

# How Communities Are Coping with the Impact of HIV and AIDS on Children

## Findings from Uganda and Zambia

In many communities, the extended family system and other traditional safety nets responsible for orphans and vulnerable children (OVC) are being severely strained by the multiple, mutually reinforcing impacts of HIV and AIDS. Building on proven strategies, World Vision continues to seek cost effective ways to help communities provide care for the unprecedented number of children and families made vulnerable by the pandemic. Through the Models of Learning programme, World Vision has developed a strategy that interlinks three core programming models to address the needs of children and others affected by HIV and AIDS.

The pilot phase of this strategy was implemented in Uganda and Zambia from 2002-2004. Assessments revealed that the three models are feasible, acceptable and effective, although the level of impact is difficult to quantify. In order to enhance its understanding about the costs, effectiveness and impact of these models, World Vision designed an Operations Research (OR) project to be conducted in two Area Development Programmes (ADPs) where these models had not been previously implemented.

### Addressing the Needs of Children Affected by HIV and AIDS World Vision's Three Core Programming Models

1. **HIV Prevention for Children:** Equipping girls and boys with values-based life skills for HIV prevention
2. **Community Care Coalitions (CCCs):** Facilitating community-led care for orphans and vulnerable children through the mobilisation and strengthening of community care coalitions
3. **Channels of Hope (CoH):** Sensitising churches and other faith communities to the needs of people affected by HIV and AIDS, and mobilizing them to respond positively and constructively.

This document focuses on the second of the three core models: the Community Care Coalition (CCC) model. This model aims to empower community groups and other stakeholders to take the lead in advocating for and providing support to orphan and vulnerable children (OVC). The first step in the research process, prior to initiating the intervention, was to conduct a baseline assessment of the existing OVC situation and community responses.

### **Methodology – How was this Assessment Conducted?**

In the two rural areas assessed – one in Zambia and the other in Uganda – baseline data for this assessment was collected to gauge the situation and community responses *before* WV began implementation. Both qualitative and quantitative data were collected from:

- ❖ Men and women in the communities who are considered to be opinion leaders;
- ❖ Boys and girls aged 10 – 17 years;
- ❖ Primary caregivers of children in the households;
- ❖ Adult household members; and
- ❖ Leaders and representatives of all the churches and other FBO congregations, relevant government ministries, NGOs and CBOs working in the ADP.

The research team initially conducted focus group discussions, in-depth and key informant interviews with 180 respondents in Zambia and 222 respondents in Uganda in order to identify the core practices, issues and beliefs around HIV and AIDS, with primary focus on children. This process was followed by the development and implementation of a quantitative survey informed and shaped by the qualitative findings.

The first *post-intervention* qualitative data will be collected in April 2006, after six months of implementation, and the quantitative surveys will be conducted in November 2006, and thereafter in November 2007 and July 2009. The findings described in this document are based on the baseline data collected between July and August 2005 from the two study ADPs.

	Uganda ADP	Zambia ADP
Total number of children in study households	1,640	1,259
Adult caregivers interviewed	511	316
Children interviewed (aged 10-17)	656	380
FBO, NGO & CBO leaders and representatives interviewed	140	136

### **What did the Baseline Survey Show?**

The data served to illuminate several important questions about how both adults and children experience the reality of orphanhood and child vulnerability in the study communities.

The current WV programme definition of 'OVC' includes:

- ❖ Orphans (single or double)
- ❖ Children who are chronically ill
- ❖ Children with chronically ill parents
- ❖ Disabled children
- ❖ Other children identified as most vulnerable by community members using local criteria

### **Communities define 'vulnerable child' more broadly than external parties**

Surprisingly, the study communities in both Uganda and Zambia had a definition of 'vulnerable child' more inclusive than the one many external agencies (including most NGOs and donors) currently use. Respondents identified several other categories,

including children from very poor homes. They identified as vulnerable those children whose parents are considered 'irresponsible', a set of behaviours which were sometimes attributed to parental abuse of alcohol. In Zambia, parental or guardian disability was thought to increase children's vulnerability. In Uganda, respondents listed teenaged parents and their children, along with children being cared for by step-parents and sometimes foster parents as vulnerable. Respondents, including the children themselves, described cases of physical, psychological and sexual abuse, deprivation and discrimination at the hands of stepparents and guardians.

Notably, adult community members' appreciation of the psychosocial needs of OVC was limited. Adults typically volunteered that provision of basic needs such as shelter, clothing, schooling, food and medical care was sufficient, while the children articulated that they needed love, attention, and protection from discrimination.

### **OVC and psychosocial needs**

"Sometimes I develop feelings and I ask myself: what if my mother passes away? Who will look after me? Our relatives have not played any significant role even when my mum is sick, so I feel insecure and always think about it."

(Female OVC, in-depth interview, Uganda)

R1 "It happens for example, when you look at your state [orphanhood], when you suffer a lot, you are overworked at home".

R2 "You may be the only one who does all chores at home. ...fetching water, you are given a pit to dig, you are stopped to go to school on some days ..."

R3 "Also when you don't dress well, sleep well. Another thing, you can see other children going off to play, yet you are doing household chores...."

Moderator: How can they (OVC) be helped?

R1 "They should be shown love."

R2 "... given whatever they need."

(Male OVC age 15-18 Focus Group Discussion Participants, Uganda)

**Percentage of children who are orphans in both ADPs is higher than the published national estimates<sup>1</sup>.**

- ❖ In Zambia, out of the 1,259 children in 316 households where interviews were completed, 277 (22%) were orphans; there was an average of 3.6 adults per orphaned child.<sup>2</sup>
- ❖ In Uganda, out of the 1,640 children in 511 households with completed interviews, 401 (24%) were orphans; there were 2.8 adults per orphaned child.
- ❖ 112 (35%) of the households in Zambia and 188 (37%) in Uganda had one or more orphans.
- ❖ When orphans and children considered vulnerable were added together, the numbers were very high. 42 percent of children in the Zambian study community and 45% in the Ugandan site were OVC.

Households with orphans were significantly more likely than those without orphans to be headed by women and elderly (over 65 years) caregivers. In both ADPs, households caring for orphans generally kept a significantly higher number of children than households without orphans.

**Age Group and Gender of Heads of Household, and mean number of children by Orphan Status of the Household<sup>3</sup>**

	Zambia			Uganda		
	Non-orphan (n=170)	Orphan (n=111)	All HHs (n=315)	Non-orphan (n=239)	Orphan (n=187)	All HHs (n=508)
Children <18 years	0	0.9	0.3	0	0	0
Youth 18-24 Years	4.1	4.5	3.8	5	3.2	6.1
Adults 25-64 Years	91.8	82	85.1	84.1	78.6	78.5
Elderly 65+ Years	4.1	12.6	10.8	10.9	18.2	15.4
Male	92.4	68.8	82.3	84.2	54.5	73.1
Female	7.6	31.3	17.7	15.8	45.5	26.9
	(n=170)	(n=112)	(n=282)	(n=241)	(n=187)	(n=428)
Mean Number children	4.12	4.98	4.46	3.42	4.33	3.82

Finally, there is an overwhelming burden of child care for adults due to the relatively high child/adult ratio in both ADPs. In Zambia, there were 1.3 children for every adult in the study community – an abnormally high ratio. In Uganda, the child/adult ratio was 1.5 children per adult. This leads to a very high dependency ratio (which factors in elderly and adult dependents as well as children).

**Orphaned children experience stigma and discrimination.**

Reports from the children (aged 10-17 years) interviewed indicate that orphaned children were more likely than non-orphans to report that they are treated differently at home. They cited labor discrimination and unfriendly attitude as examples of how they felt treated differently from other children in the household.

<sup>1</sup> Uganda DHS 2000-2001 indicated that 14% of children were orphaned, while the Uganda 2002 Census estimated this figure at 16%; in Zambia, the DHS 2000-2001 showed 21% for children aged 0-15 years were orphaned, and in 2004 Children on the Brink report (UNAIDS/UNICEF/USAID) estimated 19%.

<sup>2</sup> In many western countries, there are about 400 adults for every orphaned child.

<sup>3</sup> Includes only households that have children

### **Abuse and discrimination of OVC**

R1 “They say things like, “that child’s father died”

R2 “One may not even want such a child to eat anything from his home... Some discriminate against them and don’t want them to eat or play with their children...”

R3 “A person who isn’t related to the child discriminates against him: if such a child is in a home not for relatives and given food, someone can come and say ‘that child is sick. Why have you given him/her food on your plates?’”

(Female OVC caregivers FGD participants- Uganda)

This situation is not surprising in view of the high levels of HIV and AIDS-related stigma expressed by various groups of people interviewed. Interestingly, children expressed the highest number of derogatory or stigma-laden beliefs directed at people living with HIV. A full 92% of the NGO/FBO/CBO representatives exhibited some element of stigma during their interviews.

Between 62% - 84% of the adult household members and NGO/FBO/CBO representatives interviewed expressed the view that HIV is a punishment from God and 17% - 45% felt that people living with HIV and AIDS do not require compassion.

### **Free Primary Education policies facilitate strong OVC school enrolment, particularly in Uganda.**

Both Uganda and Zambia have a free primary education policy. In spite of this policy, school enrolment for school age children (6-17 years) was relatively low for all children in Zambia (73%). There was no significant difference between OVC and non-OVC in ‘ever having been to school’ in both countries. However, non-OVC (93%) in Uganda were significantly more likely than OVC (89%) to be currently enrolled in school. For the majority of the children who were not currently enrolled in school<sup>4</sup>, lack of school fees and other scholastic requirements was given as the main reason. Qualitative data indicated school absenteeism caused by the need to care for other siblings and chronically ill parent/guardian as a factor affecting OVC school performance.

### **Immunization coverage is relatively good.**

The Government immunization programme in both countries has been reasonably effective: more than 94 percent of children aged 0-5 years in Zambia and 92 percent in Uganda had an immunization card and were up to date with BCG, polio, DPT and measles immunizations. There was no significant difference between OVC and non-OVC.

### **HIV-related stigma and discrimination attitudes**

“My suggestion is ... we must get a solution by keeping these people who are already infected out of the community ... throw them out. because they are already dead...”

(Secondary school teacher FGD participant - Uganda)

### **OVC experience of food insecurity affects school performance**

“ When hungry at school, you can’t even grasp what is being taught in class.”

“ One at times leaves home without eating anything, starve at school then go home to find nothing. Such things can even lead one to steal.”

(Male OVC age 15-18 FGD Participants: Uganda)

### **Birth registration is a challenge in Uganda.**

The majority (72%) of the children aged 0-5 years in Zambia had their birth registered: there was no significant difference between OVC and non-OVC in birth registration. However, in Uganda, less than a half (42%) of the children had their birth registered: non-OVC (48%) were significantly more likely than OVC (29%) to have their births registered.

<sup>4</sup> This refers to both primary and secondary school attendance.

***OVC have inadequate clothing and poor protection from malaria.***

OVC in both countries are significantly more likely to have clothing needs than other children. Although malaria is endemic in both ADPs, few children sleep under a bed net.

**Percent of children having clothing items**

	<b>Zambia</b>		<b>Uganda</b>	
	<b>OVC</b> (n=522)	<b>Non-OVC</b> (n=725)	<b>OVC</b> (n=727)	<b>Non-OVC</b> (n=889)
Has 2 sets of clothes	58	69	73	69
Something to cover at night	59	77	70	77
Has a bed net	9	13*	11	12

***Getting adequate food and nutrition is a challenge for both OVC and non-OVC.***

Most of the children in the study sites experienced some form of food insecurity during the period of 30 days prior to the date of the interview. However, in both Zambia and Uganda, OVC were significantly more likely than non-OVC to experience food insecurity.

**Percent of children experiencing food insecurity**

	<b>Zambia</b>		<b>Uganda</b>	
	<b>OVC</b> (n=513)	<b>Non-OVC</b> (n=726)	<b>OVC</b> (n=727)	<b>Non-OVC</b> (n=880)
Past 30 days:				
Skipped meals	65	48	51	40
Cut the amount of food	58	44	51	41
Did not eat the whole day	39	33	31	22
Experienced any food insecurity	74	62	64	52

***OVC report that they've experienced property grabbing.***

Qualitative data indicated property grabbing is not a rare occurrence in either ADP.

***Families supporting OVC do so with limited external support.***

The existing response to OVC is limited, particularly in Keembe ADP in Zambia. Forty four percent in Zambia and 17 percent in Uganda of the NGO/FBO/CBO agencies interviewed reported that they provide some form of support for OVC and chronically ill household members.

**OVC lose rights to family assets**

"When my Dad passed away, my uncles had to share responsibility for my family. However, in the long run they failed to meet their obligations and my mother had to support us on her own ... For example, we had a house in Kampala where we used to get rent money but when our father died, we no longer received any rent ... It is my uncles in Kampala who take the money... And they don't send any money for school fees... Now we only receive assistance from neighbours and well wishers from this village.... We have tried but our uncles cannot change their mind. We can't overpower them. I'm just a child, I can't challenge them personally."

*Moderator:* You can't report them to the relevant authorities, for example the Local Councils?

"Well you can report but they give the reason that our uncles have a right to do this because the property belonged to their late brother and above all, he entrusted them as our caregivers or overseers. The authorities can't question the decisions our uncles make about us."

The coverage of these agencies in Zambia appears to be limited, however. Only 15% of OVC had received any support from outside the household in the 12 months prior to the interview date. Household caregivers were asked if the children had received, free of charge, any of the following support in the past 12 months:

- ❖ Medical - such as medical care, supplies or medicine
- ❖ Psychosocial - such as companionship, counselling from a trained counsellor or spiritual support,
- ❖ Material - such as clothing, food or financial support
- ❖ Social - such as help with household work, training for a caregiver or legal services

Less than 16 percent of the OVC in Zambia and 35 percent in Uganda had received any of this support, not even from neighbours. OVC in Uganda were more likely to receive medical (17%) and material (11%) support, while those in Zambia were more likely to receive psychosocial (6%) support. Only seven percent of OVC in Zambia and 12 percent in Uganda had received support from neighbours.

#### **External Support for OVC Households**

*"The days of humanism are long gone: these days it's each one for himself"*

*Chronically ill female respondent taking care of three children and a female relative, aged 80 years, Zambia*

*"My mother is the one who supports me despite the difficulties we face. She falls sick twice a month, this affects my performance at school. We are not visited by anyone and we struggle to look for food."*

*13 year-old first born OVC girl - Zambia*

### **Conclusions and Implications for Programming**

A central overall conclusion is that substantial work is needed to help overcome stigma and discrimination in the community towards both OVC and the chronically ill. It is also essential to engage and empower more community members to become actively engaged in OVC care, as well as to facilitate coordination of the groups within the community that are already doing so or can be engaged.

There is a need to consider various programmatic options that would help households with OVC overcome barriers to keeping children in school. WV should examine strategies to ensure that lack of scholastic materials, inadequate food and nutrition, and the need to care for chronically ill parents/guardians and/or siblings do not impede school participation and performance.

OVC home visitors should monitor and report on OVC food security and school absenteeism in order to inform the development of programme strategies to address them. In addition, although basic education is important, few OVC can get gainful employment with a primary education certificate only. OVC programme managers and their community-based partners should design gender sensitive strategies to ensure support for OVC who qualify for further secondary education or other livelihood skills training.

The high levels of food insecurity even among children who are not considered orphaned or vulnerable call for exploring various food security interventions, among them a free or highly subsidized school feeding policy and programmes.

The findings show that the need for psychosocial support for OVC is not clearly understood in the communities. Programmes seeking to improve the quality of life and well-being of OVC should establish ways of identifying and referring households with chronically ill parents and/or guardians to the relevant support provider. Extensive psychosocial care sensitisation and training for household and institutional caregivers is required.



Support for succession planning should be an integral part of OVC programming. One strategy is to have external caregivers monitor the property rights situation of OVC households and involve other groups such as CCCs and FBOs in taking early action to uphold and protect the property rights of women with deceased husbands and OVC. OVC programmes should facilitate sensitisation and education of community stakeholders including implementing partners, on the rights of women and children and the law of success in the respective countries.

### ***How will the research be used?***

A two-day workshop held in Nairobi in October 2005 brought together Africa RO staff and NO staff from Uganda and Zambia to analyse and interpret the baseline data. Using these findings, they identified areas of the project requiring modification and improvement.

Ongoing research findings and lessons learned will be disseminated to local stakeholders in the communities where the project is implemented; World Vision national office (NO) staff in Uganda and Zambia; and the Africa Hope Regional Office (RO) team to inform implementation of the project and adjust project design where necessary.

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