

# Seen and heard: Children affected by HIV and AIDS

Summary report of issues facing children  
affected by HIV and AIDS

October 2008

Summarized from:

XVII International AIDS Conference, Mexico City, 3–8 August 2008  
Children & HIV/AIDS: Action Now, Action How, Pre-Conference Symposium, 1–2 August 2008, Mexico City  
Pre-conference online discussion on children and HIV/AIDS



## Voices from the XVII International AIDS Conference

"Health and Development Networks brought six children to this conference to be reporters. You do not just get seven kids on a plane without doing a lot of advance work, without making sure that you have got planning for everything. It takes money, it takes time; but we now have seven young people who know more about HIV and AIDS than anybody else in their age group, who are going to be resources for us as the future goes on. And we need to acknowledge that that kind of upfront investment will pay off in the long run."

*- Terje Anderson, National Association of People with AIDS (USA), speaking during the rapporteur session of the XVIIth International AIDS Conference, Mexico, 2008*

"I'm glad there is an increasing emphasis on children at this conference... for too long they've been invisible, or the add-on."

*- Mary Robinson, President, Realizing Rights (Ireland)*

"How would I feel if I had HIV? I would feel sad, scared or angry. Poor children are dying of HIV. We need to stop HIV from spreading. We need to stop HIV right now. We can't let anything stop us."

*- Michael Kazaala, age 7, Young Key Correspondent (Uganda)*

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Photos: HDN Key Correspondents

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## Seen and heard: Children affected by HIV and AIDS

For too long, the millions of children affected by the HIV epidemic have been seen as statistics detailing numbers of infected infants, abandoned orphans and struggling survivors – but their own voices have not been heard. Their problems and challenges, needs and hopes, have been defined by adults – from parents and doctors to donors and government officials.

In 2008, Health & Development Networks (HDN) set out to help these children to find their voices and to provide them with a platform from which to speak not only in their home countries, but also internationally. Working in collaboration with Irish Aid, the Bernard van Leer Foundation and the Joint Learning Initiative on Children and HIV/AIDS, HDN initiated *Seen and heard: Children affected by HIV and AIDS*, a project to increase understanding and awareness of the issues facing these children and ensure that their concerns receive the high-profile attention they deserve.



HDN supporting KCs on article development

Project activities focused around the XVII International AIDS Conference (IAC) and a pre-conference symposium on children and HIV, both held in Mexico City from 1–8 August 2008. In the period leading up to these events, HealthDev.net, a dialogue and social networking platform, hosted online discussions on this theme.

To cover the conference, HDN assembled a team of writers from 10 countries to serve as Key Correspondents (KCs). They were drawn

from various fields, including nongovernmental organizations, health care, the media, and country-based organizations. Each was an expert in issues faced by children affected by HIV, and, in fact, many were directly affected themselves. All had first-hand experience with the epidemic in their home countries, which were Cambodia, India, Ireland, Thailand, Uganda, the United Kingdom, the United States of America, Viet Nam, Zambia and Zimbabwe.

The role of the KCs was first to serve as rapporteurs at the two-day pre-conference symposium, 'Children & HIV/AIDS: Action Now, Action How'. This symposium provided a forum for information sharing, collaboration and networking in order to strengthen the response to children's needs. The KCs then went on to attend the IAC, bringing their own national, professional and personal perspectives to a critical examination of the issues, assessing progress and deficits as well as opportunities for action.

The heart of the project, however, was the participation of a team of six Young KCs, aged 7 to 17, from the United Kingdom, Uganda and Mexico. These young people were the first ever to participate in an IAC. They brought a fresh perspective and, when they interviewed key participants such as Stephen Lewis (The Stephen Lewis Foundation), Mary Robinson (Realizing Rights) and Michel Sidibe (Joint United Nations Programme on HIV/AIDS (UNAIDS)), they asked direct questions about how they will support HIV-affected children. Their presence as delegates was a powerful reminder that their voices must be heard by all who hope to defeat the HIV epidemic now and in the future.



Two brothers (young KCs) hard at play

## Children and HIV: An overview

"The AIDS epidemic creates extraordinarily high risks for children, and the global commitment to protect and support AIDS-affected children is tragically insufficient. Responses should unavoidably be large-scale, integrated and national; characterized by social justice; and enabled by basic income security and universal access to essential services such as health, education and social welfare."

*- Professor Fr. Michael Kelly  
Chair, Zambia Orphans of AIDS*

Here are some statistics that give an overview of the state of the epidemic:

- **2 million** children aged 0–14 live with HIV. This number has increased eightfold in less than 20 years.
- **370,000** more children became infected in 2007.
- **198,000** received antiretroviral therapy in 2007, up from 127,000 in 2006.
- **270,000** died of largely preventable AIDS-related causes.
- **90%** of these affected children live in sub-Saharan Africa.
- Only **16 of 68** priority countries are on track to meet the 2015 Millennium Development Goal of reducing child mortality rates.
- Young people aged 15 to 24 years now account for **half of the five million new cases** of HIV infection worldwide each year.
- **12.1 million** children in sub-Saharan Africa have lost one or both parents to the HIV epidemic.
- More than **60%** of children in southern Africa live in households with an income below the poverty line.

Sources: UNICEF, UNAIDS, Human Sciences Research Council, *The Lancet*

## Key issues for children affected by HIV and AIDS

Following is a summary of the key issues that emerged during the XVII International AIDS Conference and the pre-conference symposium as highlighted by the KCs in their articles. The views of the young KCs, who were an integral part of the HDN team, are also included.

### Engaging young people

"Whatever you do for me without me you are against me."

- Rafiki Callixte  
*Les Enfants de Dieu, Rwanda*



Drawing of a conference session by Jonas Heylar, age 10, Young KC from UK

The absence of young people at AIDS conferences emerged from the XVII IAC as a critical and telling omission. HIV in children is an increasing global problem, and many specialists are dedicated to fighting it. But at the 17 International AIDS Conferences since 1985, children and adolescents have been virtually absent. This needs to change. Although children under 18 may not be able to unite and form advocacy networks the way people who inject drugs or men

who have sex with men have done, they can speak up and express themselves, inspiring people to action.

At the pre-conference symposium, the point was made that children should not be thought of as objects and statistics, but as subjects with rights. Delegates called for them to join the fight against the epidemic and for their voices to be heard.

At the IAC, experts and programme officers called for the increased 'inclusion' of children and young people, but the real impact came from young people taking centre stage themselves. Karen Dunaway Gonzalez, an HIV-positive 12-year-old from Honduras spoke at the opening ceremony and received a standing ovation from the 23,000 conference delegates.

Craig McClure, Executive Director of the International AIDS Society, said he wished there were more children at the conference; and AIDS icon and former UN official Stephen Lewis said it was "outrageous" that more young people weren't present.

The world needs to hear the words of young people directly affected by HIV – not processed, digested and delivered through adults. Volunteers from Youth Force, an organization of young adults that focuses on youth-related issues, expressed strong views on the situation. "Youth are marginalized! We need to see young people speaking with researchers throughout the conference", said 21-year-old Kyla Zanardi.

The presence of young people offers other advantages: They can help fight stigma and discrimination by showing their peers all over the world that HIV affects people of all ages, from different countries and social backgrounds.

### Strengthening families

"The family should be the centerpiece of the response, particularly for orphaned children. However the family has been decimated by the virus in so many high-prevalence countries."

*- Stephen Lewis, Chair  
The Stephen Lewis Foundation*

The issue of how to strengthen families affected by HIV formed the basis of an online discussion held on HealthDev.net, prior to the IAC. It focused on the impact of the epidemic on children, young people and their families, and the role of families in supporting those affected.

The disease takes a toll on the family's livelihood, which influences the quality of care available to children living with and affected by HIV. In many cases, HIV-positive children are left alone at home while their mothers go to work. Children themselves often have to become caretakers, with 10- and 11-year-olds shouldering the responsibility of caring for their younger siblings.

In her plenary session, Professor Linda Richter of the Human Sciences Research Council in South Africa said that policies, programmes and funding must be redirected to provide support for children to and through their families. Families care best for children, yet many efforts have ignored the clear benefits of supporting them. Instead institutions, orphanages and other forms of non-family care are relied on that have well-documented problems and cost up to 10 times more than family care. She pointed out that if families had the same amount of money per child that donors give to orphanages, they would do equally well or better. Strengthening the capacity of families through systematic, public sector initiatives has been identified globally as one of the most important strategies for building an effective response to the epidemic and for preventing and mitigating its impact on children.

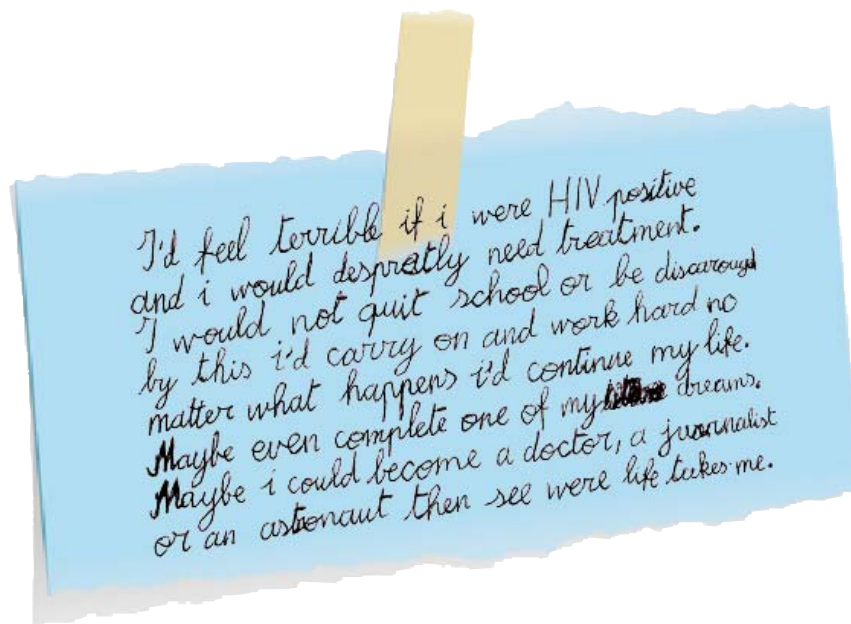


KCs uploading their articles to HealthDev.net

Another issue is the tendency of many HIV programmes to focus on individuals rather than the family. This approach to services such as preventing mother-to-child transmission, home care of a very ill person or initiation of a family member to antiretroviral treatment misses a critical opportunity to reach the family and community.

During the pre-conference symposium, speakers emphasized how deeply HIV disrupts children's lives and that more integrated, holistic approaches are vital and successful. Research on attachment has shown that separating children from their families early in life causes severe and long-lasting emotional trauma. Some current practices make a bad situation even worse, for example, taking pregnant women to one place and babies to another, while not properly looking after the grandmothers who often provide the real backbone of home-based care and deserve social support themselves. An integrated, family-centric approach, rather than a top-down model, takes these needs and relationships into account. Progress in paediatric AIDS treatment is providing opportunities to integrate treatment with the psychosocial support and social protection that are necessary for healthy children and healthy families. It must be remembered, 'there is no treatment without engagement'.

#### Challenges for the education system in responding to HIV



*- David Kazaala, age 9, Young KC from Uganda*

Professor Fr Michael Kelly, chair of Zambia Orphans of AIDS, has described schools as “multipurpose community development and welfare centres” that should be at the heart of prevention, care and support activities for the epidemic. The critical importance of education, especially for children without one or both parents, was a key theme addressed at the IAC. Presentations covered topics ranging from research that shows a strong correlation between HIV risk and limited access to education to the stigma and discrimination faced by HIV-positive children at school.

In some countries, the epidemic is reducing the demand for education, because HIV-affected households are unable to pay for children to attend school. Children, especially girls, are often taken out of school to care for the sick at home. This cuts them off not only from the lifelong benefits of literacy, but also from programmes that can educate them about HIV and other diseases. One study showed that completing a primary education can effectively reduce the risk of HIV infection, provided a protective and enabling environment exists in the school.

The impact of what children learn at school also reaches into their homes and communities. A poster presentation, 'Let's Talk and Walk the Talk', described a school-based peer-education programme in Fiji that demonstrated how children and teachers can reach large numbers of their peers and other members of the community with information and skills in HIV prevention, care and support.

"It is common and natural for adolescents to feel uncomfortable when talking to their parents about sex."

*- Galen Bertozzi, age 17, Young KC from Mexico*

Sex education is always a controversial subject, and, strong differences of opinion can influence the way young people are taught about HIV and AIDS. Many countries subscribe to the 'ABC' strategy for HIV prevention – **A**bstinence, **B**e faithful and use **C**ondoms. However, some schools with strong religious and cultural foundations limit the options to abstinence. This is because school administrators believe that the majority of young people are not sexually active; therefore abstinence is the best way to keep them free of infection. Lack of parent-child communication about HIV and sexually transmitted infections is a problem all over the world, but especially in traditional societies, such as Mexico. Despite the fact that communication is essential to provide young people with adequate information on prevention, few parents are capable of initiating a conversation with their sons or daughters on sexual education and sexually transmitted infections.

In some areas, children face a major challenge in getting an education because of stigma and discrimination. Caregivers at the Ashray Center for Children in Mumbai reported that various studies in India showed that HIV-positive children were being denied an education based on their HIV status. The reason was attributed to lack of knowledge or awareness in the general population about how HIV spreads.

In addition to discrimination against students, teachers affected by HIV also face difficulties. Many are afraid to be tested or disclose their status because of the lack of confidentiality in testing and counseling, as well as the cost of treatment. Policies addressing such important workforce issues are often weak or nonexistent; and teachers are expected to be community role models, which makes them particularly vulnerable to public opinion. At the IAC, Ekua Yankah from the United Nations Educational, Scientific and Cultural Organization (UNESCO) presented a poster outlining the issues that arose in providing support to HIV-positive teachers in eastern and southern Africa.

Given the central role that education plays not only in supporting health, but also in strengthening the economic, political and social welfare of any community, action needs to be taken now to improve the way educational institutions participate in the overall response to HIV. This is imperative because the impact of these efforts will affect the future of both today's children and subsequent generations.

#### Disclosing HIV in children

"Getting to know my status did not change the circumstances that came with living with HIV, but knowing it gave me the ability to cope and look at what I could do about it."

*- Stephanie Joy Rapper, age 16*

Debates over whether or not children living with HIV need to be informed of their status attracted considerable attention at the IAC. Many children with HIV are now surviving to middle childhood and adolescence. Research suggests that children who know their HIV status have higher self-esteem than children who do not, and parents who have told their children the truth experience less depression than those who keep it a secret. The decision to disclose a child or adolescent's HIV status should take into consideration their age, psychosocial maturity, the complexity of their family dynamics and the clinical context.

Most often children are told that the medications they are taking are vitamins or health supplements. Stephanie Joy Rapper, an HIV-positive 16-year-old, said that being informed of her status made all the difference for her. "I was told at a young age about my HIV status and that gave me the power to ask and understand a lot of things around it. But a lot of other people like me get to know their status from different sources, and they feel so devastated that their trust in their parents or guardians gets violated." Stephanie is a vocal champion, speaking out about the needs of young people living with

HIV. She makes a strong case for children's participation in decisions related to their welfare and way of life.

Christabel Opudo from Kenya is another 16-year-old helping young people living with HIV to eliminate stigma and promote acceptance through a support system known as the 'Staying Alive Youth Group'. Both Christabel and Stephanie agree that programme representatives, service providers and parents or guardians too often decide on how to respond to HIV without the full involvement of the child living with the virus. They need to realize that knowledge of HIV status, when communicated in an appropriate manner, does not need to result in extreme reactions. This view is shared by Christina Ralsgard, a medical social worker from Sweden's Karolinska University Hospital, who has counselled many young people with HIV. She says many service providers are stymied in their efforts to help by parents' refusal to consent to their children being informed of their status.



Drawing of KC Interviewing IAC 2008 participant  
by Jonas Heylar, age 10, Young KC from UK

Knowledge of parents' status is important too. One KC wrote a moving article about parents who had not told their daughter they were HIV positive. Then one day the daughter commented on the difference between chemotherapy for cancer and antiretroviral treatment "for people with HIV just like Mummy". When her mother asked how she knew, the girl said, "I have always known that you are HIV positive because I read in a magazine that Kaletra is medicine for people who have treatment for HIV".

Addressing this issue of disclosure will first require strengthening the understanding of parents and guardians, but children and young people growing up with HIV need to be aware not only of the importance of their treatment, but also of how handle other challenges affecting their welfare, including their sexuality.

### Integrating treatment programmes with psychosocial support

"If I was positive, I would feel terrible, and the medication I would take would be the HIV treatment. I would need company and friends."

*- Jonas Helyar, age 10, Young KC from the United Kingdom*

Children and families affected by HIV require integrated programmes that address their psychosocial needs, as well as their medical treatment. In addition to poverty, illness and discrimination, many of these families struggle with mental health problems.

Studies have found that some 37% of mothers with HIV-positive children are depressed; and fathers suffer from depression too. Dr Lorraine Sherr of the United Kingdom's Royal Free and University College Medical School advocated for simple interventions to treat depression that are not dependent on psychiatric medications and are easily understood. Simply encouraging depressed women to have a more positive view of their children can be a valuable intervention.

Born into difficult circumstances, HIV-positive infants show developmental delays, and their ability to reach developmental milestones continues to decline with age. But Dr Patrice Engle from California Poly State University reported that early stimulation can reduce some of the negative effects of the disease. She urged programmes to build capacity in early childhood development and to obtain adequate funding to provide sufficiently intensive interventions and support for young children at all levels. Dr Sherr stated that, "Unequivocally, one of the fundamental moves forward

for children is the integration of programming. Children don't think parallel – we need to integrate what we do for them.”

Dr. Margaret Irvine of South Africa pointed out that families may take many forms as long as they offer a stable surround for the child. Household identification is a good way to see who is there for the child and how the family fares in terms of health, nutrition, hygiene, safety and security, housing, education and peace. People's integrity and well-being should be viewed within the social context of the family and community. She argued that families should be at the center of poverty eradication both as service providers and recipients. “Families are the sustenance block for children”, she said, and she cited an African proverb: “You can tell the strength of a nation by the strength of its families.”

#### Expanding social protection for vulnerable children and families

“Children have been short-changed in the response to AIDS.”

*- Professor Linda Richter  
Human Sciences Research Council  
South Africa*

Social protection is an umbrella that covers economic strengthening and the provision of effective welfare and social support for HIV-affected households. Typically households affected by the disease experience a worsening of their socioeconomic status, which in turn hinders the quality of children's care. Plans to reduce the impact of extreme poverty through social protection are the crucial missing ingredient in current responses to children affected by HIV.



KCs framing their article ideas

According to Professor Linda Richter, targeting programmes specifically towards orphans or HIV-affected children is neither helpful nor efficient in hard-hit communities where there is widespread poverty and destitution. In these circumstances, orphans are seldom worse off than other vulnerable children and singling out specific groups can result in the stigmatization and abuse of those in need. All children in communities severely affected by HIV require support.

In some southern African countries more than 30% of families have an adult member living with HIV or have experienced a recent AIDS-related death. More than 60% of children live below the poverty line in countries already struggling with low incomes.

The support offered to individual children by local community members and organizations in these situations has been valuable, but it has fallen woefully short of meeting their needs. Few programmes aimed at children have been formulated, resourced or implemented on a scale comparable to the epidemic's impact on them and their families.

"Whatever approaches are taken," said Professor Richter, "some form of income assistance for the neediest households is critical. In many high-prevalence countries in Africa, poverty is arguably the single biggest barrier to the scale-up of HIV treatment and prevention." Further expansion of these services may not be possible without addressing individual and household incapacity, including financial incapacity, to access them.

#### AIDS treatment for children

"Bill Clinton said that medication is spreading around the world; but there is still not enough for children."

*- Jonas Helyar, age 10, Young KC from the United Kingdom*

The overwhelming majority of HIV-positive children are infected through mother-to-child transmission (MTCT), which can occur during pregnancy, delivery or breastfeeding. In the absence of any intervention, the risk of such transmission is 15–30% if the mother does not breastfeed. When an infected mother breastfeeds, the risk jumps by another 5–20% to a total of 20–45%.

One MTCT intervention is caesarean delivery; unfortunately, in resource-poor settings this is often not feasible. In some areas, it is also often neither culturally acceptable nor safe for mothers to refrain from breastfeeding. Other barriers to the prevention of MTCT

include a woman's preference for home or traditional birthing practices and resistance to HIV testing for fear that her partner will be notified and reject her, and she will face stigma and discrimination. Considerable efforts have been made to introduce and expand prevention programmes that are feasible, acceptable and cost-effective. Yet despite significant progress, they have not been implemented widely in limited-resource settings.

Prevention programmes for pregnant woman should serve as an entry point to programmes offering diagnosis and access to treatment for their infants, but there is a gap between these services. Last year, fewer than 8% of infants in low- and middle-income countries were tested for HIV within two months of their birth. Late testing means there is a delay in initiating co-trimoxazole, a prophylaxis that prevents life-threatening opportunistic infections in infants. This also delays the initiation of treatment if the diagnosis is positive. Only 10% of children living with HIV receive antiretroviral therapy.

Some of the challenges in AIDS care and treatment are the same whether the patient is a child or an adult: a weak health system infrastructure, inadequate staffing of health services, limited availability of laboratory facilities, and the absence of simple and affordable diagnostic tests.

Providing HIV services to pregnant women and children involves additional challenges:

Pregnant women may have difficulty accessing treatment services, because they can't afford transportation or the cost of testing. They may be afraid of the reaction from their family and community if they are diagnosed as positive. They may experience treatment failure due to poor nutrition or lack of clean water. They may be relying on a midwife who is insufficiently trained in preventing MTCT. Consequently, although effective treatments exist, they do not reach all the women and babies who need them.

For children, many problems stem from the fact that no treatments have been developed specifically for them. Some tablet formulations are only appropriate for adult consumption, so physicians have to chop or crush them for children. Many drugs have adverse side effects that make them more difficult to give to children.

Adherence is a major issue in paediatric treatment, especially in low-income countries. A number of factors contribute to adherence problems: inadequate dosing; high pill burden; the reluctance of young infants to take syrups and powders that taste unpleasant; a lack of willingness among caregivers to inform schools and care centres that a child is infected, which can result in missed doses

during the day; dietary restrictions; and the toxic side effects of drugs.

Unless a child adheres to a strict treatment regimen, it is likely that treatment failure will occur. The child may become resistant to or intolerant of one or more of the front-line drugs. When this happens, the problems escalate. Second-line drugs are 6 to 12 times more expensive than first-line drugs in sub-Saharan Africa, an expense that is often prohibitive.

If fixed-dose combinations appropriate for children become available, it is likely that adherence will improve, since it is much easier to take a single dose every day than multiple doses. Unfortunately, global advocacy for the specific needs of children has been insubstantial up until now.

Relationships that increase infection risk for young adolescents: sugar daddies and garden boys

"The risk of HIV exposure and infection is dramatically increased in these relationships because condoms are seldom used."

*- Wellington Mushayi  
Population Services International (PSI), Harare, Zimbabwe*

Exploitive adults who seek sexual relationships with adolescent girls and boys exist in every culture. When HIV is added into the mix, these relationships can cost lives.

The term 'sugar daddy' is often used to describe older men who have sex with adolescent girls in return for money, food, clothing or some other personal benefit. These relationships are rarely based on mutual love or affection.

Adolescent boys who have sex with older women are referred to as 'garden boys'. The term originally referred to the adolescent boys who tended household gardens. These relationships typically do not involve money. Garden boys are more likely to use this transactional sex to improve their status and gain sexual experience.

According to Wellington Mushayi, author of a study on heterosexual concurrent partnerships in Zimbabwe, the older partners have greater power than the younger and can take advantage of their position to insist on not using a condom. They don't feel at risk of contracting HIV from their young partners because the latter are sexually inexperienced and unlikely to have been infected.

Sadly, the opposite is true for the adolescents, who are at greater risk of infection because their older partners have had many more opportunities to be exposed to the virus. Young people need increased awareness about these high-risk behaviors, in order to protect themselves from exploitive relationships.

## Gender equality and HIV

"I want to see more people allowing children's voices to be heard, by putting children at the centre".

*- Bafana Khumalo  
Sonke Justice Project, South Africa*

The spread of HIV among young people aged 15–24 has become a global emergency. This age group now accounts for half of the five million new cases of HIV infection worldwide each year. An estimated 6,000 youths a day become infected, an average of one new infection every 14 seconds.

The most socially and economically disadvantaged young people appear to be especially at risk of HIV infection, and young women in developing countries are at the greatest risk. The rate of HIV infection among girls is rapidly outstripping the rate among boys. Girls already account for nearly 60% of the infections in sub-Saharan Africa, where the epidemic is most virulent.

A number of factors conspire to put girls and young women in this dangerous position:

Gender-based socialization begins even before a child's birth with the parents' attitudes and expectations. It continues through early childhood, when gender roles are established that may place girls and their future partners at risk of HIV infection. The effects of domestic violence, which is also strongly influenced by gender, often stay with them throughout their adult lives. Violence has a direct effect on children's HIV risk when it takes the form of sexual abuse, and a history of sexual abuse can have long-lasting indirect effects on girls' tendency towards high-risk behavior.

Bafana Khumalo, a practicing Lutheran minister from South Africa who works with the Sonke Justice Project, is one of the few pioneers working with men and boys to promote gender equality and oppose violence against women. He reported that many of men say they oppose violence against women, but lack the skills to tackle it. He works with boys on gender awareness to head off the same problem.

At the IAC, the discussion of gender-based violence focused on adult women's experiences. The next step may be integrating a gender perspective into educational programmes that teach children about violence. Given the acknowledged role of gender inequality in driving the spread of HIV, it would make sense to strengthen efforts to change the values of both young people and adults.

Changing dangerous gender norms and values before they are transmitted to the next generation is important work for parents, communities and children. Khumalo aims to help children learn to express their own problems and find their own solutions.

### Stigma and discrimination in HIV-affected children

"If I was HIV positive, I would feel sad and scared. I would die young and never see my family again. But I would be most worried about being excluded from others because their parents think it's contagious through daily communication."

*- Ned Helyar, age 12, Young KC from the United Kingdom*



Young KCs helping each other

Since the beginning of the HIV epidemic, the stigma of the disease has caused affected people much added misery and suffering. They are marked by their communities as different, and they are subjected to significant discrimination. The persistence of this problem is reflected in the fact that many programmes continue to include addressing stigma as part of their broader strategy.

For HIV-positive children, stigma is as real as for older people. They are set apart not only by their HIV status, but also by physical effects, such as failure to thrive, which make their disease more visible. HIV-positive children are often denied access to education, health and other crucial government-provided services. In some areas the problem is so severe and wide-ranging that some parents hide their children from other members of the community. This fear of stigma drives many people to deliberately deprive themselves and their families of access to HIV prevention, treatment, care and support services.

Unless the problem of stigma is confronted, children affected by HIV will continue to be denied their basic human rights under the Universal Declaration of Human Rights and the Convention on the Rights of the Child.

#### Access to essential services and human rights

The 1989 United Nations Children's Fund (UNICEF) Convention on the Rights of the Child outlines the rights and responsibilities of children and the roles of their guardians and nation states. Key elements state that no child should be treated unfairly; that the best interests of children must be the primary concern of those making decisions that may affect them; and that all children have the right to an education.

This convention offers valuable principles that can be applied to the challenges facing children affected by HIV:

First and foremost, they should have fair access to the health care they need. This means adequate antenatal care for their mothers and prompt diagnosis and appropriate treatment for infants. Barriers to treatment, such as the lack of paediatric ART formulations, should be eliminated. Services should be integrated, addressing both medical and psychosocial needs of the family.

Communities should not unfairly discriminate against HIV-positive children hindering their access to schools and other resources. They deserve acceptance and support.

Governments need to address the weaknesses in their health systems that prevent children and others from receiving the care they deserve. Laws should be passed to safeguard women from violence and offer protection from discrimination to workers so that adults and children can receive testing and undergo treatment without fear of reprisals. Inheritance and financial support laws that discriminate against HIV-positive family members should be changed.

Family members, health-care workers and other professional caregivers need to focus on the best interests of the child when making decisions about disclosing the child's HIV status, confronting discrimination and other issues relating to their care.

The right to an education is of particular importance. Better-educated children are good for the whole community and its future. In addition, education serves as a 'social vaccine', building awareness and helping to preventing children, and in particular girls, from becoming infected with HIV.

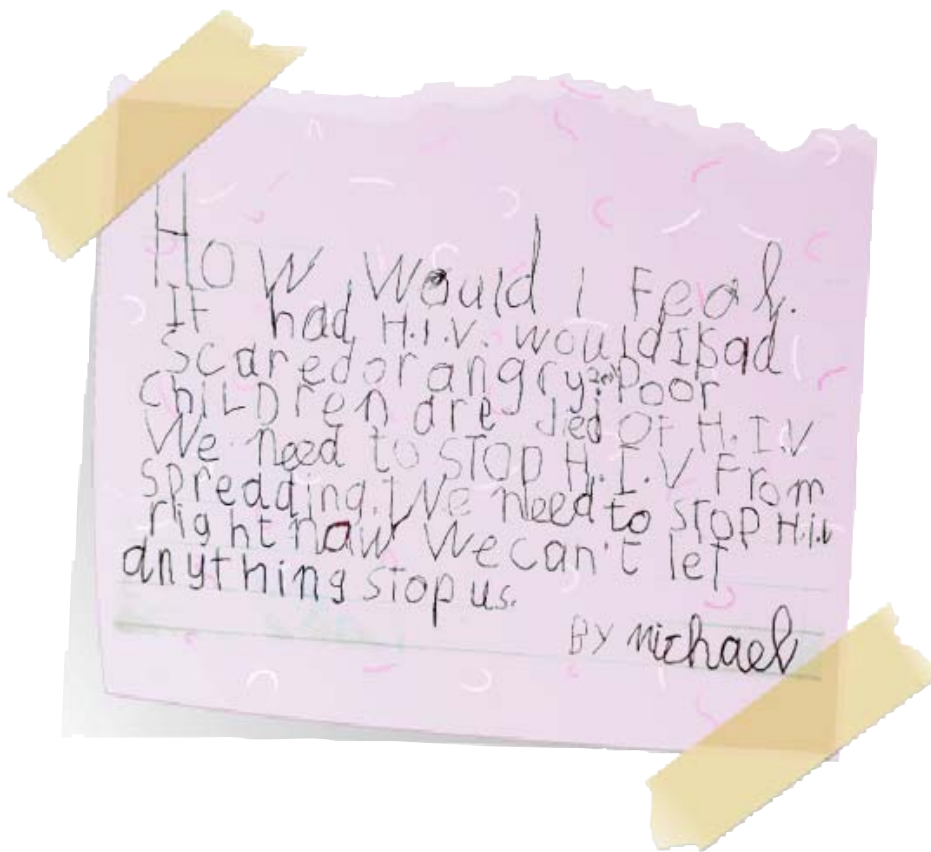
Professor Fr Michael Kelly has suggested there is a fundamental injustice in the way children are overlooked in programmatic responses to HIV. At the IAC, discussions about how to redress this failure focused on a return to four basic rights, also taken from the UNICEF Convention on the Rights of the Child:

To enjoy all rights with full equality of opportunity

To have their best interests considered a priority

To have the right to life, survival and all means of development

To have the right to be heard and have their views taken seriously.



- Michael Kazaala, Young KC, age 7 from Uganda

## Conclusion

"If I was HIV positive, I would feel scared and sad. When Bill Clinton told us a story of a boy named Jean Pierre, this story made me feel sad, but I also thought it was amazing that this 15-year-old boy was still determined to be a medical doctor, even though he's only in the third grade. It also made me determined to achieve my own goals."

*- Daniel Kazaala, age 13, Young KC from Uganda*

The HIV epidemic's growing impact on children needs to be matched by recognition of their special needs, acknowledgement of their rights and perspectives, and the assignment of adequate resources to address them.

They are not one single interest group. Meeting their needs means providing services to pregnant women and their unborn children, to infants, young children and adolescents – some of whom represent the first generation infected perinatally to grow to maturity. They include orphans and children subject to exploitation, children who are managing households and caring for sick families, well-educated children from wealthy countries, and the poorest of the poor. Like all other children, they need not only health care, but also good nutrition, shelter, clothes, education, love, affection and acceptance. They may also need help with a host of other challenges ranging from legal problems to guidance for their futures.

With two million children now living with HIV– and the number increasing – it is evident that solving their problems will require the support and effort of the whole community including children themselves. No country, community or sector of society can afford to ignore them. The care and protection of these children must be high on the HIV agenda if the disease is to be eradicated.

By raising the visibility of children affected by HIV and helping their voices to be heard, the *Seen and heard* project has given the children themselves an opportunity to begin influencing and shaping that new global agenda.



Speak your world with the Key Correspondent Team!

## Annex: Articles by the HDN Key Correspondents

The following articles were filed by the KCs during the pre-conference symposium on Children and HIV/AIDS: Act Now, Act How and the XVII International AIDS Conference, both held in Mexico City on 1–8 August 2008.

Gender equality has to start early:

<http://healthdev.net/site/post.php?s=3285>

Children deprived of essential services because of fear of stigma:

<http://healthdev.net/site/post.php?s=3051>

Heart of gold: <http://healthdev.net/site/post.php?s=3318>

One woman's fight against HIV stigma:

<http://healthdev.net/site/post.php?s=2908>

Young writers at Mexico IAC 2008 speak-their-world:

<http://healthdev.net/site/post.php?s=3393>

Where are the children?: <http://healthdev.net/site/post.php?s=3288>

Sugar daddies and garden boys: relationships that increase infection risk for young people: <http://healthdev.net/site/post.php?s=3293>

To tell or not to tell: <http://healthdev.net/site/post.php?s=3281>

Align the HIV/AIDS and development agendas to give hope for a better future to vulnerable children in Uganda:

<http://healthdev.net/site/post.php?s=3456>

Why are the young people absent from AIDS conferences?:

<http://healthdev.net/site/post.php?s=3310>

Integrating treatment programs with psychosocial support: the best models: <http://healthdev.net/site/post.php?s=3333>

Widespread rape does not appear to directly increase overall HIV prevalence in conflict-affected countries:

<http://healthdev.net/site/post.php?s=3327>

Snapshot on TB and children:

<http://healthdev.net/site/post.php?s=3286>

MSF's lessons in paediatric HIV treatment:

<http://healthdev.net/site/post.php?s=3291>

Sexuality education: a risky business:

<http://healthdev.net/site/post.php?s=3309>

Impact of HIV and AIDS on children in Zimbabwe:

<http://healthdev.net/site/post.php?s=2277>

Child HIV diagnostic kits needed, plus meaningful child involvement: <http://healthdev.net/site/post.php?s=3297>

Parent to child communication on AIDS: a fundamental yet lacking source of information: <http://healthdev.net/site/post.php?s=3292>

Engaging young people in the response to HIV/AIDS: myth or reality?: <http://healthdev.net/site/post.php?s=3316>

Challenges of the educational responses to HIV/AIDS:

<http://healthdev.net/site/post.php?s=3290>

Not having a story: it's a story in itself:

<http://healthdev.net/site/post.php?s=3289>

Supporting young sexual minorities a key to HIV prevention:

<http://healthdev.net/site/post.php?s=3306>

Meaningful participation of children vital to HIV and AIDS responses: <http://healthdev.net/site/post.php?s=3304>

More needs to be done for children in Thailand's AIDS response:

<http://healthdev.net/site/post.php?s=2616>

Children, HIV and ART: innovative tools for treatment literacy, IAC 2008: <http://healthdev.net/site/post.php?s=3305>

Saving the future from extinction:

<http://eforums.healthdev.org/read/messages?id=22276>

International HIV and Children Symposium Summary Report: Children and HIV/AIDS: Action Now, Action How? –

[www.hdnet.org](http://www.hdnet.org)