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To: Secretariat, Committee on the Rights of the Child  
Office of the UN High Commissioner for Human Rights, UNOG-OHCHR  
CH1211, Geneva 10  
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# Helping AIDS orphans in child-headed households in Uganda

## *From relief interventions to supporting child-centred community coping strategies*

*Submission for the 16<sup>th</sup> September 2005 Day of General Discussion on “children without parental care”. This submission is in response to the request for practical suggestions on the topic of: “Meeting the challenges of out-of-home care provision”*

Prepared by Plan Finland  
Kumpulantie 1 A, 8. krs  
00520 Helsinki  
Finland

Tel: + 358 9 6869 800  
matthias.wevelsiep@plan.fi

# I. The appearance of child-headed households

The purpose of this submission is to share Plan's experiences and lessons learnt over the last four years in helping child-headed households.

The phenomenon described as a "child-headed household" was first noted in the late 1980s in the Rakai district of Uganda (WHO 1990). Up until this point it was assumed that 'there is no such thing as an orphan in Africa' (Foster et al, 1997), as children without parents would be easily and naturally looked after within the households of their extended families which traditionally acted as the continent's social security system - protecting vulnerable community members, caring for the poor and sick and transmitting traditional social values and education.

## AIDS orphans

While the people living with HIV/AIDS are mostly adults, children suffer most of the consequences. Again, most affected is Sub-Saharan Africa, where eight of ten children who have lost both parents to HIV/AIDS live - some 12.3 million.

As a cause of orphanhood, HIV/AIDS is exceptional, in that if one parent is infected with HIV, the probability that the spouse is also infected is quite high. This means that children face a large risk of losing both parents in a relatively short period of time. It also means that the transformation from single orphan via "virtual double orphan" to actual double orphan is generally inevitable (Monk 2001). Between 1990 and 2001, the proportion of orphans whose parents died from HIV/AIDS rose from 3.5% to 32%. Yet less than half of the countries with the most acute crisis have national policies in place to provide essential support to children orphaned or made vulnerable by the epidemic (UNAIDS 2004).

## Why children live by themselves

There are three main reasons why children live by themselves:

- 1) The extended family is unable to cope.** This appears to be the most common.
- 2) The children feel safer by themselves.** As orphans often report being verbally abused, neglected, forced to undertake exploitative work, and not allowed to attend school.
- 3) Living by themselves is the best compromise out of a number of very poor options.** As it enables a family of brothers and sisters to stay together in an area they are familiar with, rather than being separated and sent to different places.

The second and third reason imply an element of choice by the children. *Therefore, households headed by children or adolescents represent a new coping mechanism in response to the impact of HIV/AIDS.* It is a mechanism more suited to the realities of very poor and vulnerable extended families and communities operating at the limits of their resources. It is not uncommon for child-headed households with known relatives to receive supportive visits and small amounts of material support from their extended family even though they could not live with them.

It is also a mechanism that implies some measure of capability and resourcefulness from the children and their community. Therefore programs to help them must work with them and their community to build on these capabilities, and not treat their situation as a short-term emergency that can be resolved with a short-term injection of resources. This recommendation represents the essence of this submission, and is at the heart of Plan's program approach in the communities we work in.

This in no way diminishes the reality of these children being in a multiplicity of very difficult circumstances, with no immediate adult to protect them, feed them, guide them, love them and laugh with them – leaving them at risk of hunger and neglect, of being exploited, of being physically and sexually abused and worse.

## Definition of Child-Headed Households

Given the above, we define a “Child-Headed Household” (CHH) as a household where the children are double orphans (i.e. both parents have died) and is headed by a child that is recognised as being (LWF 2004) :

- Independent
- Responsible for providing leadership and making major decisions in the running of the household;
- Responsible, along with other children, for feeding and maintaining the household;
- Caring for younger siblings and adopting de facto adult / parent roles

## II. HIV/AIDS and child-headed households in Uganda

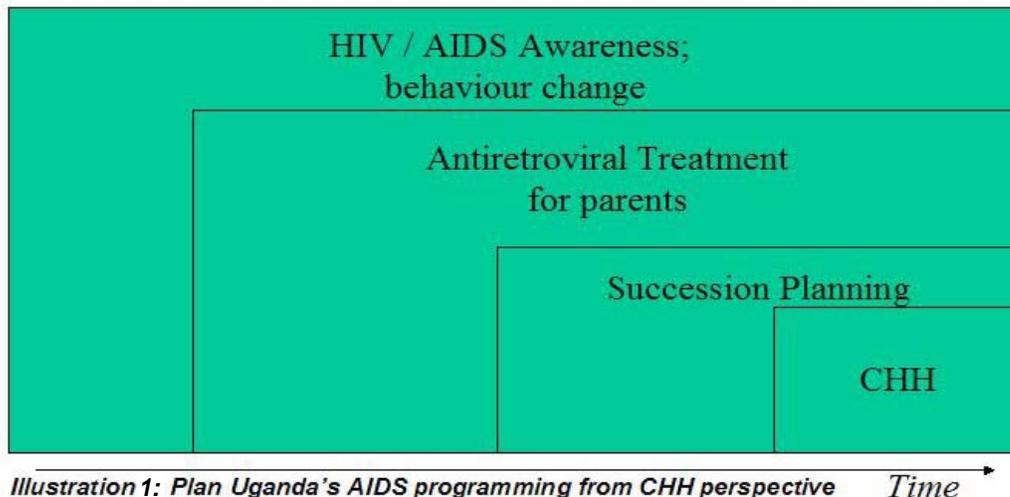
According to the National Orphans and Vulnerable Children’s Policy, Uganda has lost about one million people to AIDS and an estimated 940,000 children – 14% of the child population - had been orphaned by AIDS by the year 2003 (Ministry of Gender 2003).

In 2001, a survey by Plan estimated that around 18,000 children had been orphaned by HIV/AIDS in Plan program areas. An AIDS-related illness was the cause of death for 65% of the fathers and 73% of the mothers. One quarter of the orphans has lost both parents. According to the survey, 3% of caretakers were less than 19 years old. This is the category under which child-headed households fall, with each caretaker usually looking after a number of children. While this figure appears low, we expect it to rise considerably over the next few years.

### ***Plan Uganda’s Response to HIV/AIDS***

For more than 12 years, Plan has worked in partnership with Ugandan communities to establish successful health, education, income generation and housing/sanitation programs that are improving the lives of over 300,000 people.

In recent years, Plan Uganda has tried to address the fundamental causes of the HIV/AIDS pandemic. From the perspective of ultimately trying to prevent child-headed households, four layers of interventions can be identified, starting at different points in time. Illustration 1 shows this connection. The focus of this submission is on the fourth layer: programming for child-headed households, but we begin by briefly explaining the first three layers to put the fourth into context.



*Illustration 1: Plan Uganda’s AIDS programming from CHH perspective* Time →

### **1) HIV/AIDS Awareness and Behaviour Change**

Ideally, the existence of child-headed households can be avoided through this component. It is made up of programs such as ‘HIV/AIDS in Schools’ and ‘community awareness raising sessions’ which

involve a strong element of child participation. As a result of these awareness raising activities, many people have gone for voluntary HIV-testing and counselling.

## **2) Antiretroviral Treatment for Parents**

Antiretroviral treatment for all family members has been introduced at a learning site in the Tororo Program Unit. A community member summarizes the reason: "What's the point of saving the child if it's just going to become an orphan? Why don't they care about keeping us alive and healthy, so we can give our children a future? It may be cheaper to use Nevirapine, but not if the parents die"

## **3) Succession Planning**

Both the first and second interventions aim to prevent child-headed households from coming into existence in the first place. The third intervention of succession planning focuses on combating the negative effects of the loss of the parents. The succession planning component includes writing a will and working with parents and children on a memory book.

Plan staff members note that at this stage there is already too much talk of death which need to be balanced by with strategies to create a sense of "life enjoyment" for children so that they can enjoy the remaining time with their parents.

## ***Helping AIDS orphans living in child-headed households***

UNAIDS calls for two major interventions for children affected by the HIV/AIDS pandemic (UNAIDS, 2004): relief interventions focusing on the short term; and community development interventions focusing on long-term strategies.

Yet with the HIV/AIDS pandemic worsening every year, community development activities related to HIV/AIDS are in danger of being pushed to the background in order to focus on the "short-term emergency" of HIV/AIDS. This submission argues that even in communities under pressure, both interventions are needed in order to make a real difference in the lives of children affected by the pandemic.

This submission describes Plan's experiences with short-term relief interventions and long-term community development interventions for child-headed households over two periods: early cases in 2001-2002; and recent cases in 2002-2004.

## **First response: relief strategies**

*"There can be no 'ideal' response to the loss of a parent, only better or worse alternatives"*  
**Action for Children Affected by AIDS (1994), cited in O'Sullivan**

The early cases of child-headed households were discovered more or less by accident. In some communities, members talked about such families, but in other communities, people did not even know of their existence. As a community leader admits: "We as a community came to know that they were HIV orphans after Plan had started to give them some assistance" (Xisaasi Tebalyala Bweyeyo, Local Leader LC II).

Anecdotal evidence about communities' involvement with child-headed households reveals a mixed picture. Some communities tried to help as much as they could despite their poverty. In other cases, some communities seem to not have been supportive at all.

The stigma surrounding HIV/AIDS in that early period, combined with the loss of both parents, creates a seemingly hopeless situation for the children. Many children expressed that they simply did not know what to do after their parents died.

As child-headed households were a new phenomenon, it was not clear what approach would be most appropriate for them. Implementers of the first activities have described the initial setup as "reactive", "relief oriented" and ad-hoc, based on an analysis of the children's immediate needs. Community

coping mechanisms were only involved in a very limited way, and some of those were reduced because of the belief that “Plan will take care of it.”

Child-headed households are composed of children under exceptionally difficult circumstances, and any programming needs to take into account the ongoing characteristics of this “emergency.” Nevertheless, all interviewees, children, community leaders, teachers and Plan staff saw the need to move into more proactive programming that took account of the capabilities of the communities and the children. The next section describes how this was done.

## **Second response: child and community coping strategies**

*“The community did not know the way to handle these orphans – today the community can take its share of the responsibility.”*

**Community Leader Xisaasi**

As a result of what was learnt from the initial interventions, Plan’s approach for helping child-headed households is now very different from the onset. Program staff reports that as a first step they now sit with the local council to discuss the situation in order to involve them from the very beginning. Plan staff no longer play a lead role in identifying the children’s needs. Instead, the children themselves identify their needs with the support of a child counsellor. These child counsellors are members of the community or District, are trained by Plan and work on a volunteer basis. Therefore, the setup creates an alternative support system that slowly improves local understanding of children’s realities.

Listening and trying to understand children’s realities is a very complex process, and for anyone to work with traumatised children several sets of different approaches and strategies might be needed. As work with child-headed households continues, every new case, if well approached and documented, contributes to a set of contextualized approaches. The community leader Xisaasi underlines this shift: “Plan has been taking care of these children, but it is the decision of the local council that the community will take care of them.”

The basic needs of child-headed households are virtually the same -- access to school or vocational training, work, basic supplies for the house, house and latrine construction, basic food supplies, etc. **The importance is in how these needs are analysed and the process behind the analysis.**

A positive example of the coping strategies can be seen in the case of Wilson who was living by himself – a child-headed household of one! His coping mechanism might not be so much about having a house and garden, but how he looks at life itself. He greets you and you understand that he is a young adult, who laughs out to the people around him, and his message is that he will manage – somehow. This shows that he has assessed what he needs to get on with his life.

Program staff confirm, however, that children living by themselves are far more likely to appear vulnerable than in possession of effective coping strategies. Some children were not even able to talk to adults, being very afraid of them. Even though not talking to anyone is in itself a coping strategy, it is not necessarily a positive coping strategy, and highlights more the “vulnerability aspect”.

Therefore, the introduction of a child counsellor is very important. Strengthening children’s coping strategies, overcoming the loss of the parents and moving on with their lives, is the central objective, as these qualities support the fulfilment of all other basic needs. A child that manages to look at least to some extent positively at his or her own situation might be able to cope better. Similarly, if an adult is able to understand the realities and difficulties facing a child, by spending the time to understand, listen, and ask the right questions, s/he is in a better position to assist the child. And in addition to supportive adults, the role of other children should also be mentioned. Friendships with peers, social approval and acceptance among peers and in the community at large is a vital factor in their wellbeing.

Two key issues emerge from these experiences that deserve close attention:

### **A) Respecting the coping mechanisms of the children:**

We have learnt that we need to shift our emphasis from being *child-focused*: doing things **for** the children because they are in an emergency situation” to being *child centred* doing things **with** the children and building on coping strategies adopted by children themselves.

“Much less has been written about the way children manage the challenges that their lives present to them and how they themselves, by their actions, turn some of the challenges to good effect. This is not to deny the reality of many children’s suffering in general, but suggests a shift in emphasis, acknowledging their capacity to cope with adversity in a manner that frequently belies their age.” (O’Sullivan 2003)

The final result should be “better living conditions for child-headed households” in both the child-focused and the child-centred approaches. The difference between the two lies not in *what* is being done but *how* it is done. The following table illustrates further:

<b>Child-focused programs and CHH</b>	<b>Child-centred programs and CHH</b>
Children are primary beneficiaries.	Children are primary beneficiaries
Addresses most immediate needs.	Addresses most immediate needs
Priorities identified by specialists.	Priorities are negotiated with CHH and child counsellor
Children are seen as vulnerable.	Children are seen as vulnerable, but also in the context of their own coping strategies
The participation of children and communities is desirable.	The participation of children and communities is essential; the decision making of children is important; the decision making process is as important as the decision itself.

*Adapted from: Malaria and CCCD – Plan West Africa Regional Office*

## **B) Creating sustainable community-based safety nets**

As the number of child-headed households increases, the government of Uganda, Plan and Plan’s partners have an obligation to establish *sustainable* support structures that ensure the rights of *all* vulnerable children.

Given the limited budgets available per community, an effective and cost efficient way of doing this is to support **community based caring** for children living by themselves.

“The community may not have material resources, but they are able to offer social and emotional support to orphaned children. This would involve regular supportive visits to the children, taking an interest in the children, their progress at school, monitoring their health, involving them in recreational and social events, and offering care and ‘love’. This can be facilitated by encouraging all sections of the farm worker community including community leaders such as farm health workers, teachers and pre-school leaders, the youth and parents to offer this supportive and enabling environment.” (Walker, 2002).

Communities with child-headed households are likely to be economically overstretched, meaning that additional resources are needed to support the families or caregivers who look after the orphans and to adequately respond to the problem. These can be part of wider interventions to help the whole community, thereby ensuring that children living by themselves are seen as an integral part of the community. Promoting community based caring also makes it possible to combine immediate relief efforts with sustainable strategies, as recommended by UNAIDS. Finally, by helping the whole community, it can help, in principle, to heal damaged extended family safety nets.

# Key recommendations for helping child-headed households

*"We have a problem of not sharing love with our parents. They die when we are very young. We have nobody to show us that love. Some of us live in lonely situations."*

**An orphan in Tororo district, Uganda**

Children living in a child-headed household can cope better than we think they can, particularly with the right amount of adult support. The problem is that children in child-headed households often lack adult support and supervision. Additionally, people living with HIV/AIDS in Uganda have little or no access to adequate psychosocial support. The following recommendations build on this reality, research carried out by Plan in Uganda and available literature on child-headed households (for example Luzze 2004):

- 1) **Be community-driven, not case driven:** introduce sustainable community structures that actively follow the occurrence child-headed households, and willingly provide care for them. Plan program staff are convinced that a comprehensive approach is needed to address all of the child's needs, instead of picking one item to pay for the child. It is essential to ensuring that a child is supported over a sufficient timeframe. Worse than creating dependency, is creating dependency and then pulling out.
- 2) **Strengthen the abilities of community counsellors** to understand children's realities, and to use this understanding to provide them with feelings of security and supportive coaching. The counsellor might also be the best person to counsel if one of the children in a household or an adult caretaker is HIV positive and a child does not know about it. Instead of preparing for and coping with death, the children need to be helped to see that although they have been through incredibly difficult times, they are still alive. This corresponds with strengthening their coping mechanisms.
- 3) **Give children's coping strategies priority:** as children are very vulnerable and sensitive to criticism or challenges. It really takes good volunteers to analyse and manage these strategies. Additional research is needed here, as the information on coping strategies is very scarce.
- 4) **Take children seriously;** but also give them space to be 'children' to play, to be silly and to express their "patchwork personalities".
- 5) **Support families and individuals to give care:** They can provide guidance and a sense of security - especially if the duty of care is shared - even if high level of poverty prevents them from supporting child-headed households with resources and finance.
- 6) **Ensure that programs for child-headed households:**
  - do not destroy vital coping strategies in child-headed households;
  - do not reinforce detrimental coping strategies;
  - do not create unnecessary burdens on orphans in CHHs, and on friendly volunteers;
  - do not elevate the quality of life of CHHs beyond that of their neighbours, creating jealousy, which repels volunteers from the CHHs, and also makes CHHs vulnerable to attacks from thieves;
  - can be sustained by CHHs;
  - cater for the needs of the different age groups in a child-headed household; and
  - are long-term and phased to allow CHHs time to handle new 'projects'.
- 7) **Involve schools and teachers:** Teachers mentioned they have not been sensitized about the situations of Child-Headed Households. Sensitization is crucial, because teachers play a key role for child-headed households in showing understanding for their situation and encouraging them to stay in school. One key suggestion is to encourage schools to allow the children to use land at the school to plant, or that food grown in demonstration gardens be given to orphans.

A big challenge is finding the right support in terms of income generation and education. The children in Kampala suggested an alternative education system for child-headed households would fit better into their schedule. However, it separates children living without parental care from everyone else, possibly increasing the stigma again. It still might be an option to work with these children and other out of schools youth via non-formal educational alternatives, if it is in line with government policies.

- 8) **Use all possible community groups to help:** School health clubs could take more responsibility in supporting HIV/AIDS orphans, as they can use child-to-child approaches to better understand the situation of children in child-headed households in the community and how best to support them.
- 9) **Pilot different ways to cater for child-headed households in a community:** In a perfect world children should live with their parents, and if this is not possible with the extended family, and siblings should not be separated. But realistically: how should the child-headed households dilemma be solved? Small group homes, or group care with appropriate monitoring should be considered, integrated into the children's own communities. Any of those approaches would need to be verified through pilot projects.

So who's in charge, when it comes down to child-headed households? Everyone. First, the children. Then child counsellors are needed to understand and appreciate children's realities. Communities can provide guidance, care and the "feeling of being loved". Other children at schools and in the communities are able to understand well and empathise with what children living by themselves are undergoing. Only when working with all stakeholders can a "collective solidarity" be created, that can handle the growing number of children living without parental care.

## Sources for this submission paper

The findings of this submission were obtained from: a literature review; Semi-structured interviews with children living alone, their extended families, teachers; community members and Plan program staff. Three children from Plan Kampala's program unit helped design the questions for interviews.

## About Plan

Plan, established in 1937, is an international humanitarian, child-focused community development organisation without religious, political or governmental affiliation.

Plan is one of the world's largest development organisations. We work in 45 developing countries, investing over \$300 million annually on health, education, livelihood, housing, water and sanitation and cross-cultural learning programs.

Our vision is of a world in which all children realise their full potential in societies which respect people's rights and dignity.

We believe that long-term improvements and change can only be sustained if children are 'development actors': they participate, voice their opinions, are listened to and taken seriously because their opinions count. Children in communities we work with are often involved directly in planning, implementing and monitoring projects which benefit themselves, their families and their communities.

Resources raised from the contributions of approximately one million sponsors in 15 donor countries together with grants from public and private donors, enable us to work with poor children, their families and local communities, and support government activities and local NGOs across Africa, Asia and Latin America.

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