



# Violence against children affected by HIV/AIDS

a case study of Uganda

A contribution to the United Nations Study  
on Violence Against Children

World Vision International – Africa Office

June 2005

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Front cover drawings by orphaned Ugandan children who participated in this research

# **Violence against children affected by HIV/AIDS**

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on Violence Against Children**

**Report compiled by**

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and  
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**June 2005**

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Amboka Wameyo  
Africa Regional Advocacy Advisor

### **A note about children's names in this publication**

All the names of children have been changed to protect the identity of children.

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## Abbreviations and acronyms

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<b>ADP</b>	Area Development Programme, a World Vision–defined area of operation comprising 10–40 villages covering one to three sub-counties with populations ranging from 20,000 to 100,000 people. The overall objective of the ADP is to empower local communities to be able to meet their needs in the context of a caring community, with special emphasis on children. The ADP has a lifespan of 10–15 years.
<b>CCC</b>	Community Care Coalition
<b>CRC</b>	UN Convention on the Rights of the Child
<b>IPTG</b>	Inter-Personal Therapy for Groups
<b>OVC</b>	orphans and vulnerable children
<b>PRA</b>	Participatory Rapid Appraisal
<b>Ush</b>	Ugandan shilling (one US dollar equals approx. 1,700 Uganda shillings)
<b>USD</b>	United States dollars



## Background

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### The UN Study on Violence Against Children

In 2001 November, the United Nations General Assembly requested the Secretary-General to conduct an in-depth study on violence against children. The General Assembly's request provides a unique opportunity to expose the extent of the problem and identify safeguards to better ensure protection of children from violence. The study is rooted in the understanding that children have a fundamental right to protection from all forms of violence, and aims to promote action to prevent and eliminate violence against children at international, regional, national and local levels. As a consequence the study covers all forms of physical or mental violence, injury or abuse, neglect and negligent treatment, including sexual abuse and bullying in schools.

The approach to violence adopted in the UN Study is in line with the World Health Organisation's definition of violence: "the intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation".<sup>1</sup>

Thus, the nature of violent acts can be physical, sexual, psychological, involving deprivation or neglect. The intentional use of the word 'power' in this definition ensures the inclusion of acts that occur as a result of intimidation or threats. In addition, the WHO definition can be interpreted both as violence occurring as a result of commission (for example, actual beating or abuse), and as violence by omission (neglect).

It is hoped that the UN Report on Violence Against Children, when launched in 2006, will:

- assert the right of all children to protection from all forms of violence, and the need for effective human rights mechanisms and legal frameworks at international, regional and national levels to promote and safeguard this right;
- draw attention, through the UN General Assembly and other international, national, and sub-national mechanisms, to the scale and nature of violence against children, especially less visible forms;
- motivate States to fulfil their obligations to protect children and make commitments with regard to prevention, intervention and recovery related to violence against children;
- expand and activate dynamic and effective networks and partnerships directed at the elimination of violence against children, at international, national and local levels; and
- expand dynamic key networks and processes to support and partner with States to respond to the situation of violence against children.

### World Vision involvement in the Study

Through many years of working for children's rights, World Vision understands the detrimental effect of violence on children. In 2001 World Vision launched a campaign titled 'Imagine a World where Children are Safe' which drew attention to the violence suffered by children around the world.<sup>2</sup> This campaign taking place across different levels helped boost our national advocacy to end child abuse in Africa. Through our Area Development Programmes,

World Vision offices have undertaken research on child abuse, sexual violence and exploitation, neglect and deprivation, and used it to influence national responses to end abuse of children and to promote positive prevention and response models.

It is with this previous experience, underpinned by our corporate vision for a world in which children experience fullness of life, that World Vision engages with the

UN Study.

World Vision acknowledges the fundamental right of children to participate in their own development and to be key partners in finding solutions to problems that face them. To this end, World Vision determined to specifically document the voices of children on both their experiences of violence and their understanding of strategies to address violence.



## Definitions and scope of study

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From February to April 2005, World Vision Africa conducted participatory research to examine the nature of violence, including psychological abuse, against orphans in parts of Uganda devastated by the HIV/AIDS pandemic. This report is a summary of the main findings from that research. It highlights:

- the types, causes and psychological impact of stigmatisation of and discrimination against orphans;
- World Vision programme responses to orphans and vulnerable children; and
- recommendations for dealing with violence and abuse against children affected by HIV/AIDS.

### Violence, stigma and discrimination

Stigma and discrimination have been associated with HIV/AIDS since it first emerged. Often referred to as the 'third epidemic' (the first two being HIV and AIDS), stigma and discrimination are the social consequences of the fear generated about the disease in individuals and societies.<sup>3</sup> Stigma is the mark of disgrace or discredit, while discrimination is the negative action following from this belief.<sup>4</sup>

Stigmatisation causes psychological harm in children and is a form of violence. When children are stigmatised they are set aside and prevented from having normal interpersonal relationships with others. Often they are made to feel that there is something wrong with them and that they are worth nothing. While children are usually stigmatised by those with economic and mental power over them (including guardians, teachers and relatives), other times they are stigmatised by fellow children who have been influenced by those with power. Stigmatisation is violence

because it is the "intentional use of power ...that results in...psychological harm".<sup>5</sup>

Central to twin concepts of stigma and discrimination is the notion of unfair and unequal treatment that leads to neglect, which is also defined as violence in the context of the UN Study. Acts of discrimination contravene articles of international legal instruments, particularly the United Nations *Convention on the Rights of the Child* (CRC). The four founding principles of the CRC are non-discrimination (article 2), the best interests of children (article 3), the right to life, survival and development (article 6) and children's right to participate in decisions that affect him/her (article 12).<sup>6</sup>

### Uganda, the study area

Uganda is a country continuing to grapple with the devastating effects of HIV/AIDS more than two decades after the first incidence was recorded. It has been estimated that over the past 20 years, one million people in Uganda have died from AIDS while there are currently one million living with the disease.<sup>7</sup> The consequences of the spread of HIV/AIDS in Uganda have been extensive, affecting the social, economic and political spectrums of society. Health services have been stretched and the available workforce reduced along with agricultural productivity.

One of the most visible consequences of HIV/AIDS is the presence of orphans. An orphan is defined as a person less than 18 years of age who has lost one or both biological parents.<sup>8</sup> It is estimated that in Uganda there are currently two million orphans in total, which accounts for 14% of children;<sup>9</sup> the AIDS Commission attributes an estimated 1.7 million of these to HIV/AIDS.<sup>10</sup>

## World Vision in Uganda

World Vision Uganda seeks to address causes and effects of poverty through development, relief and advocacy. Through sponsorship of 80,000 children, World Vision Uganda is able to provide educational support, construct and equip schools and health centres, train health workers and contact farmers, participate in advocacy campaigns, distribute improved crop varieties and animal breeds, and provide clean and safe water. World Vision Uganda's programmes are also funded through donor grants.

World Vision started working in Uganda in 1986, assisting communities in the 'Luwero Triangle' in central Uganda to resettle and rebuild their infrastructure after the 1981–1986 war. Activities extended to Arua and Nebbi districts in north-western Uganda to address poverty and the lingering destruction from the 1978–1979 war. World Vision then moved into Gulu in 1988 commencing relief programmes for internally displaced people at the start of the ongoing conflict in northern Uganda.

Hoima and Masindi districts, in western Uganda, were the next areas to come on board with the initiation of projects to tackle poverty and health problems. Then, in 1991, projects were started to address HIV/AIDS problems and to support orphans in Rakai and Masaka in southern Uganda.

Responding to the famine at Kamwezi in Kabale in 1993 was World Vision's entry point into south-western Uganda. The organisation moved to the eastern region in 1995 with a project in Soroti to tackle the effects of cattle rustling and rebellion.

Today World Vision has 36 sponsorship projects in Area Development Programmes and a further 30 grant-funded projects, working in 18 of Uganda's 56 districts. The organisation's fundamental strategy is to empower communities to take charge of their own development.

This research study on the nature of violence against orphans was undertaken in Masaka district in southern Uganda where the devastation caused by HIV/AIDS is very visible. Two Area Development Programmes in this district were selected: Kaswa and Kyanamukaka.

In Kaswa, a Community Care Coalition programme (see box) has been piloted and is now well established. In Kyanamukaka, a programme of Inter-Personal Therapy for Groups (IPTG) for adults infected and affected by HIV/AIDS is in place.

Within each ADP a 'parish' was chosen for the focus of the research, with participants residing in this area. In Kaswa, the parish was Kisansala in Kingo sub-county. In Kyanamukaka, Kamwozi was the parish, in Buwunga sub-county.

### Community Care Coalitions

A Community Care Coalition comprises people who come together to coordinate care for orphans and vulnerable children. These coalitions are known by a variety of names including 'OVC care committees' and 'Child welfare committees'. Typical members of the coalitions are churches and other faith-based organisations, teachers, community leaders, people living with HIV/AIDS, traditional birth attendants, home-based care providers, health care providers, guardians of orphans and vulnerable children (OVC), development committee members and community-based organisations.

The central role of the coalition is to mobilise and coordinate OVC care activities including home visitation and care, nutritional support, psychological and spiritual support, home-based care of children and adults, provision of bursaries and school materials/equipment, HIV/AIDS prevention, de-stigmatisation of people living with HIV/AIDS and OVC, child protection and advocacy.

## Methodology

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A Participatory Action Research approach was taken in this study. Working consecutively in each ADP, five research tools were used for the purposes of triangulation: a literature review, observations, in-depth interviews, focus group discussions and Participatory Rapid Appraisal (PRA) tools.

In each ADP, interviews were held with eight orphans aged 11–15 years (see Appendix I case studies), four non-orphans aged 11–15 years, four guardians of orphans, four teachers from two different schools, two World Vision staff members, identified community leaders including a pastor and council member, and two other NGO workers. Interviews were also held with World Vision staff in the Africa Regional Office, Kenya and Uganda national offices. In all categories (except community leaders and World Vision staff), equal numbers of males and females were interviewed.

Children attending and children not attending school were interviewed. All children interviewed were asked to respond to nine true/false statements about orphans.<sup>11</sup> The children interviewed included

included both children sponsored and children not sponsored through World Vision programmes.<sup>12</sup>

A 'community advisory group' in the form of the parish Community Care Coalition in each ADP was established. A focus group discussion was conducted with the CCC at the commencement and conclusion of the research to ensure community ownership of the findings and recommendations. A focus group discussion was also held with a peer support group of people living with HIV/AIDS.

Group workshops – two sessions each using PRA tools – were conducted with a group of eight (four male, four female) orphans aged (i) 5–10 years and (ii) 11–15 years. One workshop session was conducted with non-orphans aged 11–15 years. These sessions were undertaken at two different schools in each ADP. Each session included singing and picture drawing (their homes before/after parent died and what makes them sad/happy), followed by discussions<sup>13</sup> (see Appendix III for examples). They were also asked to respond to the same true/false statements as the children interviewed.

### **True or false statements**

1. Orphans are given more work than other children in the family.
2. Orphans often get harsher punishments if they make a mistake.
3. Orphans are given less food to eat than the rest of the family.
4. Orphans do not go to school for economic reasons.
5. Orphans are not allowed to eat with the rest of the family.
6. Some people believe that orphans caused the death of their parents.
7. Some people believe that orphans will misbehave and die from AIDS like their parents did.
8. Some orphans run away to live on the street because things at home are so bad.
9. Girl orphans are more vulnerable to sexual abuse than other children.

## Findings and discussion

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### Stigma and discrimination

The initial response from participants to the research was often that stigma and discrimination against orphans of HIV/AIDS was not a problem in “our” home, school or community. However, as rapport was built the problem was revealed, with widespread consensus, to be significant.

Of the 16 orphans interviewed, 14 agreed that it was a problem while all 16 were able to give examples of discrimination (13 related to personal experience). In the group workshops, 29 of the 32 participants agreed that it was a problem. Six of the eight non-orphans individually interviewed said that it was an issue, while all could provide examples. In workshops with non-orphans, only two did not believe orphans to be discriminated against. All but one of the eight guardians interviewed thought it was an issue and provided examples (although none themselves admitted to discriminating). All teachers, community leaders and World Vision staff agreed that it was a problem. The Local Council 3 Chairman<sup>14</sup> for Kyanamukaka estimated that 98% of guardians discriminate against orphans in their care. A pastor interviewed in Kaswa approximated that it was an issue in at least 85% of such households.

Stigma was articulated in terms of orphans being a “burden” to the community, with growing numbers and limited resources available to care for them. Without parents to look after them, they were seen as “on their own” and ultimately needing to care for themselves. Orphans were described as looking visibly different to other children by guardians, teachers, community leaders, other children and themselves. It was stated, for instance, that orphans generally do not look cared-for, with poor clothing (often without a school uniform) and poor

health and hygiene shown by the presence of lice, jiggers (flea larvae) or symptoms of AIDS. It was also stated that orphans were quiet, often seemed sad and tended to keep to themselves, in contrast to other children. This is psychological abuse that is a direct result of stigmatisation.

Self-stigma was expressed in different ways by orphans. Some stated fears about how their peers would relate to them if their parentless status and association with HIV/AIDS were revealed. They said that they felt different and self-conscious about their status as orphans. For instance, in a workshop held with orphans aged 11–15 years, it was briefly clarified at the beginning with participants that all those present had lost one or both parents. A few minutes later, they were offered the chance to ask questions, to which a boy queried: “How did you know I was an orphan?” In an interview with a girl orphan, she said that going to church is difficult because other children are there with their parents while she only has her siblings. As she lives far from where she attends church, the other children don’t know what happened to her parents and she avoids discussion with them about it.

Discrimination or unequal treatment of orphans in comparison to other children was found to exist as a manifestation of stigmatisation in a number of places. There was widespread agreement that discrimination was present in the family home where guardians (aunts, uncles, grandparents, older siblings) and children (cousins, step-siblings) treated orphans differently. Step-mothers were repeatedly reported as discriminating against orphans whose mother was a deceased wife of their husband. Discrimination was also stated as a concern at school, where other children, and sometimes teachers, mistreated them.

In communities where children were known to be orphans, they were thought to be vulnerable, without parents to protect them, to poor treatment from community members. The different types of discrimination reported were covert as well as overt and both direct and indirect. Project participants described different forms of abuse and violence that resulted from stigma and discrimination. They were rarely reported in isolation: physical abuse, for instance, was often suffered alongside emotional abuse and child labour.

### Physical abuse

Physical abuse was revealed as a direct result of discrimination. There are reports of orphans being slapped and caned with sticks and logs, with guardians and children at home and school reported as inflicting this violence against orphans.

Caning and hitting children as a form of punishment is to a certain extent culturally accepted. However, the physical treatment of orphans was described as violent, and as being different to the treatment received by other children because of its greater frequency (daily to monthly) and severity. Also, the motives were different and understood to be the guardians' anger and frustration about having to care for the orphans when their resources were limited. Specific reasons (where provided) motivating the abusive punishment by guardians included bed-wetting, late return home from school, slow completion of household chores, and mistakes such as dropping food or losing a container. Where other children delivered the violence, the motives and reasons were reported as anger over having to share their homes and parents with orphans, and a fear of orphans because of their association with HIV/AIDS.

*A drawing by a 13 year-old boy during a focus group discussion, in which he illustrates being chased and hit by his elder brother (guardian) with a hoe and being hit by children at school who tease him.*



**Case study: 'Blessed Hope'**

'Blessed Hope' is a 14 year-old orphaned girl who lives with her paternal aunt, uncle, two younger male cousins and one younger sister. She stated that she gets into trouble and is beaten more frequently than her cousins. If she makes the same mistake as her cousin (e.g. losing a school book), she will get beaten by her aunt yet her cousin will not. 'Blessed Hope' also told of her friend at school whose guardian heats plastic bags on the fire to burn her with. Her guardian does not do this to her own children, only to the orphans she has staying with her. 'Blessed Hope' and her friend think she gets treated like this because she is an orphan and her guardian does not want to care for her.

**Case study: 'Frank'**

'Frank' is 49 years old and lives with his wife and nine children, four of whom are orphans. He told of how his adult brother, also a guardian, had previously beaten an eight year-old orphan in his care. After his brother admitted he was planning to kill the orphan, 'Frank' intervened and made arrangements for the orphan to live with him. He also shared how his grandparents had struggled as guardians for his two orphaned nephews. They would go out and drink, and if the chores were not done when they came home they would abuse the orphans. Once when 'Frank' visited his grandparents he found his grandfather strangling one of the orphans. He asked why, and his grandfather said it was because the orphan had cooked him the wrong type of food. He tried to counsel his grandfather to stop, which he did, but then proceeded to beat the orphan ten times. The orphan ran away shortly afterwards.

**Psychological abuse**

Psychological abuse was described as another outcome of discrimination. Research participants defined it as verbal abuse, name-calling, belittling and negative comparisons to other children. The discrimination was present in the words used, tone of voice and non-verbal gestures.

Participants stated that culturally, people naturally talk harshly to children, with little warmth in tone or word choice. However, orphans are spoken to more severely than other children. The abuse was seen as 'psychological' as opposed to simply verbal because the words chosen were intended (negligently or purposely) to affect them emotionally.<sup>15</sup>

**Quotes from orphans of comments made to them by their guardians**

*"You orphan, we are suffering with you. Your mother gave us nothing; now we are stuck with you."*

*"You orphan, you are so stupid. You eat too much when you don't dig."*

*"Why do you come back late from school? You have no mother."*

*"Where will you go now that your father has died of AIDS? Who will pay your school fees?"*

*"Your mother brought AIDS and shame to our family."*

*"It's not me who gave birth to you so why should I spend money on you?"*

*"You child of bad omen."*

*"You are a dead body."*



**Quotes of comments made by other children, at school or at home**

"Go and eat your mother's grave."

"Look at those ones, their mothers died of AIDS. They are going to die of AIDS too."

"You are lazy. Why don't you leave our family and go away."

"How come you got a new house from World Vision when you are only orphans?"

"Your parents died of AIDS."

"You grew by chance. You struggled to grow."

A drawing by a 13 year-old girl in Primary 7, in which she shows her cousin abusing her because she doesn't work enough at home and eats too much. It also illustrates her guardian beating her.



**Case study: 'Prossy'**

'Prossy' is a 14 year-old orphaned girl who lives with her paternal uncle, aunt, two younger male cousins and two younger brothers. 'Prossy' said she doesn't feel good at home because "I know they don't want us there. I know that my uncle doesn't want to look after me and my brothers because he sees us as a financial burden. I can hear it in his voice and the way he talks to us.

My aunt and uncle fight at home. I heard my aunt say to my uncle that it would be easier if she left with their sons so that he could stay behind and suffer with the orphans."

'Prossy' said she feels "so bad", especially when she is verbally abused.



**Case study: 'Joy'**

'Joy' is 15 years old and has lived with her paternal uncle, aunt, one cousin, two step-siblings and one brother since her mother died three years ago of AIDS. Her father died five years ago, also of AIDS, leaving behind three wives. 'Joy' (along with her brother) has AIDS herself, and struggles to attend school regularly because of her illness.

The two step-siblings she lives with and who share the same father are HIV-negative. They abuse her and make comments such as, "You are sick. Don't come near us." At school the other children refuse to sit near her brother, who has bad skin rashes, and they run away when he coughs. Some of the children in her village yell at her, "We don't want to visit your home because there is sickness and disease." They point at her and say, "That girl is sick."

**Neglect**

Neglect by guardians and extended family members was another type of violence revealed. It was characterised by a failure to provide sufficient food, clothing, bedding, educational opportunities, health care and/or protection from harm. In the context of limited available resources, failure to provide for orphans needs was seen as discrimination in relation to what other children received.

The examples of neglect provided were numerous and varied, including:

- guardians taking for themselves or their children goods intended for orphans by NGOs;
- enrolment of orphans in government schools and guardians' own children in private schools; and
- early marriages for girl orphans so that guardians could relinquish their responsibilities early.

The following song, which orphans chose to sing during a focus group discussion, expresses a fear by the orphans that they must work hard for their guardians to ensure their ongoing care:

**Orphans' song**

*"The guardians are expecting  
good things from us.  
They have made us their bank.  
I will try to study hard  
to impress the guardians  
if God is on my side." (repeat)*

Orphans living with AIDS also experience poor access to adequate health care. Uganda Cares, a medical organisation in Masaka, offers anti-retroviral drugs free of charge for sufferers of AIDS in the district.

Dr Penninah Lutung from Uganda Cares stated that of their 1398 patients, only 127 are children (with an estimated 75% being orphans). She believes the reason for such a low attendance rate by orphans is not

poverty, but neglect by guardians unwilling to transport them to the clinic and participate as their required 'treatment buddy'. Of the children who attend, many walk on their own from nearby villages while others are brought to the clinic by

volunteers (including World Vision). One orphan with AIDS who was interviewed stated that prior to being taken to the clinic by volunteers she was unable to attend, because her aunt and uncle (guardians) would not take her.

### Case study: 'Steven'

'Steven' is 14 and has been living with his paternal uncle, aunt and three older and three younger cousins since his mother died of AIDS in 2003 (his father died in 2000).

His younger brother lives with other relatives and he sees him irregularly.

'Steven' says that his guardians compare him negatively to their own children, and think of him last when they give out food, buy clothes or school books. When there is not enough money for all the school fees and books, he stays at home while his cousins still go to school. He sleeps in a sack of cloth while everyone else in the family sleeps on a mattress.

### Child labour

Child labour was reported where orphans undertook excessive and age-inappropriate household tasks. The nature of life as subsistence farmers for many in Uganda is that it requires a significant amount of work to survive. However, it was frequently stated by research participants that orphans were assigned considerably more chores, in number and difficulty, than other children in the house. The practice of orphans doing

jobs for people in their village for minimal pay was also described. Examples included fetching a jerry can of water for 100 Ugandan shillings (six US cents) and digging a plot of land for Ush500 (30 US cents). Orphans were required to do such work to pay for their school fees and books. It was stated that in many cases the child had to give the money to the guardian immediately, and there were occasions when the money earned was not spent on the orphans.

*A drawing by a 10 year-old girl orphan who takes the cows for grazing every morning, making her habitually late for school. She is required to do the majority of housework at home where she lives with her aunt and uncle.*



**Case study: 'John'**

'John' is 13 years old and lives with his maternal grandmother and two younger sisters. His father died of AIDS in 2003, and the last time he saw his mother was at his father's funeral, after which he was told that she went to work in Kampala. His grandmother owns a bar which she makes 'John' work in at night. Sometimes he has to stay home from school to work in the house. His grandmother does not buy his materials for school; he has to do work for neighbours to earn money to buy them.

**Case study: 'Christine'**

'Christine' is a 12 year-old orphan. Following the AIDS-related death of her mother in 2002, she lived with her grandfather (until he died) before moving to her current home, where she stays with her maternal grandmother and great-aunt. She has four brothers and two sisters who live with relatives elsewhere. She preferred living with her grandfather because there were other children there with whom she could share the housework. Some days 'Christine' doesn't go to school because her grandmother keeps her at home to do work. They would like her to stay home from school more than she does. She digs once a week and fetches water six times a week for people in her village, for which she gets paid 100 shillings each time. Her grandmother insists that she does this, as it is the only source of income for the household.

**Sexual abuse**

Sexual abuse, primarily of girl orphans, was another form of violence reported against orphans of HIV/AIDS. One of the true/false statements given to all children interviewed was "Girl orphans are more vulnerable to sexual abuse than other children." More than half of respondents answered this in the affirmative. When asked to explain why

they agreed with this statement, a common response was that girls were targeted for sex because they did not have "parents" to protect them. There were differing opinions as to whether guardians would bother to seek justice if an orphan in their care was sexually abused. Also, it was thought that some orphaned girls don't have a choice but to become prostitutes, since there is no-one to care for or protect them.

**Case study: 'Hope'**

'Hope' is 15 years old and has been living with one older and two younger brothers since her father died of AIDS in 1999 and her mother in 2001. She finished primary school in 2004 and has not attended high school because they cannot afford the fees.

One day last year on her way to school, she met a man who said he wanted to "admire" her. She said no, was scared that she might get pregnant. He "tricked" her into having sex with him and gave her Ush10,000 (USD6.00) in the hope that she would not tell anyone about what had happened. She told her brother who went and told the man to leave her alone. Following the rape, 'Hope' became pregnant and had a baby girl who died one week after birth. A week after the interview, she was visited and found to have a fever and facial rash – common initial symptoms of AIDS.

## Why discrimination?

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Having explored the types of violence to which HIV/AIDS orphans are subject as a result of stigmatisation and discrimination, the various reasons for their discrimination are now discussed. Although complex and numerous, the reasons for discrimination against orphans that participants provided included fear and lack of information about HIV/AIDS, poverty, and cultural and familial practices.

### HIV/AIDS

HIV/AIDS itself was expressed as a cause of discrimination, mostly where an orphan was either known or feared to be infected. A fear of transmission was expressed by some children. One orphan worried about playing with a friend whose history she did not know, while a family caring for an orphan with AIDS feared sharing food or utensils in case they caught it.

Some orphans expressed shame that their parents had died of the disease and, as stated previously, feared that if their peers knew they would be treated differently. Numerous research participants said that the origin of discrimination against infected orphans was the view that they were not worth caring for, since they were going to die anyway.

### Poverty

Poverty and limited resources were offered as the main cause of stigma and discrimination, since the capacity of many guardians to provide for their own children is already challenged. It was argued as a cause even where guardians were known to be relatively wealthy, as they sought to maintain or increase (often with the domestic help of orphans) their own

standard of living. In Masaka, the majority of people are subsistence farmers, reliant on their gardens and products from animals to survive. Where they can produce excess, it is sold to buy other household necessities such as paraffin and salt and, when possible, to pay for school fees.

It is arguably a natural response for parents to want to provide the utmost for their own children. It can be difficult when their ability to do so is reduced by the requirement (planned or unplanned) to care for additional children. While it was agreed that guardians should treat orphans in their care equally to their own children, this was acknowledged as difficult – largely due to poverty, but also emotionally and culturally.

### Familial practices

Familial practices were stated as another cause of discrimination. As the extended family has traditionally provided the social and cultural framework for the community, there has been an expectation that it would assume the care of an orphaned relative. However, the ability and goodwill of the extended family to care is argued to have been increasingly challenged with the rising number of orphans.

The growing presence of child-headed families is evidence of this, with orphans being left to care for themselves without the assistance of extended family. Where extended family members have become guardians, the 'care' has largely only been extended to basic necessities, not emotional or additional physical comforts.

Furthermore, it was repeatedly stated by guardians, orphans and other children that orphans are "on their own" because their parents have died. There was no

expectation that anyone should try to replace or offer an orphan a substitute for his or her parents.

In Uganda, polygamy is a recognised and accepted practice. A man's status and wealth in the community has traditionally been expressed by the number of his wives and children, with greater numbers meaning greater status. There are reports that these practices are changing in light of the AIDS epidemic, and repeated calls have been made locally and internationally for polygamy to be outlawed on the basis that it is discriminatory and causes suffering for women and children. However, in a recent Ugandan newspaper article it was stated that this "may seem unrealistic amid the grinding struggle of daily life in the countryside, or the crass materialism of the cities."<sup>16</sup>

Many of the children who participated in this research spoke of fathers who have multiple wives or children informally with other women. It was argued as a cause of discrimination against orphans of HIV/AIDS on the basis of the often-difficult family dynamics created when a man with multiple wives either dies himself or one of his wives dies. For instance, one girl whose mother

had died spoke of her father who lived in her old house nearby with his new wife and children, while she stayed with her siblings and paternal grandparents.

### **Culture and values**

The culture and values of a community influences people's experience and understanding of, and response, to events. The increasing number of orphans as a result of the HIV/AIDS epidemic has affected family and community relations and values.

Ugandan culture has traditionally seen children as a gift and a resource for the family, as well as an indicator of status and perceived wealth. There has been a change in this perception with overwhelming numbers of children requiring care and a reduced adult presence as a result of HIV/AIDS. Children, particularly orphans, are being viewed now as a 'burden' as extended family members struggle to respond to their needs while also caring for their own children. Greater 'value' is accorded to children who have parents who nurture them and commit resources to their development.

## Conclusion

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This research revealed that stigmatisation of and discrimination against orphans are themselves violence. They also lead to different forms of abuse including physical abuse, psychological abuse, child labour, neglect and sexual abuse. The consequence of discrimination for orphans is that it reduces their scope for development, physically and mentally, as well as in their skills and knowledge. Socially they are excluded through being perceived as “burdens” to their extended and new foster families.

### Reduced human capacity

Stigmatising of and discriminating against orphans, particularly HIV/AIDS orphans, has a detrimental effect on human development (i.e. physical and mental health, knowledge and skills). In comparison to children who have their parents, orphans’ opportunities for development can be significantly reduced.

#### Physical

Orphans’ opportunities for physical development can be limited as they are denied access to health care and adequate food. Depending on the stage of development at which this occurs, the resulting impact on the child can include impaired health leading to reduced physical capacity for work and educational progress.

#### Mental

In terms of mental health, the key message conveyed to orphans is that they are a burden to their guardians and families. They are made to feel different and self-conscious about their orphaned status, which is seen in negative terms. The message conveyed to them in differing ways is that their lives and needs are not worth expending time or resources on. This affects an orphan’s

perception of self and sense of self-worth, and amounts to psychological abuse.<sup>17</sup> In interviews and workshops with orphans, they were asked how the discriminatory treatment made them feel. The common response was that it makes them “feel bad”. They stated that they felt inferior and not valued in the same way as other children who have their parents.

Furthermore, stigma and discrimination compound an orphan’s sense of grief over the loss of their parents, since being made to feel bad about the loss of their parents further reduces the opportunity for them to grieve. One orphan stated that being verbally insulted by his guardians “makes me miss my parents even more”.

Orphans in interviews and workshops were asked what they do to make themselves feel better when they are feeling “bad”. The majority said they would spend time on their own, reading, going for a walk, praying or else going and doing a job for a neighbour to earn some money. Fewer stated they would play (e.g. football) or talk with a friend. Some said they just stayed sad, while others felt that doing these activities made them feel better.

When then asked for ideas as to how to address the issue of discrimination, it was commonly stated that people should stop it because they themselves might one day lose a parent, or die themselves leaving behind children, and they wouldn’t want to be treated in this way. Also, one orphan said that “Those people who discriminate against orphans should stop it, because it is not like they chose to lose their parents.”

#### Knowledge and skills

An orphan’s scope for formal knowledge and skill development is reduced by stigma and discrimination. Compared to non-

orphans, an orphan's chances of attending school are reduced.

One teacher interviewed stated that the number of orphans in class is significantly different in Primary year 7 compared to Primary 1. He stated cost as one reason, with stationery requirements and examination fees increasing with each year level. (The government of Uganda has implemented a 'Universal Primary Education' policy providing free education for all children. However, despite being 'free', money is still required to be paid towards building funds and local materials.)

When they do have the opportunity to attend school, orphans' capacity to study effectively may be reduced due to exhaustion from household chores or poor nutrition.

Discrimination also reduces orphans' chances of attending a good quality school, which is important when the differences between schools' standards is large.

### **Social ecology**

Stigma and discrimination reduce the 'social ecology' (social connections and support) available to orphans. As two orphans reported in interviews, before their parents died of AIDS they would see their aunts and

uncles regularly; now they don't. They both believe that the reason for this is the way their parents died, and that their relatives don't want to help them because they are a burden, especially when they are struggling to survive themselves.

Moreover, where orphans are infected with HIV/AIDS, their social support system is minimised even further because some people still fear catching the disease through social contact.

The burden of working has been transferred to orphans, particularly those who find themselves looking after grandparents. They have taken on responsibilities that otherwise would have been assigned to their parents. The long-term impact of this on the community could be significant.

With reduced opportunities, this generation of orphans will be 'visible' as the ones who are less likely to be educated, employed and owners of land.

It is imperative that efforts be undertaken to improve the life chances of orphans so that the perception of them as a burden is challenged. The onus of caring for orphans needs to be taken away from orphans themselves and "transferred onto the shoulders of society and government".<sup>18</sup>



## Recommendations

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The following recommendations have been developed based on suggestions provided by research participants and in discussion with the Community Care Coalitions in each ADP.

### Training and support

1. Training and support is required for guardians and other children in households where orphans are living. A training package should be developed and delivered to guardians covering issues such as the care and support needs of orphans, changes to family/household, use of the memory book,<sup>19</sup> HIV/AIDS, and managing difficult behaviour.<sup>20</sup>

The CCC and community volunteers should also be trained on these issues, to provide support to the families where orphans are staying and to further monitor situations where orphans are believed to be treated poorly including where they are abused.

In addition, a peer support group could be established for guardians, drawing on the experiences of those who are managing successfully to care for orphans.

### Alternative household model

2. Training of guardians to better care for orphans is the optimal way to address the issue of discrimination. However, it will not be able to improve the situation for all orphans – for example, in instances where guardians are reluctant to change or in child-headed households. Given the seriousness of the issue, an alternative ‘group home’

(not orphanage) model should be developed for consideration. The CCC would be responsible for the oversight of a (self-sustaining) home situated within its parish.

Such a home catering for between four and six orphans would provide a supportive environment, catering for their physical, social, emotional and material needs. Community volunteers would be selected (by the CCC and orphan) and provide weekly and ongoing emotional support and guidance for each orphan in the house.

It would be different from an orphanage in terms of size, community involvement and responsibility for the home.

Funding would need to be provided for the initial establishment costs, such as construction, garden and livestock. However, it is anticipated that within 1–2 years, the home could become self-sufficient.

### Education for orphans

3. In line with the right to basic education, NGO educational support for children (including orphans) attending school ends with the completion of primary school (Primary 7). Yet while this ensures that orphans receive a basic education, it does not equip them with skills or knowledge to enhance their future livelihood prospects. It also does little to address the community perception of orphans as a burden.

Consideration should be given to offering orphans opportunities for further study, including in vocational or high school.

**Increased resources**

4. The recommendations provided here are specific in the sense that they address issues related directly to the problem of discrimination against orphans of HIV/AIDS. Throughout the course of this research, it became clear (particularly through contact with the CCCs) that the issue of limited

resources in the communities needs also to be addressed. Some interviewees suggested that an improvement in the income of local communities might lead to better care for orphans. To this end, training of guardians should be offered in combination with income-generating or micro-enterprise activities.

## Appendix I

### Further case studies

'William' is 12 years old and in Primary Four. Since his mother and father died (unsure how) six years ago, he has been living his paternal aunt, uncle and their three children. He thinks stigma and discrimination against orphans is a big problem.

His cousins are treated better than he is, having clothes bought for them, going to the hairdressers (his aunt cuts his hair) and given chores such as sweeping while he digs. They regularly yell abuse and throw stones at him, for which they do not get into trouble when he reports them to his aunt. When he retaliates, she canes him. If he drops food during dinner he doesn't get any more but his cousins do when it happens to them. When he does something to upset his aunt, she yells, "You go away to where your mother is."

'William' has to work for neighbours to earn money to pay for his government school fees while his cousins attend private schools. He says this treatment at home makes him miss his parents even more. He would like to be treated nicely and says things should be equal. He enjoys studying science at school and wants to become a doctor to make lots of money.

'Grace' is 13 years old and in Primary Six and is sponsored by World Vision. She lives with her paternal grandmother, grandfather, one sister and two brothers. She has been living there since her mother and father had a "big fight" in 2002. Her mother died in August 2003, while her father, whom she sees irregularly, is still alive – living nearby with a wife and children, none of whom 'Grace' has met.

She says stigma and discrimination is an issue for orphans. At home her grandparents only garden, and expect 'Grace' and her siblings to garden as well as do the rest of the housework. They don't want them to go to school (and struggle to pay fees) but to stay at home and do the chores. Her grandmother tells them "Your mother died, so you have to care for yourselves", and "Your mother brought AIDS and shame to this family." The other kids at school don't know that her mother died, or how, and 'Grace' thinks they would treat her differently if they knew. When she gets sick at school she gets better treatment than when at home because "at home nobody cares".

'Grace' is worried that she will die of AIDS and is scared playing with friends she doesn't know well in case she catches it. She would like to become a nurse to care for sick people.

## Appendix II

### Orphans' songs

Song performed by orphans at the CCC, Kaswa meeting, Tuesday 22 February 2005

*Hear how AIDS came to kill us.  
They say it came from Europe but how did it come to Africa?  
Many had misconceptions about it.  
Some say it was witches.  
The Europeans say that it's acquired through sexual intercourse (adultery, fornication).  
The drugs for it are not available, yet the machines can see the virus.*

*Those who have people living with HIV/AIDS don't run away from them.  
Create a conversation with them.  
AIDS you are lying, why kill us the brothers and sisters?  
Now I am warning you all, the virus it's so tough.  
So be careful with the friends you have,  
especially the grown-ups, the fathers and mothers,  
be careful.*

*AIDS the destroyer of villages (repeat four times)  
AIDS the destroyer of people (repeat four times)*

Song performed by group of 5–10 year old orphans in Kaswa ADP, Friday 4 March 2005

*The guardians are expecting good things from us.  
They have made us their bank.  
I will try to study hard to impress the guardians  
if God is on my side. (repeat)*

### Appendix III

#### Children's drawings

An orphan's house (a) before and (b) after her father died

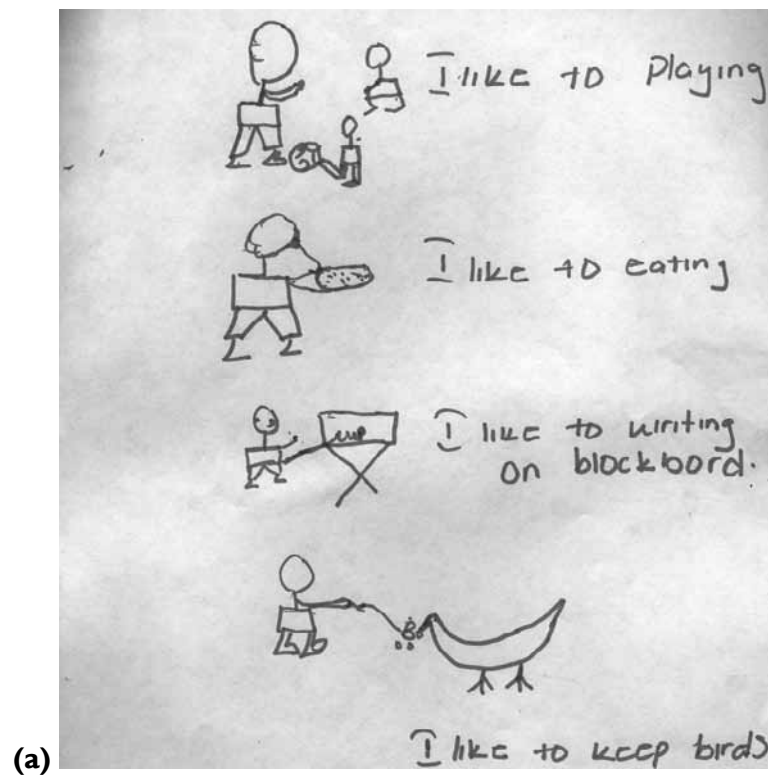


(a)



(b)

Drawings of what makes an orphan (a) happy and (b) sad



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