

# Children living with and affected by HIV



**Rachel Baggaley**

Education is a fundamental right for every child. Principle 7 of the United Nations (UN) Declaration of the Rights of the Child states as follows:

The child is entitled to receive education, which shall be free and compulsory, at least in the elementary stages. He shall be given an education which will promote his general culture and enable him, on a basis of equal opportunity, to develop his abilities, his individual judgement, and his sense of moral and social responsibility, and to become a useful member of society.

The best interests of the child shall be the guiding principle of those responsible for his education and guidance...

...society and the public authorities shall endeavour to promote the enjoyment of this right<sup>1</sup>.

Article 29 of the UN Convention of the Rights of the Child, which has been signed by all members of the Commonwealth, and which endorses children's right to education and the responsibility of governments to provide it, reaffirmed this commitment<sup>2</sup>. The importance of education has been further highlighted in the UN's Millennium Development Goals, signed by all UN member states, which lists universal primary education as the second goal on the list after the eradication of extreme hunger<sup>3</sup>.

The fact remains, however, that millions of children around the world, for one reason or another, are denied this most basic right. In many cases, they are denied it because of the influence, whether direct or indirect, of HIV.

HIV undermines millions of people's human rights. Sadly, some current responses to it exacerbate rather than help to reduce the abuse of rights. The rights affected include the right to healthcare, employment and protection from discrimination. Children's rights are no exception, and children affected by HIV are often unable to realise the specific right to education – whether as a result of sickness, because of the lack of surviving family to assist or pay for education, because they need to work to support a family weakened by the death or sickness of an HIV-positive parent, or for many other reasons

Children are on the front line of the HIV epidemic. They are vulnerable to the infection itself, and they are also particularly vulnerable to the destruction of family structures around them. Globally, children under the age of 15 account for one in six HIV-related deaths and one in seven new infections (mostly through

mother-to-child transmission). Sub-Saharan Africa is particularly affected. 64% of all people infected with HIV – some 24.5 million – live in the region<sup>4</sup>; and of these, fully two million are children younger than 15. Commonwealth developing countries are particularly heavily affected. 60% of the 40 million people living with HIV are in Commonwealth countries, and the nine most seriously affected countries are all Commonwealth members. In 2005, there were approximately 12 million orphans in sub-Saharan Africa, and a staggering 9% of all children under 15 in the region had lost at least one parent to HIV. Often the loss of one parent is cruelly followed by the death of the other. Due to the transmission pathways of HIV, it is not uncommon for children to lose both their parents.

Children who have lost one or both parents are deprived of affection, support and protection, and often have little time to work out how to cope. Siblings are frequently separated as the burden of raising them is shared out amongst relatives, and sometimes older children find themselves suddenly responsible for caring for their own siblings. In the latter case, they are almost invariably forced to work to provide for them. Of course, their education is one of the first casualties of this kind of disruption. In 2005, 62% of sub-Saharan African children who had lost both parents attended school, in comparison to 70% of children living with at least one parent<sup>5</sup>. Additionally, only 20% of children who are forced to live on the streets have any contact with outreach services, and fewer than 10% of households supporting orphans are reached by community-based or public sector support<sup>6</sup>. Speaking generally, the loss of a family, and the support it provides, is inadequately compensated by any form of public sector or civil society intervention. It need not, however, take the death of a parent from HIV, or even the onset of illness, to obstruct a child's education. Not all children affected by HIV are necessarily orphans – a recent study in Kenya showed that children of HIV-positive parents are significantly less likely to attend school than children whose parents are uninfected; and research in rural Tanzania has documented that children whose parents are sick are more likely to have their schooling interrupted and to spend fewer hours in school than other children<sup>7</sup>.

Despite all the commitments that have been made to tackle HIV, only half of the world's countries has a policy to address the needs of children orphaned or made vulnerable by the HIV epidemic, to ensure equal access to education and other services, and to protect them from abuse and stigmatisation.



As appalling as this statistic sounds on the face of it, even a cursory examination of the challenges and inequalities faced by orphans and vulnerable children (OVC) makes it appear far worse. Quite apart from the obvious emotional and psychological trauma of losing one or both parents, often after watching them struggle with a chronic illness – and of being party to the discrimination, stigmatisation and fear that so often occur when their deaths are associated with HIV – OVC find themselves additionally vulnerable to a gamut of further privations. These might include abuse, which may be financial, physical, sexual, through their being forced to work or contribute unreasonably by their new ‘carers’, or through the misappropriation of their parent’s money, land or property; the inability to satisfy their nutritional needs, through lack of resources and poor care; or serious medical challenges. Should the children themselves be infected, they may have HIV-related illnesses to contend with, and in all probability without the resources necessary to obtain medicine and care. The World Health Organization (WHO) estimates that children are underrepresented in their access to the necessary drugs to deal with the effects of HIV<sup>8</sup>. Even if they are not themselves infected, there are all too often great disparities in health status between OVC and non-affected children. As the statistics for orphans’ education show so clearly, each one of these issues impacts on children’s ability to claim their right to education.

## Why education is important

Two main arguments can be put forward for the need to provide education to all children. The first, as laid out above, is because it is a fundamental human right. Every child must be enabled to claim his or her right to education. To deny these rights to so many children, through no fault of their own – when the governments of rich and poor nations alike are in a position to do so much – is inexcusable.

The second, in the context of HIV, is a more simple question of ethics. To deny OVC basic education is to deny them the knowledge, life skills and ability to identify and avoid risk that might protect them and those around them from HIV. It is also to deny them the further skills that might allow them to build a future for themselves and their families, when poverty and a lack of education are strongly linked. It is to deny young girls the education and awareness necessary for them to realise the importance of gender equality and the ability to negotiate their own sexual behaviour, and therefore to increase massively their vulnerability to HIV; and it is to propagate the cycle of poverty, ignorance and gender inequality that has caused HIV to spread so rapidly. Essentially, it is to ensure the survival of HIV at the expense of the survival of many of these children.

The problem therefore is well known, and the impact of HIV on children’s education is not disputed. More important than explaining problems, though, is the matter of providing solutions. A short paper is insufficient to explain in detail how to guarantee education to the world’s OVC, even if we already had all the answers; but many of the key issues are well known and easy to outline.

## Before- and after-school care

School is of little use to you if you are so exhausted that you take nothing in, or face regular beatings for falling asleep in class. It is

also difficult to study when you are so hungry all day that you feel like you’re going to faint. The simplest of interventions can ensure that education becomes an experience that actually provides the benefits intended, rather than being a trial to be endured or a pointless expenditure of time and money. Providing breakfast for children who have not received a meal at home, for instance, so that they can then go on to make the most of the learning day. Or, after school, offering mentoring or other social support, so that children have a safe environment in which to do their homework and are protected as far as possible – even if only briefly – from outside chores and other responsibilities. Such programmes can also be adapted to offer more specialised psychosocial support and trauma counselling, or help detect signs that children are being abused.

## Community schools

Community schools are often not formal schools, but rather education run from within the community, sometimes run by community members, but paying special attention to input from the young people they benefit. Staff members often have a background that includes some form of youth and social work, and so are able to take a more holistic approach to education, which ought to be of greatest benefit to OVC. This type of education is more accessible to young people affected by HIV, whether through being orphaned, being sick, being forced by circumstances to work for part or all of the day, having to care for siblings, and so on.

## Extra support for children who have missed out on education

It may seem obvious, but it is often not done: OVC returning to school – after, for instance, the deaths of their parents, or a stint looking after their younger siblings – need, and deserve, additional support. Such support could come in the form of specialised tutoring to get them back on track academically; a watchful eye from the staff to ensure that they are coping with loss or stress; or even just a little additional understanding and a few breaks here and there. Academic excellence is not to be expected immediately from bereaved children returning to schooling after a long absence. Such considerations are often so basic they are overlooked. Christian Aid (CA) backs programmes providing this type of support in a number of countries, including those recovering from recent conflict, where such problems are often exacerbated.

## Post-conflict settings

In post-conflict countries – such as Sierra Leone, Democratic Republic of Congo (DRC) and Mozambique, in each of which CA has partner programmes providing educational support to OVC – many children affected by HIV have also missed out on education during the war years. The effects of long-term violence and social disruption add to (and often compound) the effects of HIV on young people, and such children have an urgent need for additional tailored support to get them back into mainstream education, or to provide them with life skills and vocational training.



## Case Study – Zambia Keeping parents alive

Almost a million Zambians are now estimated to be living with HIV, and as a result there are approximately 570,000 Zambian children orphaned by HIV. Many are serial orphans: that is to say, not only have they lost one or both parents, but their first and second sets of carers too – either due to old age (in the case of grandparents) or due to HIV-related illness.

One of the most important ways to prevent this is to provide treatment and support for parents living with HIV. The Catholic Archdiocese of Lusaka (CADL) runs a home-based care

programme working with chronically ill people, many of whom are living with HIV. Neighbourhood groups work within their communities to provide medical and nursing support and help with practical tasks like collecting water, washing and cleaning. All projects are given training on how to care for people with HIV and how to give pastoral support. Welfare assistance consists of food, drugs and support for medical investigations. CADL has thousands of volunteers working in 60 registered projects, caring for over 12,000 people living with HIV. The project also provides HIV education, with the aim of helping people to avoid HIV and remove the stigma and discrimination faced by individuals and families living with it. CADL also supports OVC themselves to attend school by paying for school fees, uniforms and other school requisites, and by supporting vocational skills training for older children.



**Background to photograph:**

*Gertrude’s mother Patience is HIV positive. Her father has already died. ADL carer Vincent helps Patience stay healthy. For now, Gertrude still has her mother to look after her, but without access to life-saving anti-retroviral drugs, Patience will die. She worries about who will take care of her 6 children when she is gone, but she also says that without Vincent’s support, she would be dead already.*

*Photographer: David Rose  
Partner: Archdiocese of Lusaka (ADL)*

### HIV statistics and primary and secondary school attendance for Zambia

Orphans due to AIDS (0-17 years)	710,000	
HIV Prevalence (15-49 years)	17%	
People living with HIV under 15	130,000	
People living with HIV 15+	1,000,000	
Under 5 mortality rate (per 1000)	Male: 96	Female: 93
% School attendance	Orphans: 73	Non-orphans: 78
% Primary education	Male: 96	Female: 93
% Secondary education	Male: 47	Female: 42

Sources: UN, UNAIDS, WHO

## Case Study – Jamaica HIV prevention for disenfranchised young people

Children & Community for Change (3Cs) works with the communities of Mandela Terrace and Spanish town, deprived areas of Kingston. HIV is a growing problem in these communities and in Jamaica as a whole, and is very closely associated with poverty and sex work. Children whose parents have HIV are often victims of severe stigma, and poor disenfranchised children have been shown to be at risk from HIV infection.

The programme run by 3Cs provides support to parents as well as children. The project works in poor urban communities, with children who are disadvantaged and who have often missed school. A high proportion is semi-literate. Many have been abused by family members and have experienced violence, and can be aggressive themselves as a result. Often the children's parents are single, unemployed and poor. 3Cs assists both children and their parents within their communities, supporting them to achieve academically (thus also helping improve their self-esteem) and helping them protect themselves from HIV.

3Cs runs after-school homework programmes, and also uses this time to talk about such issues as HIV and violence. To help them reach young people, they use music to educate: peer educators go to communities in poor urban areas and set up a sound system, get an audience together and perform songs about social issues, including HIV, domestic violence and self esteem. 'We do drumming, dance and other areas of the performing arts,' says Cebert Hines, 3Cs Director, 'as a major strategy in HIV prevention, and also building up the self-esteem of the kids'.



3Cs also employs art therapy to allow children to express how they feel about such issues as family, community, relationships and sex. Rachele Anderson, 20, works as a Peer educator for 3Cs. 'It's good for young people to come to 3Cs,' she says, 'to make them more aware – educate them so that they know when they are ready [for sex], as well as the right and proper way of doing it'.

### HIV statistics and primary school attendance for Jamaica

HIV Prevalence (15-49 years)	1.5%	
People living with HIV (15+)	25,000	
Under 5 mortality rate (per 1000)	Male: 21	Female: 19
% Primary education	Male: 94	Female: 95

Sources: UN, UNAIDS, WHO



**Case Study – South Africa** Supporting child-headed households and grandmothers



*Nomfundo Majola, 18, nursed her father, mother and baby sister as they died of HIV. Now she's looking after five younger brothers and sisters. Thandanani takes clothes and food to the family, and also focuses on helping Nomfundo to cope emotionally, making sure she has the time and space to grieve.*

*Photo: Christian Aid/Jodi Bieber*

More than one in five adults in South Africa is HIV positive, and HIV has left more than a million South African children orphaned. Many grandparents and older siblings are now taking on the responsibility of looking after them.

*Thandanani* is a Zulu word meaning 'love each other'. Thandanani Children's Foundation provides support for children in and around Pietermaritzburg who have been orphaned by HIV. Through child-care committees made up of local volunteers, Thandanani helps orphaned brothers and sisters to stay together in their own home, minimising as far as possible the disruption caused by their becoming orphans. Through the use of residential 'therapeutic weekends', Thandanani also provides emotional support for grieving children.

Volunteers visit the orphaned families regularly, taking on the role of 'surrogate parents' wherever needed. They provide practical help, such as food parcels and school uniforms, as well as helping orphans to link up with the state-run services, such as school fees exemptions, which are there to help them. Thandanani volunteers also help orphans and grandparents with the paperwork needed to obtain documents, such as birth certificates. Thandanani volunteers currently support more than 1,400 children.

Thandanani is also involved directly with education. Many currently-supported families include pre-school children; Thandanani looks after them during the day, enabling their older brothers and sisters to attend school. For younger children, Thandanani provides direct support for – at time of writing – seven early learning centres run by local volunteers. These centres provide care and education for many children aged up to six years.

**HIV/AIDS statistics and primary school attendance for South Africa**

Orphans due to AIDS (0-17 years)	1,200,000	
HIV Prevalence (15-49 years)	18.8%	
People living with HIV under 15	240,000	
People living with HIV 15+	5,300,000	
Under 5 mortality rate (per 1000)	Male: 72	Female: 62
% Primary education	Male: 89	Female: 89

Sources: UN, UNAIDS, WHO

**Case Study – India** Providing care and support for young women living with HIV

India is the country with the second largest population of people living with HIV, after South Africa. Women involved with sex work constitute one group that is particularly vulnerable to HIV.

Christian Aid (CA) partner Sanlaap is based in Calcutta, West Bengal, and provides psychosocial counselling for children and victims of abuse. It runs a centre, the SNEHA centre (*Sneha* means 'love and affection'), in which young HIV-positive girls are cared for and eventually enabled to return to their communities. The centre provides a home for young girls who have been rescued from trafficking, 16 of whom – at time of writing – are HIV positive. Sanlaap tries to re-integrate the girls back with their families where possible, and provides them with antiretroviral therapy to treat their HIV infection. The girls discuss their CD4 counts, and the counsellor encourages them to ask questions of the doctor about their treatment.

Sanlaap also has 14 drop-in centres in the red light areas of Calcutta; these work with women, children and youth, raising awareness of such issues as HIV whilst providing non-formal and supplementary education, vocational training and a safe place to play.



*Sanved dancers from Sanlaap perform at the House of Commons. The creative language of dance is used as a form of therapy, advocacy and artistic expression, and highlights the issue of women and child exploitation in India.*

*Photo: Christian Aid/Judith Escibano*

**HIV statistics for India**

HIV Prevalence (15-49 years)	0.9%	
People living with HIV under 15	120,000	
People living with HIV 15+	5,600,000	
Under 5 mortality rate (per 1000)	Male: 81	Female: 89

Sources: UN, UNAIDS, WHO



## Counselling for teachers to help them cope with OVC

It is as well to remember the teachers from whom all this extra care is expected, or by whom new measures must be implemented. Not every teacher is qualified to provide trauma counselling – indeed, the overwhelming majority are not. Teachers can often, without necessarily knowing it, add to the burden of OVCs – by punishing them for absences or lateness, for example, when they have in fact been looking after a sick parent; or by sending them home if they do not have the correct uniform, which they are unable to afford.

In Zimbabwe, CA supports a counselling programme for primary school teachers, which has resulted in a significantly higher school attendance amongst OVC. Following the training the teachers received as part of the programme, they were able to recognise the needs and vulnerabilities of the OVC they taught. As a result, the children felt supported rather than discriminated against.

Where a public health crisis forces populations to demand more from its professionals, it is up to governments, donors and non-governmental organizations (NGOs) to recognise the need to support them. It is impossible to establish dedicated counselling centres, for instance, in every small community; but with the appropriate support (and training where necessary), community figures such as teachers and religious leaders can do much to ease the path of OVC back into functional education.

## Coping with traumatised/disenfranchised children

The effects of HIV on children include many different kinds of exposure to traumatic experiences, some of which have been listed above. It is also well documented that the psychological effects of trauma and the disenfranchisement so often caused by bereavement, family upheaval or social problems can make it difficult for children to fit in or study well in school. Children may become difficult to manage for poorly equipped or inexperienced teachers. Support systems that acknowledge the effects of such trauma on children need to be in place, both for the children and for the untrained professionals whose task it will necessarily be to manage their education.

## Drug use and alcohol

Intravenous drug use with shared needles is one of the most efficient ways possible of spreading HIV, and the children who are at risk – street children in particular – need to be made aware of the risk factors; but alcohol and substance abuse of other kinds can also affect young people's risk of acquiring HIV. Such substances can reduce inhibitions and lead to high-risk sexual practices among young people. Few programmes exist which address this issue outright, particularly in developing countries.

## Sexual coercion by teachers

Although this can be a problem anywhere in the world, in any social context, it has been well recognised in high-prevalence HIV-affected settings, with higher-than-average populations of

vulnerable children and young people. Safety systems need to be in place for prevention and detection of sexual abuse of children of any kind, designed with an understanding that the emotional, financial or even nutritional needs of children affected by HIV can make them especially vulnerable to abuse.

## Child-headed households

As previously mentioned, the deaths of parents can leave children in charge of their households, with younger siblings, land and property to look after – making survival a daily struggle. The demands on time and money are huge, and young people are ill-equipped to meet them. All possible help, whether from NGOs, community-based organizations (CBOs) or through direct government support, must be given to such households.

## Street children

The number of child-headed households and street children in many countries has increased due to HIV, particularly in sub-Saharan Africa. These children are easily exposed to exploitation, violence and abuse. Innovative methods are urgently needed to support and protect OVC in these situations – particularly girl orphans and child mothers, who are frequently subject to sexual exploitation and violence.

## Gender equality

Education is especially important for girls – or rather, it is imperative, given the odds which are stacked against them, that girls are given a genuinely equal opportunity to pursue their education. Globally, more women than men are infected with HIV and in some African countries (Lesotho, for instance, or South Africa), HIV prevalence for women aged 15–24 is over twice that for men of the same age<sup>9</sup>. Women are at greater risk of contracting HIV from a given sexual encounter, a situation made all the worse for a huge imbalance of power in favour of men as far as negotiating sexual behaviour is concerned – something true all across the world. Education – and, quite specifically, clear, accurate, evidence based and non-ideological sex education – can give girls the chance to inform themselves about risk behaviour and learn how to avoid making themselves vulnerable to HIV.

Given the sometimes staggering statistics of the HIV epidemic, it occasionally seems surprising that societies have not totally collapsed. With morbidity and mortality as high as they are, the outlook for children in some countries can look bleak. The numbers, however, fail to tell the full story: CA's experience on the ground, time and time again, is that millions of children infected, affected or orphaned by HIV do in fact receive loving care from their relatives and wider communities, within those communities, and that these efforts all too often do not show up on the statistical radar of governments or NGOs.

It is the duty of governments and civil society, then, to make this caring job easier; to recognise the needs of OVC and to respond to them in whatever ways possible. OVC cannot be left at the bottom of the heap for lack of a voice or the means to push for their needs. Carers and teachers must be identified, supported and trained, and children must without exception be given the opportunity to pursue their education. Despite the best intentions



of those who do take up the duty of care, the reality, as far as education is concerned, can fall far short of the schooling that could be provided with adequate government or outside support.

Education, whether it be academic or vocational, is the best and most effective means of allowing a child to realise their potential. It is the duty of those in power, and those with the means, to make it available to all – and not only primary education, but secondary and tertiary education as well. The investment is not just in individuals, or even in their communities – education will also benefit countries in the long run.

## Endnotes

- 1 UN Declaration of the Rights of the Child, proclaimed by General Assembly resolution 1386(XIV) of 20 November 1959. <http://www.unhchr.ch/html/menu3/b/25.htm>
- 2 UN Convention of the Rights of the Child. 61st Plenary meeting, November 1989. <http://www.un.org/documents/ga/res/44/a44r025.htm>
- 3 [www.un.org/millenniumgoals](http://www.un.org/millenniumgoals)
- 4 UNAIDS 2006
- 5 United Nations General Assembly 2006: Declaration of Commitment on HIV/AIDS: Five Years Later.
- 6 United Nations General Assembly 2006: Declaration of Commitment on HIV/AIDS: Five Years Later.
- 7 UNICEF & UNAIDS 2006: Africa's orphaned and vulnerable generations.
- 8 Progress on access to global Antiretroviral Therapy: A report on "3 by 5" and beyond (March 2006). Geneva, World Health Organisation and UNAIDS.
- 9 UNAIDS 2006.

## Biographical notes

**Dr Rachel Baggaley** is head of the HIV unit for Christian Aid and is honorary research fellow at the London School of Hygiene and Tropical Medicine. She is a medical doctor and has worked on HIV since the late 1980s. She spent six years in Zambia coordinating voluntary counselling and testing and care services for Kara Counselling and Training Trust. She then worked with the World Health Organization (WHO) in Geneva on antiretroviral treatment and prevention of mother to child transmission issues. She now coordinates HIV work for Christian Aid (CA), a British-based international development agency. CA supports 190 community-based partner organisations working on HIV prevention and care interventions, including community care for orphans and vulnerable children affected by HIV.

## Resources

### General

- UN Convention on the Rights of the Child [www.unicef.org/crc/](http://www.unicef.org/crc/)
- The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS [www.unicef.org/aids/files/Framework\\_English.pdf](http://www.unicef.org/aids/files/Framework_English.pdf)
- State of the World's Children, 2005: Childhood Under Threat [www.unicef.org/publications/files/SOWC\\_2005\\_\(English\).pdf](http://www.unicef.org/publications/files/SOWC_2005_(English).pdf)
- State of the World's Children, 2006: Excluded and Invisible [www.unicef.org/publications/index\\_30398.html](http://www.unicef.org/publications/index_30398.html)
- Children on the Brink, 2004 [www.unicef.org/publications/index\\_22212.html](http://www.unicef.org/publications/index_22212.html)

### Involving children/child protection

- Ethical Approaches to Gathering Information from Children in International Settings [www.popcouncil.org/pdfs/horizons/childrenethics.pdf](http://www.popcouncil.org/pdfs/horizons/childrenethics.pdf)
- Setting the Standard: A common approach to child protection for International NGOs [www.peopleinaid.org/download/Setting%20The%20Standards.pdf](http://www.peopleinaid.org/download/Setting%20The%20Standards.pdf)
- Children as Partners in Planning [www.savethechildren.org.uk/scuk/jsp/resources/](http://www.savethechildren.org.uk/scuk/jsp/resources/)
- Global Movement for Children [www.gmfc.org](http://www.gmfc.org)

### Community-based care

- Orphans and Other Vulnerable Children Support Toolkit [www.ovcsupport.net](http://www.ovcsupport.net)
- Building Blocks: Africa-wide briefing notes [www.aidsalliance.org/sw9170.asp](http://www.aidsalliance.org/sw9170.asp)
- Community-Based Care for Separated Children <http://se-web-01.rb.se/Shop/Products/Product.aspx?ItemId=398>
- Restoring Playfulness <http://se-web-01.rb.se/Shop/Products/Product.aspx?ItemId=361>
- The Journey of Life [www.repssi.org](http://www.repssi.org)
- Roofs and Roots [H.Abuzaid@scfuk.org.uk](mailto:H.Abuzaid@scfuk.org.uk)
- Facing the Crisis [www.savethechildren.org.uk/scuk/jsp/resources/](http://www.savethechildren.org.uk/scuk/jsp/resources/)

### Faith-based resources

- A matter of belonging: *How faith-based organisations can strengthen families and communities to support orphans and vulnerable children.* A UNICEF/Christian Aid/Islamic Relief handbook [www.christian-aid.org](http://www.christian-aid.org)
- What Religious Leaders Can Do About HIV/AIDS: Actions for children and young people [www.unicef.org/aids/files/Unicef\\_HIV\\_Aids.pdf](http://www.unicef.org/aids/files/Unicef_HIV_Aids.pdf)