more. Drugs are one of the main reasons a tot is on the street. Drugs are worse than not having food and water to eat and drink. Once there is addiction to a drug and you have no way of getting more then you have no chance of living.

People that are to blame is their parents . I t is their fault that they are not sheltered , getting

everything they want (spoiled...ex. going every where the may chose)not caring what they do with their lives. If they could not take responsibility why then did they have sex an be a father or mother. They had a choice and so all that happens to their children, they are the ones to that should take responsibility, and the blame.

Some teens that are living on the streets and probably have a meal a week probably by pit-pocketing or prostitution or eating out of the garbage. They have sex for money to able to have something in their stomachs. Can you feel the pain they go through every day, week , month! I can since I fast all day for 30 days (one month) to feel how they feel and to see what they go through.

I wish that there could be a way to get all off of the "street kids" and find them a place where they can be loved ,cared for , have good education, health and where they can get three meals a day and extra snacks and to top it off ,to be HAPPY!! As Ivy said we HAVE TO TAKE ACTION!!

This is a very important topic and I really enjoy reading this. Keep it up. I hope I read another article that you have made. :) :P Nadine



# HIV/AIDS and the Forgotten Children

What happens to children when they lose one or both parents to complications associated with HIV/AIDS? How does losing a parent to AIDS affect a child's mental health? How can the public sector safeguard the well-being of HIV-affected children and help ensure that these kids grow healthy and strong?

These are just some of the questions HRSA and two of its sister agencies in HHS are trying to answer.

Over the past 3 years, HRSA has supported the HIV/AIDS Mental Health Services Demonstration Program in partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institutes of Health. Funded at more than \$4 million per year, the program supports 11 diverse projects across the Nation.

Prior to the development of this demonstration, which was the first to earmark federal dollars to meet the mental health needs of people living with or affected by HIV/AIDS, policymakers and program planners knew very little about the mental health needs of children and adolescents who lose one or both parents to HIV/AIDS.

However, two of the sites—the Special Needs Clinic at Columbia Presbyterian Medical Center in New York City and Kinship Connection at the Elizabeth General Medical Center in New Jersey—serve large numbers of children, many of whom have lost one or both parents to HIV/AIDS or are facing the death of a parent. Both projects serve a predominantly urban African American and Latino population that has been hard hit by the AIDS epidemic.

"Every day in our work, we are forced to confront the harsh reality that HIV is a family disease that disproportionately affects communities of color," says Martha Saldarriaga, who heads up the Kinship Connection project. "One-quarter to one-half of our clients are dealing with end stage HIV illness, and one of our biggest challenges is getting parents to face the fact that someone will need to take care of their children after they die. Far too often, parents put off making these decisions until it's too late or until their ability to make decisions is compromised by AIDS-related dementia."

The typical Kinship client is a socially isolated single mother diagnosed with AIDS who has a T-cell count below 200 and two to four minor children. The New Jersey project also has found that the children and teenagers they serve are at increased risk for substance abuse and early sexual activity, which may lead to teenage pregnancy and HIV infection.

"We have found that developing an individualized treatment plan tailored to the unique needs of each family is the most effective way to serve our clients," Saldarriaga says, adding that it can take as many as a dozen visits to the family's home before they will agree to accept services. "We match client or family needs with the skills and cultural understanding of the family therapists on our staff. The assigned staff person is responsible

for coordinating services for the client and family to ensure they get the full range of services and support they need." She adds that treatment plans are reviewed and updated every 12 weeks.

Once parents have identified someone to take care of their children after their death, Kinship Connection staff involve caregivers in the delivery of services to the family. "One of the most difficult things we deal with is helping children through the transition from the family they have always known to an unfamiliar, reconfigured family. This transition is particularly tough for adolescents who, over time, have assumed the role of primary caregiver and may feel protective of their parents."

The Special Needs Clinic (SNC) in New York City, takes a different approach to meeting the needs of HIV-affected children and adolescents. Using a multidisciplinary mental health team, including child psychiatrists, psychologists, social workers, and case managers, the SNC identifies and engages families receiving medical care at Presbyterian Hospital in ongoing mental health services at the SNC. This comprehensive, family-based approach allows for the treatment of both adults and children in one mental health site where mental health care is closely coordinated with medical care and HIV treatment for adults and youth.

"In New York City, an estimated 30,000 children are projected to lose their mothers to AIDS by the year 2001," says SNC Director Jennifer Havens, M.D. "The families who come to us tend to have a long history of psychosocial and mental health problems. In many cases, mental illness, substance abuse, violence, and trauma have affected multiple generations within the family. Usually, these problems have not been addressed, and multiple members of the family require coordinated care in order to stabilize the child's environment so that interventions on behalf of the child can be effective."

To make matters worse, Havens says that 22 percent of the children referred to SNC are infected themselves and that most of these youth have experienced abuse, neglect, and family disruption. "To say that the children and families we serve have extraordinarily complex needs would be an enormous understatement," Havens says. "These families historically have been poorly served and tend to be invisible to our service systems. HIV illness connects them with the medical system in real ways. We have to seize this opportunity to also address the mental health needs of their children and adolescents."

Over the course of the demonstration, both programs have learned several important lessons:

- Mental health services for children and adolescents can play an important role in breaking the cycle of substance abuse and untreated mental illness, and may help keep these children from following in their parents' footsteps.
- The vast majority of HIV-infected women are poor. Concrete service needs—such as food, money, shelter, and child safety—must be addressed before mental health services can be effective. This approach helps establish a spirit of trust, and clients

are more likely to accept mental health services.

- Continuity of mental health services across the continuum of parental HIV illness, death, and family reconfiguration is essential to meeting the mental health needs of HIV-affected children and adolescents.
- When parents put off deciding who will care for their children upon their death—
  especially those who are unable to do so because they are struggling ineffectively
  with mental illness and/or substance abuse—children and new caregivers are more
  likely to have difficulty handling the psychosocial and economic stress that comes
  with a parent's death.
- Mental health, medical, and substance abuse treatment for HIV-affected adults and children must be closely linked, coordinated, and co-located.
- The social and cultural stigmas associated with mental health, substance abuse, and HIV/AIDS often prevent families from accessing services. Many parents strongly desire secrecy and confidentiality because they want to protect their children from ridicule and because they are afraid that child welfare programs may take their children away from them.
- Frequent staff outreach and flexible scheduling often is needed to keep HIV-affected
  families engaged in services. It is often helpful to provide services in the home in
  order to gain the family's trust. Home-based services are especially important for
  parents with end stage HIV disease.
- Women caring for children face unique logistical barriers to accessing services. These include the need for child care to attend appointments, the cost of transporting the entire family, and managing appointments for multiple family members.
- Frequently coordinated case-conferencing is necessary to address both the needs of individual family members and the family as a unit.

"For all of the devastation that has come with the HIV/AIDS epidemic over the past 2 decades, we are now learning that there is something we can do to help keep these children on track and to help them live constructive, productive, and healthy lives," Havens says. "We now know how complex their needs are and the kinds of services that will be successful. Our next step is to expand our service capacity on a national basis to meet the needs of the growing number of children and adolescents who are living with, and losing, parents with HIV/AIDS."

For more information about the HIV/AIDS Mental Health Services Demonstration Program, call 1-800-789-CMHS (2647) or go to <a href="https://www.mentalhealth.org">www.mentalhealth.org</a>.



# **Some Facts**

With each passing minute HIV/AIDS takes the life of another child. In 2001 there were 5 million new infections – 800,000 of them children. 13 million children have been orphaned by AIDS, a number that is expected to more than triple by 2010.

More than 95 percent of the estimated 40 million people infected with the HIV virus live in the developing world, in poor countries with few resources for health care. The impact of AIDS and the prospect of future damage to communities and economies in developing world is devastating. CORE Group **PVOs** working are in partnership with governments communities to save the lives of children through educational and health programs.



The Child Infected With HIV Relevant CRC articles {key words} Child specific issues Issues Knowledge of 13: Information Support issues HIV status 16: Privacy 17: Access to information sources Participation in 13: Information 16: Privacy And exclusion From research 17: Access to information sources And consent 19: Protection against all forms of abuse including negligent treatment **Issues** 24: Highest attainable standard of health and Facilities for treatment 25: Periodic review of treatment Psychological 18: Common responsibility of parents and social 19: Protection against all forms of abuse support from including negligent treatment family and 20: Care if deprived of family environment 23: Disability services 24: Highest attainable standard of health and facilities for treatment 26: Social insurance 27: Standard of living 39: Reintegration after exploitation Access to and 24: Highest attainable standard of health and quality of care facilities for treatment 25: Periodic review of treatment 26: Social insurance 24: Highest attainable standard of health and Prevention and Treatment of facilities for treatment **Opportunistic** 25: Periodic review of treatment Infections 24: Highest attainable standard of health and Access to Prescription facilities for treatment Drugs 26: Social insurance **Immunization** 

24: Highest attainable standard of health and Facilities for treatment

Child growth and development

educational vocational and

Access to

28: Education

recreational

29: Personality and abilities 31: Rest and leisure(engage in play)

32: Child labor and economic exploitation

opportunities

The four general principals (Article 2, Article 3, Article 6, Article 12) should be considered for each issue presented.

Source: HEALTH AND HUMAN RIGHTS Vol. 3 No. 2002

# The Child Infected With HIV (cont.)

Issues in HIV/ AIDS preven- tion, care, and research	Specific issues Imm relevant to this population	ediately relevant CRC articles (by key words)
	Sexuality and	13: Information
	sexual health	15: Freedom of association
	and reproductive	16: Privacy
	health	17: Access to information sources
		19: Protection against all forms of abuse
		including negligent treatment
		24: Highest attainable standard of health and
		facilities for treatment
		29: Personality and abilities
		39: Reintegration after exploitation
	8	53. Reintegration after exploration
	Nutrition	23: Disability
	Including infant	24: Highest attainable standard of health and
	Feeding	facilities for treatment
	8	27: Standard of living
Children in	Adoption	9: No forced separation
difficult	_	11: Illicit transfer and non-return of children
circumstances		19: Protection against all forms of abuse
		including negligent treatment
		20: Care if deprived of family environment
		21: Adoption
		24: Highest attainable standard of health and facilities for
		treatment
	The	Child Affected by HIV/AIDS
Impact on	Children whose	9: No forced separation
Family and	parents or	18: Common responsibility of parents
Community	siblings are	20: Care if deprived of family environment
	Living with HIV/	27: Standard of living
	AIDS	e e e e e e e e e e e e e e e e e e e
	Children	19: Protection against all forms of abuse
	Orphaned by	including negligent treatment
	AIDS	20: Care if deprived of family environment
		21: Adoption
	Exhaustion of	18: Common responsibility of parents
	Extended	19: Protection against all forms of abuse
	Family's coping	including negligent treatment
	Capacity	26: Social insurance
		27: Standard of living
		32: Child labor and economic exploitation
		36: Protection against all other forms of exploitation
		39: Reintegration after exploitation

The Child Affected by HIV/AIDS (cont.)				
Issues in HIV/ AIDS preven tion,care and research	specific issues relevant to this population	Immediately relevant CRC articles (by key words)		
Impact on Services	Loss of educational and Vocational Opportunities	<ul><li>28: Education</li><li>32: Child labor and economic exploitation</li><li>39: Reintegration after exploitation</li></ul>		
	Diminished Access to Prevention, care And social Services	<ul><li>18: Common responsibility of parents</li><li>24: Highest attainable standard of health and facilities for treatment</li><li>26: Social insurance</li><li>27: Standard of living</li></ul>		
Exploitation of Children	Greater likely- hood of family Reliance on child Labor	<ul> <li>19: Protection against all forms of abuse including negligent treatment</li> <li>27: Standard of living</li> <li>28: Education</li> <li>31: Rest and leisure (engage in play)</li> <li>32: Child labor and economic exploitation</li> <li>36: Protection against all other forms of exploitation</li> <li>39: Reintegration after exploitation</li> </ul>		
	Greater risk of Sexual exploita- tion	<ul> <li>19: Protection against all forms of abuse including negligent treatment</li> <li>27: Standard of living</li> <li>28: Education</li> <li>29: Personality and abilities</li> <li>31: Rest and leisure (engage in play)</li> <li>34: Protection against sexual exploitation and sexual abuse</li> <li>36: Protection against all other forms of exploitation</li> <li>39: Reintegration after exploitation</li> </ul>		

# The Child Affected by HIV/AIDS (cont.)

Issues in HIV/ AIDS preven tion,care and research	specific issues relevant to this population	Immediately relevant CRC articles (by key words)
Impact on Services	Loss of educational and Vocational Opportunities	<ul><li>28: Education</li><li>32: Child labor and economic exploitation</li><li>39: Reintegration after exploitation</li></ul>
	Diminished Access to Prevention, care And social Services	<ul><li>18: Common responsibility of parents</li><li>24: Highest attainable standard of health and facilities for treatment</li><li>26: Social insurance</li><li>27: Standard of living</li></ul>
Exploitation of Children	Greater likely- hood of family Reliance on child Labor	<ul> <li>19: Protection against all forms of abuse including negligent treatment</li> <li>27: Standard of living</li> <li>28: Education</li> <li>31: Rest and leisure (engage in play)</li> <li>32: Child labor and economic exploitation</li> <li>36: Protection against all other forms of exploitation</li> <li>39: Reintegration after exploitation</li> </ul>
	Greater risk of Sexual exploita- tion	<ul> <li>19: Protection against all forms of abuse including negligent treatment</li> <li>27: Standard of living</li> <li>28: Education</li> <li>29: Personality and abilities</li> <li>31: Rest and leisure (engage in play)</li> <li>34: Protection against sexual exploitation and sexual abuse</li> <li>36: Protection against all other forms of exploitation</li> <li>39: Reintegration after exploitation</li> </ul>

#### The Child Vulnerable to HIV/AIDS (cont.)

Issues in HIV/Specific issues Immediately relevant CRC articles (by key AIDS prevenrelevant to this words) Tion, care, and population Research Awareness and Ability to 13: Information Skills modulate risk of 17: Access to information sources Acquiring HIV 24: Highest attainable standard of health and Infection facilities for treatment (negotiation 29: Personality and abilities sexual practices 34: Protection against sexual exploitation and condoms, other sexual abuse preventive behaviors Livelihood Child labor 19: Protection against all forms of abuse Exploitation of including negligent treatment Children 27: Standard of living 28: Education 31: Rest and leisure (engage in play) 32: Child labor and economic exploitation 36: Protection against all other forms of exploitation 39: Reintegration after exploitation Sexual exploit-19: Protection against all forms of abuse Tion including negligent treatment 27: Standard of living 28: Education 29: Personality and abilities 31: Rest and leisure (engage in play) 34: Protection against sexual exploitation and sexual 36: Protection against all other forms of exploitation 39: Reintegration after exploitation Services and Access to 13: Information **Programs** education 17: access to information sources 27: Standard of living 28: Education 29: Personality and abilities Access to health 18: Common responsibility of parents Services 23: Disability (including sexual 24: Highest attainable standard of health and health and facilities for treatment

26: Social insurance

reproductive

health)

# The Child Vulnerable to HIV/AIDS (cont.)

T.	Issues in HIV/ AIDS preven- Tion, care and Research	Specific issues relevant to this population	Immediately relevant CRC articles (by key words)
		Access to social Services	<ul> <li>18: Common responsibility of parents</li> <li>23: Disability</li> <li>24: Highest attainable standard of health and facilities for treatment</li> <li>26: Social insurance</li> <li>27: Standard of living</li> </ul>
	Children Difficult Circumstances	In times of conflict and internally Displaced	<ul> <li>23: Disability</li> <li>24: Highest attainable standard of health and facilities for treatment</li> <li>38: Protection and care</li> <li>39: Reintegration after exploitation</li> </ul>
		Institutionaliza- Tion(prison Mental institu- Tions, etc.)	<ul> <li>23: Disability</li> <li>24: Highest attainable standard of health and facilities for treatment</li> <li>25: Periodic review of treatment</li> <li>37: Appropriate assistance</li> <li>40: Special concerns/privacy</li> </ul>
		Homelessness	<ul> <li>20: Care if deprived of family environment</li> <li>23: Disability</li> <li>24: Highest attainable standard of health and facilities for treatment</li> <li>26: Social insurance</li> <li>27: Standard of living</li> </ul>
		Exposure to Violence	<ul> <li>18: Common responsibility of parents</li> <li>19: Protection against all forms of abuse         <ul> <li>Including negligent treatment</li> </ul> </li> <li>27: Standard of living</li> <li>31: Rest and leisure (engage in play)</li> <li>32: Child labor and economic exploitation</li> <li>36: Protection against all other forms of exploitation</li> </ul>
T or		Injecting drug Use by children Asylum seekers And refugees	33: Protection from illicit use of narcotic drugs  8: Preservation of identity 10: Family reunification 11: Illicit transfer and non-return of children 20: Care if deprived of family environment 22: Refugee status 23: Disability

Yes, you're positive, but there's nothing we can do for you

By Sandhya Srinivasan

What can the National AIDS Control Programme achieve in the absence of integration of HIV-related services into the health system as a whole? The second in a series assessing the HIV/AIDS situation in India

When the National AIDS Control Programme was first set up in 1992 its first priority was to make people aware of HIV.

HIV is transmitted through unprotected sex, infected blood and blood products and from an HIV-positive pregnant woman to her baby either during pregnancy or through breast-milk. The programme publicised these facts.

In some ways the programme took a bold step by starting to talk about sex - the main route of transmission of HIV - in a society which didn't like to talk about such things. Public information campaigns were launched which actually spoke of how HIV infection was acquired - and how it wasn't, through casual contact, for example. These continue to meet with resistance: some feel that talking publicly about sex corrupts the young and is antithetical to Indian culture. Doubts have also been expressed about the quality of information provided: some messages seem to confuse and create fear more than they educate.

The programme also sought to provide a bare minimum of preventive services by protecting blood supply and setting up an effective treatment programme for sexually transmitted diseases (people who already have certain STDs are more vulnerable to HIV if exposed to it through sexual contact, so

treating STDs would make people less likely to get infected with HIV if exposed to the virus). Finally, the programme worked at developing a system to monitor the prevalence of HIV in various parts of the country by conducting unlinked anonymous tests on STD clinic users, commercial sex workers, injecting drug users, pregnant women attending antenatal clinics, and gay men.

### Phase II: More of the same

The second phase of the National AIDS Control Programme (1999 to 2004) tries to take all these activities one step further and build on them.

The primary focus of the second stage of the programme has been 'targeted intervention' to increase awareness among those believed to be at high risk of infection, and to change their behaviour. This includes the promotion of condom use among these groups.

Other activities include developing a safe blood supply through the establishment of properly-equipped blood banks where all blood is tested for HIV and other infections before use; promoting blood donation and banning trade in blood; setting up testing centres where people are encouraged to go for testing which is preceded and followed by counselling; further establishing STD treatment services, and setting up a programme to provide a short course of anti-retroviral drugs to pregnant women reporting to antenatal clinics who test positive for HIV (called the PMTCT or prevent mother-to-child transmission programme).

Phase II of the NACP also has, as stated objectives, the provision of decentralised services and strengthening of the

system's long-term capacity to respond to HIV.

Finally, the number of sentinel surveillance sites, conducting HIV tests for monitoring purposes, increased dramatically in the second phase. These were in STD clinics and antenatal clinics and among groups of sex workers. As a result, it is believed, surveillance data collected in the last few years may present a more accurate picture of the prevalence of HIV infection in India. (Still, the programme continues to be plagued by queries about the quality of its data and many limitations have been noted by public health experts and activist groups.)

NACP II was implemented at the state level using state AIDS control societies, autonomous bodies headed by a senior civil servant, but with independent financial authority. These societies funded voluntary organisations to carry out prevention.

# The targeted approach

Overall, the targeted approach dominates the second phase of the National AIDS Control Programme. The targeted approach is touted as a success story in states like Manipur and Tamil Nadu where HIV prevalence has reduced among target groups such as injecting drug users (in Manipur), commercial sex workers and clients of STD clinics (Tamil Nadu). Indeed, surveillance figures for 2000 and 2001 show a drop in HIV prevalence in targeted groups in a number of states. However, it is not clear if figures for the two years can be compared. Interestingly, the NACO website does not contain any HIV prevalence figures after 2001.

The programme quotes reports from successful AIDS control efforts to argue that the best way to reduce HIV transmission is to target interventions at groups most vulnerable to HIV. These

vulnerable 'core transmitter' groups are preferred for interventions to groups that are more difficult to identify and approach, such as clients of sex workers.

It is true that in the US and Australia, for example, wellorganised information programmes for gay men, by organisations of gay men, are believed to have brought a sharp reduction in HIV prevalence relatively soon after the appearance of HIV infection in these groups.

What about those outside the target group?

A number of activists have complained that the targeted approach misses people who are outside the target group. So, for example, messages on the risk of unsafe sex between men are presented only in situations where men congregate to have sex with other men, or to groups self-identified as having sex with other men. Since messages on the risks of gay sex are not presented to the general population, those who do not identify themselves as gay are excluded from important information.

Likewise, partners of injecting drug users risk acquiring HIV but there are few efforts to speak to them as a group.

Targeting groups for interventions also stigmatises these groups.

Surveillance figures in recent years indicate that HIV infection is not confined to the 'target groups' of people with high risk behaviour. A number of women who are HIV positive report having had sex with only one partner -- their husband. However, there is no effort to reach the 'low risk' woman and discuss how she might protect herself from infection.

# Need for quality counselling

The general call for people to get themselves tested for HIV is not supported by counselling services before and after testing. The voluntary counselling and testing centres (VCTCs) set up by the programme are reportedly under-staffed and counsellors are often poorly trained. There are too many reported incidents of people being informed of their HIV status in front of other patients, of little or no effort being made to educate those who test negative of how to avoid risk behaviour.

Yes, you're positive, but there's nothing we can do for you

It must seem particularly unjust to those who are encouraged to test themselves and find themselves HIV positive, that they have nowhere to go.

A few voluntary organisations do provide treatment and support but they can meet just a fraction of the demand for such care. In general, both private and public health services are completely unprepared to respond to the growing need to care for people with HIV. Private services generally refuse treatment, or provide it at exorbitant costs to those who can afford it. Very few public health services are equipped to provide treatment of any kind. Drugs are in short supply, as are protective materials to be used for all patients (following universal precautions). And few personnel have been trained in standard procedures to prevent transmission of HIV or other infections. The kind of resource allocation, education and regulation needed to ensure treatment to people with HIV-related health problems do not exist.

In such a situation, there is no scope for treatment with antiretrovirals through the public health system, a demand made by some groups working with people with HIV.

## A weakened health system

There is much talk about integration of HIV prevention and treatment into the system. However, not only are preventive programmes patchy and integration poor, there is no integration of HIV-related services into the health system as a whole.

Further, public health services in India have deteriorated steadily over the last few decades. There is no evidence of efforts being made to strengthen the health system and prepare it for a growing burden of ill people. Barely 20% of all health-related expenditure is made by the government; the rest is within the private sector, where payment is made by individuals spending their own money since health insurance is available to a negligible percentage of people in India. The increase in HIV-related problems calls for increased government spending on health. As more awareness is generated and more people test positive, this demand is bound to grow.

This increase in government spending on health is a decades-old demand. Instead, the amount spent on health has gone down, not up. There are innumerable instances illustrating the collapse of health care through the government, from the rural primary health centre all the way up to the municipal hospital representing the tertiary level of care. Equipment does not work, drugs and other materials are not available, staff are absent, and so on.

In fact this general deterioration of public health services actually increases people's vulnerability to HIV as shortages encourage the reuse of unsterilised equipment.

Further, the absence of treatment may in fact exacerbate the stigma attached to HIV.

HIV is driven by inequities

HIV is intrinsically linked to poverty and to inequalities of all kinds - social, economic and gender. However, awareness and other preventive programmes do not address inequities that are intrinsic to the problem. The married woman is unable to refuse her husband unprotected sex. The commercial sex worker will not insist on her client using a condom if he threatens to go elsewhere. The national HIV programme fails to take into inequities into account.