

# We Can Tell Them:

## AIDS Doesn't Come Through Being Together

Children's Experience of HIV and AIDS Related Stigma In Zambia  
2002-2003



*'People at church, while others are late. People are praying in the church building, which is just finished being constructed. The woman who conducted prayers is teaching people not to mistreat orphans but to care for them. She even offers to pray for them'*

Girl, aged 11  
Out of School Group, urban



Sue Clay, Virginia Bond, Laura Nyblade

In association with  
Levy Chilikwela, Titus Kafuma, Gita Sheth, Annie Chanda,  
Neater Malambo, Bertha Milimo, Florence Moyo,  
Janet Chisaila, Edwin Mwanza, Danny Njovu.

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**KARA COUNSELLING**  
*Positive and Fully Alive!*

 **ICRW**  
International Center for  
Research On Women

 **ZAMBART PROJECT**

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The title of this report is a quote from one of the children who participated in the research in Lusaka, who was asked how stigma could be reduced. 'I can tell them AIDS doesn't come through being together', was his answer.

All the names of the children in this report have been changed to protect their confidentiality. Photographs taken during the research workshops have been omitted for the same reason.

First Edition: November 2003

**Design:** James Howlett

**Illustrations:** Petra Rohr-Rouendaal

**Cover Picture:**

*'This is a happy family who is keeping three double orphans and treating them the same as their own children. They all go to draw water while the mother has gone to sell at the market'*

Girl, aged 10, community school, Urban

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This report is dedicated to all the children who took part in the study and in particular, to the memory of Richard (one of the Choma children) who sadly passed away in April 2003.

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## Introduction

Twenty years into the HIV and AIDS epidemic in Zambia, people are very much preoccupied with the impact of the epidemic, including the rising number of orphans. Without their parents, many children are growing up in families where economic resources are stretched to breaking point. Seventeen per cent of children under 18 years old in Lusaka are estimated to be orphans, and at least 40% of households are now supporting one or more orphans (UNAIDS 2002, UNICEF 1999). It is within this context that our study took place, with the aim of documenting children's experiences of HIV related stigma and how it affects their lives.

In 2002 Kara Counselling and Training Trust, in conjunction with ZAMBART, carried out a study to investigate children's experiences of HIV-related stigma in Zambia.<sup>1</sup> This was a sub-study of the research project "Understanding HIV and TB related stigma in urban and rural Zambia".<sup>2</sup>

The preliminary findings of the community research provoked the need for this sub-study since it was evident that there were distressingly negative attitudes to children whose parents were suspected to have HIV or AIDS or to have died from AIDS. Scorn about their parents assumed behaviour, fear about orphans being HIV-positive and limited resources deflected stigma and discrimination onto orphans and street children in the community. We wanted to learn from the children themselves how they

experienced and coped with this stigma and discrimination.

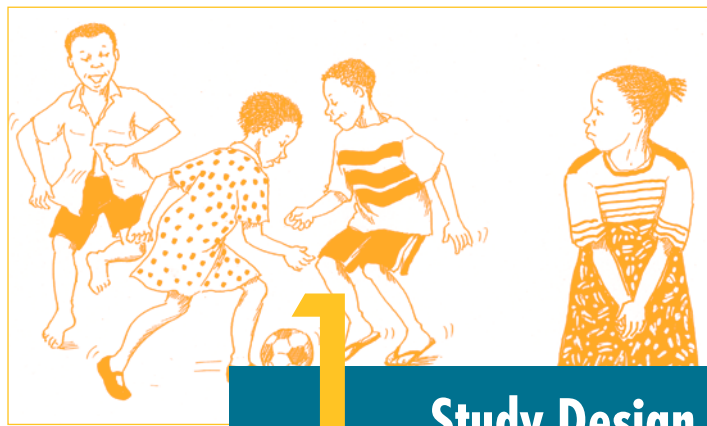
Additional funding was secured for the children's study through ICRW from GlaxoSmithKline's Positive Action Programme. Kara led this component of the research since ZAMBART felt it lacked the appropriate skills to work directly with children.

The study coincided with Kara's development of special services for children. Child counselling services, youth-friendly corners in Voluntary Counselling and Testing (VCT) Centres and day care services for children living with HIV were established at Jon Hospice in Lusaka and at Kara Choma. To understand more about children's experiences would strengthen the development of these programmes.

The Children's Study grew out of the wider research on stigma. Because of the importance of the issues and the breadth of the findings it has been written up as a separate report. In this report we have combined the findings from the children's study and the wider community study to arrive at a holistic picture of children's experiences of HIV-related stigma and discrimination from the perspective of adults and children within the same communities.

<sup>1</sup> Kara Counselling and Training Trust (Kara) is one of the pioneering non-governmental organisations in the field of counselling and HIV and AIDS in Zambia. Zambia AIDS Related Tuberculosis Research project (ZAMBART) is a research programme run jointly between the University Teaching Hospital in Lusaka and the London School of Tropical Medicine.

<sup>2</sup> In 2001 ZAMBART received funding from USAID through the International Center for Research on Women (ICRW) to carry out this 2-year multi-country study in conjunction with Ethiopia and Tanzania. In Zambia, the study was housed at Kara and some of the fieldwork was carried out jointly with Kara staff.



## Study Design and Methods

### Research Objectives

a. To document children's experiences of HIV and AIDS and TB related stigma and discrimination both directed at themselves (as children with HIV or AIDS or TB symptoms or as children of families directly affected by the epidemics) and at their families. It was also planned to look at the different forms of stigma and discrimination. For example, name calling or teasing, bullying, being denied access to basic services, denied rights, isolation and the different types of stigma - self-stigma, felt stigma, enacted stigma were to be explored.

b. To understand what causes children to experience HIV, AIDS and TB related stigma. For example, are people's feelings and judgments about the parents projected onto the children? Are children of people living with HIV and AIDS regarded as a burden by the extended family? Are people genuinely afraid that the children themselves could infect others with HIV?

c. To assess the impact of children's experiences on their well being. How do children cope with any resulting emotional pain and anger, with low self-esteem, with shame, with fear, with their future? More pragmatically, how do they cope with the responsibility of caring for sick parents and family? Who do they discuss such problems with?

d. To explore the role of children in propagating HIV, AIDS and TB related stigma and discrimination. When and why do children stigmatise?

e. To identify what strategies either do or might reduce any HIV and AIDS related stigma and discrimination that children face (existence & access to legal rights; support groups including counselling services; programmes, materials and institutions that support children; appropriate support from relatives)

### Definitions

For the purposes of this study, the term 'Orphan' describes a child who has lost one or both parents. The term 'double orphan', sometimes used by the children during the workshops, refers to those who have lost both parents.

The term 'Street Children' refers to children who spend a large part of their lives on the street and who defined themselves as 'street kids'.

'School attenders' includes the children who attended either government schools or the Community School.

Table 1: Children Respondents by Sex and Site

	Total	Girls	Boys	Orphans
Lusaka Misisi & Kamwala	39	22	17	30
Choma Town	21	12	9	11
Chilalantambo	18	10	8	5
<b>Total</b>	<b>78</b>	<b>44</b>	<b>34</b>	<b>46</b>

Table 2: Children Respondents by Group

	School-attenders Groups	Non-school attenders Groups	Street children Groups <sup>4</sup>	Treatment Group <sup>5</sup>	Workshop Venue
Lusaka Misisi & Kamwala	20	10	9	-	Kara Thornpark Training Centre
Choma Town	-	10	11	-	Kara Choma Centre
Chilalantambo	9	9	-	-	Village Community Centre
<b>Total</b>	<b>29</b>	<b>19</b>	<b>19</b>	<b>11</b>	

### Study Populations

The children were selected from the same research sites as the main study - namely Misisi and Kamwala in Lusaka, and, Choma Town and Chilalantambo village in Southern Province. Four different groups of children were targeted - school attenders, non-school attenders, members of HIV and TB treatment groups and street children, in order to provide a cross section of children from the communities. It was assumed that orphans would be present in all groups.

In Lusaka, children were selected through: teachers at the St Laurence Community and Kamwala basic schools; staff at a street children's centre in Lusaka (Fountain of Hope); and a member of the Misisi neighbourhood Health Committee helped identify out of school children. In Choma, the street children were brought to the centre by one of the older street boys who is known to Kara and the Choma Treatment Group was an existing group of children who are on antiretroviral treatment supported by Kara Choma. In Chilalantambo, the village headman had informed parents and guardians about the research and children were picked by him from the village and surrounding areas on the day.

In total, 78 children participated - 46 of whom were orphans (see Tables 1 and 2 for a breakdown by sex and group). The age range was from 7 years to 15 years.

### Ethical Considerations

Ethical clearance for the research in Zambia was obtained from the Research Ethics Committee at The University of Zambia. As far as possible we obtained written consent from parents and

guardians for all the children to take part in the research, and ensured that they understood what was involved. We also worked closely with community-based organisations that had established - or could establish - contact with the children.

Research conducted with children needs to be carried out sensitively and we aimed to provide enough support and expertise to ensure that no harm was caused to the children in the process of the study.

Of concern to us were the following:

- Talking about difficult or painful experiences and feelings related to rejection or stigma, may lead to children becoming distressed and less able to cope with their situations.
- Children may disclose experiences or information that they have never shared with anyone before (this has already been found even during initial child counselling sessions)
- It would be harder to guarantee confidentiality when working with a group of children, who may not understand the concept or the importance of it.

In order to minimise these concerns we took the following measures:

- Careful planning of the way in which we carried out the research, and the tools we used. This included involving 4 older children (11-14 years) from local schools<sup>6</sup> who did not participate in the research but helped develop the tools.

<sup>3</sup> See the Zambian Country Report (Bond et al 2003) for a detailed description of the methods used in the wider community research.

<sup>4</sup> Note: some of the children in the Street Children Groups and Treatment Group were attending school

<sup>5</sup> 'Treatment Groups': Kara Choma is supporting a group of children who are living with HIV and on ARV treatment

<sup>6</sup> Thorn Park Basic School and Kamwala Boys School.

- A thorough discussion with, and briefing of, all research assistants, researchers and child counsellors involved in the workshops.
- Use of trained and experienced child counsellors to facilitate the workshops with the children and carry out the interviews
- Opportunities for the children to share their experiences either in a group, or on an individual one to one basis
- On-going support to the children involved, in the form of two follow-up counselling sessions and access to referral for longer term counselling if appropriate or desired.

Since Kara has built up some experience in the field of child counselling, we were also aware of the benefits that the children may gain from their involvement in the research. These included receiving affirmation and strength from sharing their stories and being listened to, having some fun (using creative methods in the workshops), getting support from their peers and gaining access to ongoing counselling if they so wished.

### Methodology Community study

In the community research, all key-informants and focus group discussion (FGD) participants were asked direct questions about children that revolved around how the community regarded children whose parents are assumed to have HIV or AIDS or to have died from AIDS, and how these children were affected by their parents' illnesses. They were also asked to describe how people with HIV were dealt with in a school setting and whether school children were at risk of getting infected with HIV.<sup>7</sup> In both rural and urban sites, primary and secondary school children were FGD participants, and in the urban site, children attending a community school also participated. A total of 67 school children participated in the community research.

### Developing Research Tools for Children

There was a need to develop some research tools that would help us to find out from the children what they understood about the complex issue of stigma in a relatively short period of time. The methods

used in the Save the Children study (2002) inspired us with initial ideas. We decided to hold one-day participatory workshops with each group of children, which included group and individual activities.

The main development of the research tools took place during a 'Tools Development Workshop' involving a group of child counsellors and four children who did not participate in the study. We presented some initial ideas to the latter children, who then helped us develop the content of a story and the briefs for drama and play exercises. We also tried out name games to see which worked the best, and did our own drawings as a group, to get a feel for the tools.

### One-Day Participatory Workshops

The workshops were led by the child counsellors and conducted mainly in Nyanja (in Lusaka) and Tonga (in Choma). The consultant and research manager were present for all the workshops, and translations took place simultaneously as needed. Research assistants observed, recorded notes and individual interviews, and helped with some of the games.

All the workshops began with breakfast to try to ensure no child was hungry during the activities.

**Programme for Children's Workshops**

Welcoming, breakfast, settling-in

**Introduction to the meeting:**

- Name Game
- Story of Mary; story questions; what is stigma?

**Song (Children's choice)**

- Drawing: Where does stigma happen? Introduction to exercise Drawing Talking about the pictures

**Tea break**

- Drama and Play - How can we help children who face stigma? Split into 2 groups according to age, explain briefing (5-10 year olds-Toys/play) (11-15 year olds- Drama Sketch)

**Lunch**

- Individual Interviews

**Closing:** song; presents

**The Story of "Mary":** The aim of a story was to introduce the topic of stigma, in order to illustrate the meaning of the word and how it might affect children. The story used was based on one made up by a Grade 7 girl during the Tools Development Workshop. It is an elaboration of the 'Cinderella' story, with a different context, and turned out to reflect the everyday experiences of many of the children involved in the study. The story was translated into Nyanja and Tonga by the research assistants (see Appendix 1 for full story).

The story was a good introduction to the subject and was easily understood by the children, many of whom were familiar with oral story telling. The story was relayed by a counsellor and was told in a participatory manner, with the storyteller checking whether the children were listening and understanding the story. The story was a good tool for establishing the children's understanding and experience of 'stigma'.

The main limitation was that, having heard the story, the children focused on the story content - 'Mary's experience' - and it took a while before children talked about their own experiences. After the first two workshops, we introduced a song and a break after the story and this helped the children move from Mary's story to their own experiences.

**Drawing Pictures:** Drawing is a recognised tool to use with children since they are able to convey in their drawings, thoughts and feelings they may find difficult to express in speech or writing due to limited vocabulary or suppressed emotions (Swart 1990).

The children were asked to think of a place - school, church, market, clinic, street, neighbourhood, home - and then were asked to think about how a child who was HIV positive, or a child whose parents had died from AIDS, might be treated in this place.

Using this method, the children were free to draw pictures from their imagination, from their own experiences, or, about a third person. In the event, most children described the pictures as their own experiences.

Nearly all children enjoyed the drawing, which they took very seriously, and an atmosphere of intensity usually developed as they produced amazing pictures. Accompanied by the children's own narrative, the pictures capture many different forms of stigma as well as evidence of communities and households advocating against stigma. The only real limitation was that some of the younger children did not understand the briefing and produced beautiful, but rather unrelated pictures.

Some examples of the pictures appear throughout this report, and they have proven to be powerful visuals in our disseminations to date.



*"This picture is about infected people who are sleeping on the floor, looking very lonely and eating on their own, while those that are not infected are joyful, playing and have vowed never to mix with the others for fear of infection."*  
-Girl, aged 13, School-attenders, urban

**Drama:** Drama is a popular form of expression in Zambia and we decided to use drama/role-plays with the older children in the study, as a way of trying to get a deeper view of their ideas and experiences around stigma. The briefing for the drama exercise was to plan a sketch about a boy or girl who was experiencing some kind of stigma in any chosen setting and to include ideas of how to challenge stigma and teach others about how stigma affects people.

The drama exercise worked well with all the groups of children. Only one non-school attender group struggled in the beginning to present their sketch, out of shyness. All the groups developed their sketches without any adult help or intervention, and all fulfilled the brief of displaying stigma in different situations.

<sup>7</sup> Visuals of schools and school children were used for these two questions. See the Zambian Country report for more details.



The only limitation is that the power of the drama is hard to capture with pen and paper. As much as possible the themes and issues were pulled out in discussions and debriefs after the sketches.

**Playing with Toys:** Children release their feelings and gain mastery over painful or traumatic experiences through play. In each workshop we took a collection of soft toys (teddy-bears, dollies, other stuffed animals), which the children were free to play with during the breaks and individual interviews.

In order to explore the younger children's understanding of stigma and whether they could find ways to help children experiencing stigma, we used the toys for an exercise supervised by a trained child counsellor who uses play therapy regularly to explore children's feelings.

The briefing for the play exercise revolved around one toy who was sick and who had been called names or rejected by the other children. The children were asked if they could do anything to help the sick 'dolly'.

All the children enjoyed the exercise. For many it was the first time they had played with such toys and their attachment to the 'dollies' was moving. Most of the children understood the setting and expressed aggression and discrimination against the 'sick' toy as part of the story. Some also showed examples of trying to help the sick one.

One of the limitations was that the exercise was lead by an adult, as a directed play exercise, and the children at first were not so free, especially to interact between each other (just watching the child counsellor instead). Some of the children were distracted by the toys and wished only to play their own games. Similar to drama, it is hard to capture the full dynamics of the exercise on paper.

**Semi-Structured Individual Interviews:**

Initially the idea of the individual interviews was developed both as a way of seeing how each child was feeling after the morning group exercises and as an opportunity to gain a more in-depth profile of each child and their unique experiences. It soon became evident that most of the children were more

comfortable talking in depth on a one to one basis than in the group, and these interviews very quickly transformed into counselling sessions (see appendix 2 for full questionnaire).

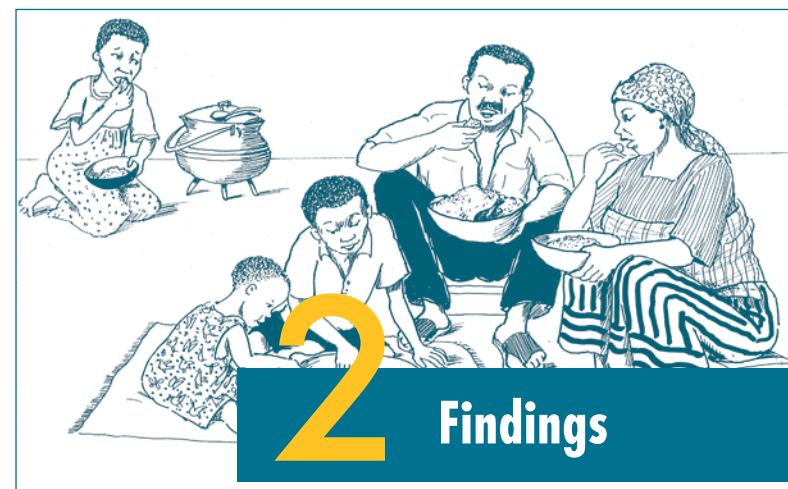
Some counsellors were more experienced than others at exploring issues with children, and some of the counsellors and research assistants got so caught up in the children's plight and the counselling, that they only recorded limited information. However, individual time provided an important chance for children to express feelings, often of sadness and grief. Some had never before talked about their parent's death or their anxieties about the future. Many broke down in tears.

And valuable insight was obtained through a careful debriefing and analysis of the interviews.

The main limitation on the interviews was time. Since the children really did want to talk and responded to the counsellors, the sessions were limited by time constraints only.

**Follow-up support:** All the children received a follow-up visit, either as a group or individually, after the initial workshops. All children were informed of Kara's counselling centres and the ways in which they could access counselling as an on-going process if they so wished.

For most of the children the most outstanding memories of the workshops were the presents, drinks and toys. Several of the older children talked further with the child counsellors about their experiences of stigma. Three, who were not in touch with services, were referred for on-going counselling. One girl told of how she had discussed what she had learnt about TB with her Mother, who, as a result, had stopped mistreating a neighbour's child.



**Children's definition of stigma**

[Stigma is] *"treating someone badly, treating others like animals"* (14 year old boy, School-attenders group, urban)

Like many adults in the study, children were not familiar with the English term 'stigma' but when it was explained to them that, in relation to HIV and AIDS, stigma referred to people being treated badly on the basis of others assuming that they had HIV, they quickly recognised what HIV related stigma and discrimination was and how they perceived or experienced it in their own lives. They were also less cautious and more honest than educated adults about revealing stigma that they have witnessed. For example, a teenage school girl relates:

*"I had a certain aunt of mine – she had AIDS. The way she was looked at by the family and other people – she was a disgrace to the whole family. By that time she was abandoned"* (Secondary school girl, rural)

This was reflected, for example, in all the drama sketches, which spontaneously looked at stigma from different angles – from the perspective of out of school teenage girls, of street children, of orphans. One drama sketch, performed by the Lusaka School-going group, showed a young man who had finally completed his studies and succumbed to peer pressure to have sex with a girl. When he got sick, his friends no longer wanted to see him and he planned to travel to South Africa

where no one would know him. This would ensure, the children explained, that he would not have to face the judgements of his parents and other people.

In another focus group discussion with urban secondary school children, the children described the following as examples of stigma within a clinic setting: a nurse wearing double gloves with a HIV-positive patient; being told you are *"naughty if you are visiting the clinic often with different diseases"*; being shouted at when you are in pain; and being beaten. This shows how school children are aware what stigma is and how it hurts.

**Harsh reality of children's lives**

Children's experiences of stigma cannot be separated from the wider context of their lives. Nearly all the children in the study came from a harsh background of poverty, shortage of resources, unemployment, hunger, limited health care and high HIV prevalence. Many families are struggling to meet basic needs let alone care for sick relatives and absorb additional children. All these pressures on families increase the likelihood of children with HIV and/or orphans facing stigma and exclusion. This connection between poverty and the frequency of stigmatising actions was especially strong in Zambia in the multi-country study – a reflection of the prevalence and impact of the HIV epidemic and limited capacity in the context of extreme poverty.<sup>8</sup> Some adults commented how in the past, orphans were easily absorbed by the extended family but now it is so hard to take in an orphan.

<sup>8</sup> For a fuller discussion of the link between poverty and stigmatizing actions see the Zambia Country Report.



*"It is a burden, because the economy is bad which is causing all these problems we are talking about, because like in the past when uncles and aunts looked after the children. In the past there were no orphans, when your mother dies, you will be looked after by another family. I won't even know that I am orphan until I grow up. So I will just say, so I was an orphan in that house, they kept me very well, in return he can also support those parents. But these days how can one look after an orphan?"* (health providers, urban)

**The multiple stigmas faced by children**

HIV related stigma is often overlaid with other stigmas faced by children – the stigma of being poor, not going to school, having shabby clothes, living in poor housing. There are core stigmas that are common to the different groups of children (blame, mistreatment, deprivation) as well as particular forms of stigma which focus on children's circumstances or lifestyles (see Figure 1). For example, orphans can be excluded from family life and education and blamed for their parents' death. Street children face

*"The girl is crying because of too much mistreatment. She is suffering from TB and the parents are in the house without a care of any kind"*

Girl, 13 years old, Out of School Group, Urban

insults about being 'dirty', are constantly moved on, or completely ignored, and are accused of being thieves and prostitutes. If an orphan is also known or suspected to be living with HIV, further stigmas come into play: isolation from friends, exclusion from school, segregation in the family.

*"My cousins used to accuse me for things which I never did and I would be beaten for not accepting. Also they never used to give me any food. 'Your Mother and Father never brought food for you to eat, no wonder you are an orphan and poor'...so I decided to leave for Lusaka for good..."*  
(15 year old boy, Street Children, urban)

**Figure 1** illustrates how children's experiences of stigma are dynamic, multi-layered, spiralling and set against a background of poverty, high HIV prevalence and powerlessness. Children may move between different stigmatised groups or may belong to more than one group at a given time. Sometimes the shift in identity from one stigmatised group to another stigmatised group is precipitated by stigma. For example, in our study, some of the children living with HIV were also orphans, and, several of the street children had run away to the streets to escape from abusive situations at home, where they had been mistreated as orphans. Stigma is related to individuals having a 'spoilt identity' (Goffman 1963). As the children's identities become more 'spoilt', the more marginalized and powerless the children become the less chance they have of challenging stigma, escaping from their predicament or, indeed, surviving.

**Core Stigmas**

The core stigmas experienced by children across the different marginalized groups fall into three categories: blame, mistreatment and deprivation and often occur alongside one another, with blame justifying mistreatment and deprivation in the context of poverty.

**Blame**

Blame is one of the main forms of stigma faced by children. Goffman (1963) writes that family members often carry the 'discredit' brought by a stigmatised person. The discredited status contaminates those closely associated with the person carrying

the stigma. For example, in one of the urban households, a TB patient staying with his sister relates how he and his young son were made to eat separately from and given less food than the other household members and how confused and hurt his son was about this eating arrangement.

Blame manifests in many guises: harsh words, isolation, avoidance, neglect, and sometimes violence. Children report that they often feel *blamed* for the situations they find themselves in, as well as for the actions and lives of their parents.

In our study we found evidence of children being blamed for:

- Being orphans
- Being HIV positive
- The fact that their parents have died from AIDS
- Being a 'burden'
- Being street children

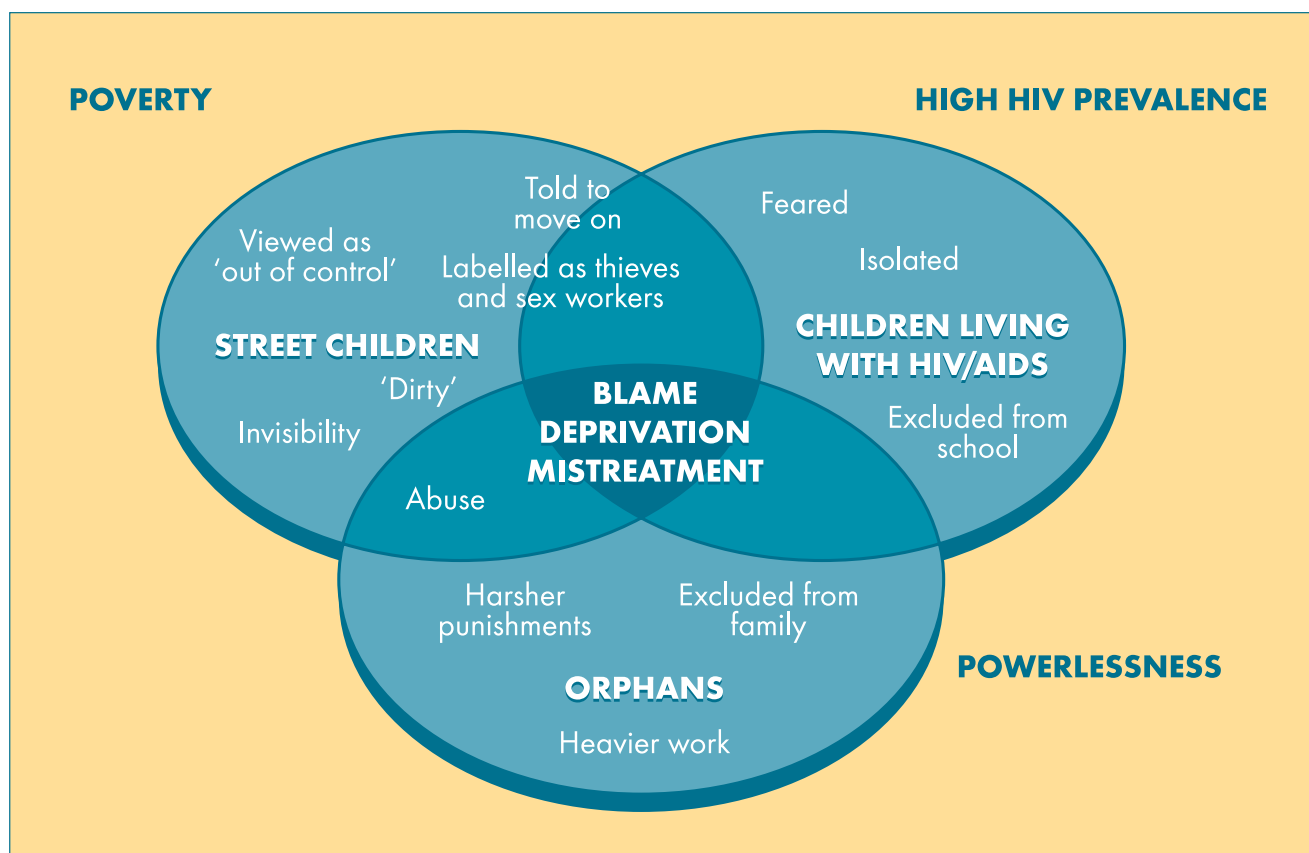
**Blamed for being orphans:**

The number of children who are orphaned is increasing daily in Zambia. In our rural site, there were 350 children attending the village school. Of those, 72 were orphans (21 were double orphans).

In rural areas, double orphans are more likely to be looked after by their grandmother; in urban areas double orphans are more likely to be looked after by aunts and uncles. (ZDHS 2002). Many of the children in our study related their experiences of stigma and discrimination to the fact that they are orphans. When resources are scarce and economic pressures make caring for one more person seem insurmountable, many families who take in orphans sub-consciously blame children for being orphans.

If orphans make mistakes, the focus of scolding and punishments is hinged on the child's identity as an orphan. Maddy, a 13 year old girl from Misisi, told of how her aunt used to punish her if she came back from selling vegetables at the market, without the correct money.

*"If I make any shortages she would beat me and call me an orphan, saying 'no wonder you don't have any parents'"*  
(13 year old girl, urban out of school)



**Figure 1. Children From Stigmatised Groups Face Multiple and Spiralling Stigmas**

Godfridah, a teenage girl of 15 years, also had stories of how she was never allowed to forget that she was an orphan. When her parents had died she had felt that she was somehow to blame and this blame, reminded her about her loss and her orphan hood.

*"I was taken to the relatives and I used to be mistreated. Whenever I made a mistake I would be beaten, told all sorts of insults and always told I am an orphan. This used to remind me about my parents and I just cried".*  
(15 year old girl, community school, urban)

### Blamed for parents dying of AIDS:

Orphans whose parents have died from AIDS carry the blame and shame that accompanied their parents' illness and death and are judged because of their parents presumed behaviour, and treated unequally.

Hanz, a child from Misisi Community school, talked about his friend, whose stepmother shouted at him 'no wonder your father died of AIDS!', after he made a mistake.

When asked how the children whose parents die from AIDS are treated in the village, one traditional birth attendant said:

*"Others are even told off about what killed their parents and care given to their own children is different to the orphans"*  
(traditional birth attendant, rural)

Because their parents have been labelled as 'promiscuous' and therefore not 'worthy' of help, this acquired blame can even result in families refusing to care for the orphans.

*"They say to the children that their parents never used to behave - hence they will suffer 'we will not help you'"* (young women, rural)

Children are also accused of inheriting both their parents' 'misbehaviour' and their illness and that it is inevitable that the children will bring problems.

*"They say that the children are following their parent's behaviour. These children are full of sicknesses".* (primary school children, rural)

Being blamed for events over which they have no control is confusing for children.

*"...because a lot who are looking after the orphans in these homes, the way they keep them or they are looked after brings a lot of sympathy - insulting them to say, 'Get out! It is not me who killed your father and mother. It is their own fault because they used to misbehave'. So that child will be affected, trying to think how the parents were misbehaving".*  
(health providers, urban)

One boy orphan in an urban school feared stigma so much at school that he did not tell any of his friends that his parents had died.

### Blamed for being HIV positive:

When a child's parents die, some relatives may suspect that the children are also HIV positive and fear the risk of contracting HIV. Some families may also fear stigmatisation from the rest of the community if they agree to care for a child whose parents died from AIDS and who is HIV positive.

*"The children who have the disease may be called unclean because the relatives would stay away from them".*  
(secondary school girls, rural)

This stigma also feeds the idea that children with HIV are 'a waste of resources' and can justify withholding medicine and education.

*"They say that even if they educate them, they will just waste their money because that person is dying. Many say that if they grow they can spread the disease".*  
(secondary school girls, rural)

Children themselves reported that they somehow felt it was their fault, if they were sick. Chipo, aged 13, from the Treatment Group talked of how her friends avoided her when she had been sick:

*"At home my friends never used to like me. They said I had measles and TB. They used to run away from me".*  
(13 year old girl, treatment group, rural)

Jonathan, from the Community School, said that rumours about a parents death, results in others stigmatising the child.

*"...if they suspect the parent died of HIV/AIDS, friends don't want to play with you....the teacher can also treat someone badly".*  
(15 year old boy, community school, urban)

### Blamed for being a burden:

The harsh economic conditions affecting most families in Zambia takes its toll not only on available resources but also on the sympathy usually reserved for times of misfortune. Instead of being offered comfort and understanding, orphans are more and more becoming viewed as a burden on families, who feel too stretched to welcome them in.

*"Well they are looked as a burden to families because they bring extra cost to the family budget".* (Hospice nurse, rural)

Sometimes, treatment of orphans was said to be determined by people's 'hearts'.

*"This is determined by what is inside the person's heart: some are isolating the orphans. [They say] 'It is not me who sent your parents to the bar'...."* (Business Woman, rural)

Joyce, 15 years old from Kamwala, talked about how she never really felt at home staying with her aunt and how she could never feel sure that she would be able to stay long-term.

*"She used to say 'when you fail your exams, I'll take you to the village'. But she didn't say it to her own children, who all go to a rich school".* (15 year old girl orphan, School attenders group, urban)

### Blamed for being on the street:

Many orphans end up living or working on the streets, and face further stigma, for being street children. Swart (1990) describes how community members in Johannesburg, see street children either as 'waifs' in need of care and guidance, or as 'pests' defiling the environment. In both cases, people feel free to abuse them.

*"They are said to be upcoming street kids whose parents are soon dying of HIV/AIDS".*  
(young men, urban)

In our study, many members of the community showed understanding as to why children end up living on the streets. And yet the street children's experiences did not reflect this compassion.

*"In this community, it's very difficult to look after children, people in this area are living under poverty I can say, very few people can manage to look after these people that is why you find a situation where by most of those street kids you see in town are coming from this place right. It's just difficult for the people in this community to look after them, if you look at the current situation".*  
(Social Worker, Urban)

The street children in both Lusaka and Choma talked about how they are regularly mistreated on the streets, by adults, by other children, by police and passers-by. Instead of sympathy, they are labelled as 'bad' children, who must have done something to deserve to be on the streets. They are blamed for being there, insulted, mistrusted, ignored, beaten.



*"Selling apples. This is where we are mistreated, in the streets by some people"*

Girl, aged 14  
Street Children, urban

### Mistreatment

We have chosen the term 'mistreatment' to cover the experiences of stigma that children have in many families, which are often justified by the blame heaped on children. The mistreatment, or abuse, described by the children as their experiences of stigma included: being given a heavier workload than other children at home; needing to 'work for their keep'; sexual abuse; and receiving harsher punishments.<sup>9</sup>

### Heavier work:

One of the manifestations of stigma towards orphans is that they are given a heavier workload to do in the house, in exchange for being kept by the family. It is generally expected that any child will carry out some household tasks: sweeping, washing plates and fetching water. However again and again, the children in the study, both orphans and non-orphans, reported that orphans are given more and heavier work to do than the other children and they experienced this as discrimination and sometimes, as a punishment, simply for being an orphan.

After listening to the workshop story of 'Mary', the children in Misisi discussed for a long time about the many children like Mary in their community who have to do all the work in the house.

*"Their aunt tells them to draw water using big containers, and to do all the household chores. She mistreats the children".*

*"Sometimes they are made to carry big things like water containers, and walk in the hot sun".*

*"There are a lot of children like Mary, some think of committing suicide".*

*"When my father died, I stayed with my aunt who mistreated me, doing all the jobs at home".*  
(out of school group, urban)

Girls are often expected to work even harder. One boy, from the Community School in Misisi, described how his father mistreated his sister, after their mother died.

*"The father gives the girl more work to do than the boy. He does not care whether the children are overworked or sick.....The father is not even concerned about her as long as the work is done"* (15 year old boy, community school group, urban)

Carrying heavier containers of water or drawing water more often was commonly reported as a task that always was asked of orphans. Tennant, 11 years, from Misisi, told how the girls were often made to carry even bigger water containers than the boys. *"This is child abuse!"* he proclaimed.

One of the street children recounted how he had run away from home because he was told to do all the housework alone. The drama depicted by the urban street children showed an orphan who is taken in by a family when his father dies. His aunt mistreats him by telling him to do the cooking, cleaning, washing, laundry. He is told to sit on the floor instead of the chairs and to eat separately. The children who performed the play explained the aunt's behaviour by saying she thought he had 'come to disturb the peace of their family'.

Sometimes the burden of the work can interfere with school, as reported by one of the pupils from Kamwala, talking about his school friend.

*"A certain child is mistreated by the stepfather who is giving him hard work to do when it is time to go to school".*  
(school-attenders group, urban)

In the drama presented by the school children in Chilalantambo, the orphan was given so much work to do (including bathing the aunt's other children), that she had no time to study. Fortunately in the story, she was so clever she still came top of the class.

### Sent out to work:

When a family takes an orphan in, they often expect that child to contribute to the household by working. Often orphans are sent out to earn money, usually to sell goods in the market. 'I work for food' said Van, 9 years old from Chilalantambo. His step-brother goes to school, but he must work to stay with the family.

One 11-year-old girl from Misisi reported that her aunt sent her out on an empty stomach, to sell mealie-meal<sup>10</sup>. When she returned, the family had finished eating and there was no food left. Being sent out to work and, as a consequence, missing meals, a reoccurring story among the orphans. Donald, a 15 year old, from the Community school, told how his aunt had sent him to sell at the market when he was very young and he did not understand how to work out the amount of change to be given to customers. When he returned with 'lost profits' he was beaten and chased from the house.

This type of mistreatment is described by some of the adults in the community as a way of showing the children that they are too much of a burden. In giving them so much work, some adults even hope that the children may leave home.

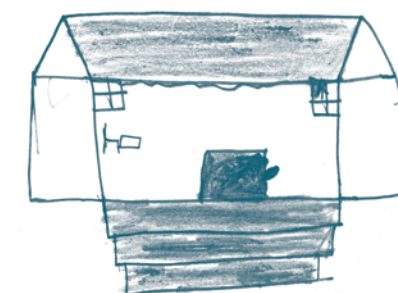
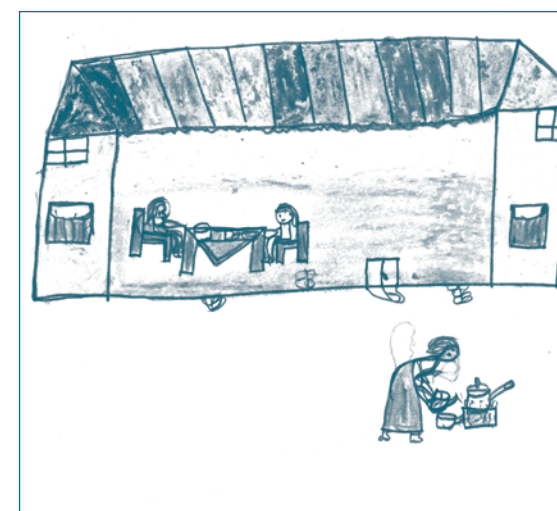
*"Even if one gets these orphans, it will be very difficult to look after them, and maybe these days people are just interested in the money and the things the deceased left behind. After everything has finished these children are mistreated, chased from homes, given conditions if they want to eat whatever they have prepared*

*"The father does not care whether the children are sick or overworked. The Mother died of HIV/AIDS. The girl is sick and the brother takes her to the clinic. The father is not even concerned about her as long as the work is done"*  
Boy, 15 years old, Community School, Urban



*at home, like sending to them to markets, on the streets to sell little things, so that they are seen as burden to some families. This is another way of chasing them, you find a lot of street kids these days".*  
(TB patients, urban)

*"The parents of the orphan died of HIV/AIDS. The aunt and cousin mistreat the orphan. No food is left or given to the orphan to eat and the aunt with the cousin gives the orphan household work to do, but them, they are just sitting"*  
Girl, aged 13, Out of School Group, urban



<sup>9</sup> In a recent Zambian study, most children (72%) said that they believed that adults treated orphans differently from other children and 42% of the children said that adults favour children with parents, while 28% said that orphans are mistreated. (Scope OVC study)

<sup>10</sup> Mealie-meal is the staple food in Zambia, made from ground maize.

Again girls often face greater pressure to earn their living and are more likely to be sent to sell at the market. The pressure on the children to earn their keep can lead to selling sex. If girls are told not to return home unless they have sold the goods, or earned the money, they may be drawn into transactional sex to meet these demands.

*"That is why children get confused, like the girls they will try to be independent and try going around with men to make ends meet. Doing that she will meet the fate that killed the parents that is the HIV/AIDS, all this it is because of the bad treatment from the people keeping them".* (Health providers, urban)

This is a reoccurring theme in both urban and rural sites and further portrayed in the drama sketch performed by the out of school teenage girls in Misisi (see Box 2) which was a mirror of their own lives.<sup>11</sup> The sketch also resonates with findings from the multi-country study (see Nyblade et al 2003) that girls and women (including mothers) are more vulnerable to being blamed for becoming HIV-positive.

In the village, the scenario is similar for orphans, though the work is in the fields rather than the streets. Owen from Chilalantambo is sent out to the fields to 'work for others and earn what I can'. His friend Golden, as well as drawing water and cooking for others, must herd the cattle for his step-mother.



*"I usually do the work at home. There is no one to help me. Cooking, washing, sweeping, planting"*

Girl, aged 11  
Street Children, rural

### Box 2: 'Girls at Risk'

Drama sketch, urban out of school group

#### Girls at Risk

The story involved three sisters and their parents. There is no food at home and the father tells the older girls to go out and 'look for money'. The girls dress up and go out late in the night. When they return the next morning, the mother scolds them and tells them they are 'being reckless'. The girls hand some money to the father, who is very happy now. The young sister is worried about her sisters.

One day one of the older girls returns from a night out feeling very sick and in pain. Her mother takes her to the clinic - she is diagnosed with HIV. The father now shouts at her and tells her she has been misbehaving and it is her own fault that she is infected. He does not want her in his house.

The mother and other sisters beg for his mercy and the mother reminds him, that it was he who sent the daughter out to find money in the first place.

Sometimes this type of mistreatment leads to children taking drastic measures, which may have long-term consequences. Pretty, from the Street Children's group in Lusaka, described how her friend fled from home.

*"Life for orphans is not easy. They stop going to school due to lack of support. For example, I have a friend who ran away from the guardian's house because of heavy mistreatment. She had gone to the boy friend's house and started staying with him, who is now the husband."* (15 year old girl, street children's group, urban)

*"A picture about an orphan who is usually mistreated. Cooking, drawing water, herding. After finishing all the work, he goes to school"*

Boy, aged 13  
Out of School Group, rural



*This word and this picture by B. M.*

In Choma, most of the children do not live on the streets permanently, but work there, selling vegetables and fritters in order to bring money home for their families. They spend the majority of their time on the streets. Some were staying with older grandparents, others had sick relatives or younger brothers and sisters whom they were supporting.

Mada, 14, from Choma, stays with her Mother who is sick. She sells apples in Choma to support the family.

*"When I go to town and there is no business that day, it means we won't have something to eat at home. Thieves grab our food, the council and police chase us from the corridors [pavements]. I have never been called names but I feel different to those who don't sell on the street".* (14 year old girl, street children group, rural)

#### Sexual abuse of girl orphans:

Not only outside the home, but within the household, girl orphans are extremely vulnerable to sexual abuse. This was not reported by any of the children in the study but adults in the community frequently discussed this abuse and other studies in Zambia confirm the frequency of sexual abuse within the home (ZDHS 2002).

*"...in terms of behaviour you find that they are forced into certain situations and abuse situations which they wouldn't have been if their parents would have been alive. There is a case of one child, a month ago, her father died. She went to live with an uncle after sometime he started abusing her...in a normal situations she would not have been exposed to that, but because of the illness"* (doctor, rural)

#### Harsher punishments:

A recurring theme reported by the children in the study was that if they make a mistake, orphans are given punishments that are harsher than other children might be given. Sometimes their mistakes are blamed on the fact that they are orphans and sometimes they are brutally reminded of their parents' death, when they are in trouble.



*"This picture is about a girl whose parents died of AIDS. She is sent to the market to buy things and on the way home the money gets lost. After reporting back to her aunt the aunt just poured hot water on the orphan, but she can't pour hot water on her own children."*

Girl, aged 12,  
Out of School Group, urban

Moddy (community School group, urban), whose parents died from TB, stays with her aunt. One day she accidentally tore her dress while she was playing. As punishment, the aunt sent her to draw water while the other family members were eating, and then gave her extra work. She stayed without food for the whole day.

Often the punishments seem to reflect the anger or frustration of the adults – often women -, rather than the severity of the child's mistake. Orphans bear the brunt of this anger, which is fuelled by poverty and lack of resources. From the outside, it is easy to understand the anger and desperation of a parent or guardian who has only a little money to feed the family, when the money gets lost, but when the anger is turned on children in verbal and physical abuse, the children feel they are blamed and stigmatised simply for being orphans.

*"Another day the lock of the grill door was damaged and my step-brother didn't know what to do about it...so I was told to sit on a chair next to the door all night- if the thief comes, I have to wake them up. I had to sit all night since I would be answerable if anything was stolen".* (Boy, 16 years, street children group, urban)

<sup>11</sup> Counsellors were so concerned about the possible involvement of these three teenage girls (aged 13 and 14 years) in sex work that during the lunch break, they took them aside and discussed condom use with them.

Within the household, the stigmatisers of orphans are often reported to be women - aunts and step-mothers in particular. This is a reflection in part of women's responsibilities to feed the household and nurture the children; in the context of HIV infection and extreme poverty, women are stretched to breaking point and it is easy to see how this stress could be directed against the most powerless in the household - namely orphans.

*"You now find eating will be only in the evenings, the uncle thinks they eat even during lunch, but it is not the case [since] the wife married to the uncle doesn't want the children. The only thing she does, is to send them to go and sell Sorghum to the markets. If you don't finish what you are given [sell the sorghum], it means that the child won't eat the food".*  
(Health providers, urban)

The vulnerability of the children's situation is also used as a punishment or a threat, as a constant reminder of the fact they have little power and are dependent on their guardians. Patricia, 17, described how she first found out that her real mother had died, and that her mother was her step-mother.

*"I did something wrong and when correcting me she said you shouldn't trouble me after all I am not your real Mother..."* (17 year old girl, School-attenders group, urban)

Many orphans feel that no matter what they do, they will always be punished more harshly, and they will feel that any kind of punishment is something to do with the death of their parents.

### Deprivation

Stigma associated with deprivation is often intertwined with poverty. Where resources are scarce, the way in which they are allocated is loaded with meaning. This is true both in families and communities. Children from all the groups were deprived either materially or emotionally, and the children often described this as a form of stigma. This deprivation often starts during the parents' illness, and extends to affect their life after their parents die, becoming particularly acute if they end up on the streets and/or HIV-positive.

*"I have talked to children who have left education because their parents are too ill to go for work - they are released from work, they are no longer working, education wise nothing, two, food wise they have to be forced to look for food and doing income generating activities at a very low age..."*  
(doctor, Choma Hospital)

*"There is this child whose parents have died of HIV/AIDS and the child also is HIV positive with TB and she is being looked after by an uncle, but he is not looking after her the way he is suppose to do but they are still living in her late father's house, but the support, financial and material aspect is not there, don't even know the emotional aspect of the girl, so this child is more like an out cast in her fathers house".* (health worker, urban)

Children living with HIV are also deprived of good health. Being sick on and off for the children in the treatment group made them feel different and could instigate stigma, although many of them did not seem to understand (or perhaps were too young to understand) their HIV status. A rural health worker relates how a child living with HIV asked him, *"Why is it that I am not like others. Always I have these frequent headaches, I have to lay down...when I run a little bit I get tired, my friends can play football, me just one or two minutes I get tired. Why? Am I different from others?"*

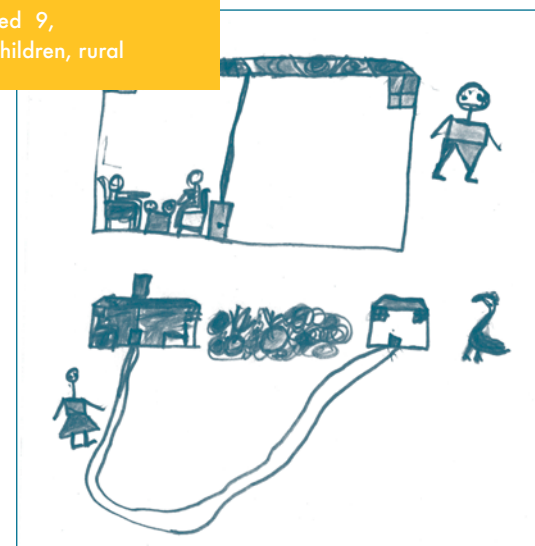
### Material Deprivation

**Deprived of food:** Orphans often mentioned being made to eat last or alone, and being sent out during meal times to do chores. Withdrawing food was often used as a punishment or a way of rejecting an orphan. Mealtimes in Zambia are an important event and no matter how poor, there will usually be a time when the family sits together to eat. To be excluded from a meal, or told to 'eat alone' gives a child a clear message of not belonging.

Some members of the community recognised the mistreatment that some orphans face and the way in which food is used to show anger or displeasure.

*"The orphan is sent to the market to buy vegetables and chicken, while others are eating"*

Girl, aged 9,  
Street Children, rural



*"The children will remain orphans. So these children [are] being blamed for their parent's behaviour. You find even in homes where these children are kept, they are given K100 to go and buy tomatoes and they demand the change from them. If they don't bring the change, no food for that child. That is just another way of trying to chase the children from their homes".* (health providers, urban)

**Deprived of education:** One of the greatest losses suffered by children affected by HIV is that of education. This can happen because of poverty or because of deliberate exclusion when children are believed to be HIV positive.

Many of the orphaned children spoke of how they felt that they had no opportunity to attend school. Although many understood that there was no money for school fees, they witnessed cousins or stepbrothers attending school while they were kept at home to work. This is what they described as stigma - that because they are orphans, they are not considered for education. Many felt that if their parents were alive, they would find a way to help them to go to school.

*"There is no sponsorship but I believe if my Mum and Dad were around I was going to start school"* (14 year old girl, out of school group, urban)

*"It pains me that I don't go to school because if my father was here I was going to go to school"* (13 year old girl, out of school group, urban)

*"I am usually mistreated by my stepmother. I work for food. My stepbrother goes to school but I don't".* (9-year-old boy, out of school group, urban)

Members of the community were also aware of the impact that the parents' deaths had on the child's education, where resources are scarce or grandparents became the guardians, or a family resents caring for the child.

*"Those children are not well taken care of. They are abandoned. Sometimes you find that a child who used to go to school, but after the money left by parents is finished, they stop school. Many stop school - we see them. They really don't stop well and are given hard jobs".* (Gardener, rural)

*"Children really suffer in terms of education, no one is willing to take them to school, no one to give them food..."*  
(health worker, urban)

Children living with HIV are often excluded from education because of stigma perpetrated by both teachers and other pupils. One of girls in the Treatment Group told of how she was recently feeling quite sick but was under pressure to do well at school from her Auntie. She had attended school but the teacher had sent her home again. When she reached home, her Auntie scolded her and told her to return to school. This stigma is recognised by members of the community who predict that children living with, or 'suspected' to be living with, HIV will face adversity at school.

*"Even at school, if the school-going [child] is also showing signs and symptoms, the fellow pupils wouldn't want to mix, thinking may be they might contract the disease. The child feels how and the performance in class goes down".* (Pregnant women, rural )

*"Teacher will not say anything they will just look at her, maybe gossip her and other pupils will be looking at her with bad eyes and this will make her stop going to school because of the bad treatment at school". (Rural women)*

In the rural site, a counsellor supporting children living with HIV recalled how teachers who know that the children are suffering from HIV, don't let *"that child mix or relate with other people, there is that barrier"*.

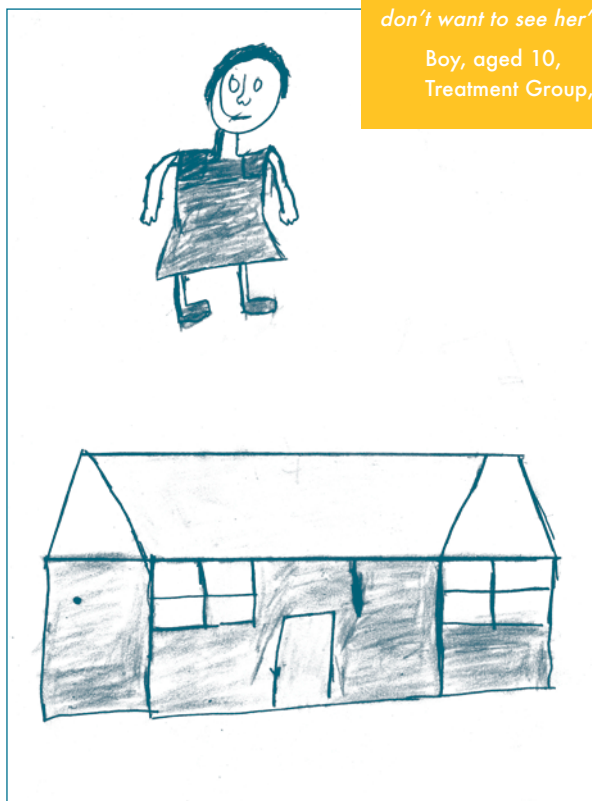
The children living with HIV reported incidents where they had experienced stigma directed against them at school. They talked of friends who refused to sit next to them or play with them or even to be associated with them and of teachers who excluded them for apparent sickness, even though they were feeling fine. For some of these children their experience of school is one filled with loneliness and exclusion.

*"My teacher chased me from school because of I had sores on my body. I didn't have problems with my friends"*.

(10 year old girl, Treatment group, rural)

*"This picture shows a child who is alone because her friends don't want to see her"*

Boy, aged 10,  
Treatment Group, rural



*"There were times at school I was treated badly by friends who didn't want to play with me because I had TB. I felt I was different to them. They thought they might contract the disease from me"*.

(10 year old boy, Treatment group, rural)

The fact that most street children are obviously not in school is a reason to stigmatise them. For example, Wele, aged 13, and his parents were chased from their village by his uncle, after his mother fell sick with TB. Wele lives in Choma and sells fritters by the bus station.

*"The police also chase us away. They say 'go to school'. We are different from other boys who have everything because we are poor and are called street vendors. Even at home, they laugh at us when we go to sell. I don't feel alright, anyway it hurts inside me."*

(boy, 13 years, street children, rural)

**Deprived of Shelter:** If children leave homes where they are being mistreated, or if there is no one to take care of them after their parents die, then they are deprived of shelter. Street children face a particular type of stigma because they are both 'displaced' and 'cast out' from the rest of society and completely visible, living in public view, having no homes to go to. Common stories from the street children were of adults insulting them - usually with reference to their appearance ('dirty' 'smelling') or to how they 'made the town dirty'. Street children recounted how the police instructed them to move and to sell their goods in the market.

In Lusaka, the children had often run away from abusive situations at home, or literally did not have anywhere to stay, after deaths or break ups in their family. Most of the children were sleeping at the Street Children's Centre. The Choma street children mostly had shelter - with relatives - but were working on the streets.

When the street children in Choma performed their drama sketch during the workshop, they chose to depict life on the streets. Children gathered to begin selling and at first, were intimidated by older street vendors, who insulted them and told them to stay

*"This is about life on the street. A street kid asks for help from people passing by like 'Boss come and help me, my friend has abused me by having sexual intercourse. He used force, I never allowed him' 'You street kids get away from my sight'"*

Boy, aged 16  
Street Children, urban



away from certain areas. Then the children were chased by the police. They were told that they 'don't belong in Choma' and were making their town 'dirty'.

The drawings and children's descriptions also reflected the hardship of life on the streets, including the sexual abuse of both girls and boys who live or earn their living on the streets.

**Emotional Deprivation**

Emotional deprivation is both an experience of stigma and one of the consequences; partly as a result of stigma children are neglected or unloved, and then grow up without adult affirmation, or without being, or feeling included, in a family, or supported by friends.

**Deprived of love:** Taken in by over-stretched, and over-stressed families, carrying the blame and shame of their parents' illness and sometimes their own infection, children learn to survive in situations where there is little or no love or affection by adults. This lack of affirmation from adults - no one 'looking out for you', taking care of you and wanting to know where you are and what you have been doing - leads to a sense of some children being 'invisible'. Children have a diminished sense of identity if they spend most of their time outside the home and out of school.

During the workshops, the out of school children who were exceptionally deprived, displayed huge difficulty in participating in some of the activities, particularly the introduction games and the drama.

For children who receive little attention at home or elsewhere, the act of putting themselves in the spotlight, or 'performing' in front of others became a major struggle. Ironically, even the urban street children, in touch with the

street children's centre, retained a stronger sense of identity and self, which is reinforced by regular contact with the institution and the centre staff.

Deprivation therefore arises partly from stigma and this seriously undermines a child's sense of identity. These children grow up feeling worthless and never embraced by others.

**Box 3: "Who am I?"**  
a name game

At the start of each workshop, we played a name-game with the children, so that the child counsellors and research assistants could get to know them.

The game involved standing in a circle, with each person taking turns to say his or her name and doing an action or gesture to go with it. The next person then repeated their name and gesture, before saying their own name.

For nearly all the groups of children, the game seemed to be a fun way of introducing themselves and each other. However for the children from the urban area who were out of school, the game seemed to be the most difficult task.

Standing up and saying your name in a group with strange adults can feel like an insurmountable feat, when you are not used to anyone asking who you are.

The community also acknowledged that although families will often take orphans in, they would not receive the same kind of love as other children.

*"These children are suffering, but I can look after the children because the parents died but love will not reach like the parents of that child better than me because I also have my own children and my children loves me and to make them happy like their parents used to, is not very easy". (gatekeepers, rural)*

Children articulated this lack of love, mainly in terms of feeling alone, and missing their parents.

*"I know I am an orphan. My father and mother died. I feel like I'm just alone".*

(10 year old girl, Treatment group, rural)

**Deprived of a sense of belonging:** Many children reported feeling lonely most of the time and many expressed a sense of 'not belonging', reinforced by guardians viewing them as disruptive and other children resenting their presence. There are many ways a child will experience 'not belonging' through mistreatment, blame, abuse, neglect and these conspire to make the child feel unwanted and alone.

A sense of belonging is necessary for healthy social development. If children feel rejected, isolated, unloved or not valued, this will have a detrimental effect on their self-esteem and identity in the present and in the future. They may find it difficult to mix with other children or adults and feel isolated even in everyday activities.

Feelings of rejection can turn to anger and aggression. A child may reach a point where there is nothing left to lose and start engaging in risk-taking behaviour.

Street children in particular are likely to grow up feeling that they are not part of a community and without a sense of belonging or security. Everyday experiences of stigma continually reinforce this feeling. Passers-by render them invisible, marketers hurl insults, police chase them. Even pleas for help go unheard.

*"I feel bad when I think of my parents and, when I see friends who have both parents, I cry to myself".*

(16 year old boy, street children group, urban)

#### **Deprived of support to cope with loss and grief:**

Orphans may have nursed parents through illness and witnessed their painful deaths.<sup>12</sup> When they lose their parents, children face uncertainty about their future. They may be separated from siblings, withdrawn from school, moved from the

friends and community that are familiar to them. These are all traumatic experiences, particularly if you are a child with little or no power over the future.

The silence that surrounds the death of parents can be very harmful for children. At the time when children need the most support, they are usually deprived of adults who will take time to talk with them, who can support them or offer reassurance and guidance. When children are emotionally deprived and have no one to talk to about their grief, loss and experiences, this may lead to trauma, self-blame and anxiety.

*"So I used to feel bad, I cry all the time and even wonder why my parents had to die".*

(10 year old girl, Treatment group, rural)

*"I don't know what killed my parents and people at home don't even want me to ask them about the death of my parents".* (11 year old girl, Community School group, urban)

Forty-six out of the 78 children in the study were orphans and had lost either one or both parents. Many had witnessed the death of their parents and some had lost siblings too. Except for a few children in the study, most did not know the cause of death of their parents. They were not prepared for the parent's death. Some suspected the cause of death as HIV and AIDS or TB.

Some children may witness multiple deaths - sometimes being moved from one family to another as aunts or uncles fall sick. This is likely to increase a sense of self-blame and guilt for the children, who may feel indirectly responsible for the deaths, and who will grow up without the security of a constant adult in their life. Some children will find it difficult to form attachments either to adults, or later in life as adults themselves. They may never be able to trust that someone will stay with them, having experienced abandonment so many times.

What was more evident from these children's stories was that there were very few who felt loved and supported either by the surviving parent or the guardians. This often meant that they had little

chance to discuss how they felt about their parents' deaths, or to be given emotional support to come to terms with their new situation. Many have to cope with their grief alone. For many children the opportunity to grieve and mourn the loss of their parents - and to some extent - their security, had been surpassed by anxieties about the future, and trying to settle into new homes/families.

During the individual interviews some of the children told us that they had never talked about their parents' deaths to anyone before. Many were visibly upset, crying and shaking, having not expressed their grief before.

The long-term effects of not expressing feelings are well recognised by counsellors and include: depression, loneliness, isolation, feeling powerless, aggression and emotional outbursts. Coping with the trauma of death alone can have a profound impact on a child's well being. Many of the children reported that they often felt lonely and depressed.

When asked about the impact of AIDS on children, many adults recognised the difficulties faced by children, whose parents get sick. The effects on children that adults mentioned in the study included: loneliness; self-isolation; anxiety about the future; depression; failing at school; and being 'disappointed with life'.

*"Parents, mother and father are breadwinners. But then to see them go - the children are lost, they don't know what to do - they don't know where to go. How do they feed themselves and how do they get clothes? In a house, nobody is going to look after them."*  
(Man retiree, rural)

*"They are affected in the case that they have no one to look after them. I think that it is a very big effect to lose their parents, a very big effect on a child".* (Head Teacher, rural)

#### **Children's role in stigmatising others**

Most of the stigma experienced by children is perpetrated by adults. However children also experience stigma from their peers, and some children even stigmatise adults. Children learn how to treat other people from adults and in a society that demonises HIV and AIDS, it is inevitable that children will pick up on this attitude and at times become the perpetrators of stigma.

In our study we found several examples where this happens, particularly where children voice or enact stigma against children living with HIV. It was evident from both adults and children in the community that children are often told by parents and guardians not to play with children who were believed to be living with HIV, were orphans or whose parents were assumed to have TB or HIV or AIDS. This stigma filters down and results in some children being excluded by other children, especially at school or in the neighbourhood.

One of the boys in the study admitted to stigmatising a young boy who was believed to have AIDS. He and his friend refused to let the young boy play football with them. In the household study, TB patients recalled how their children would often stay away from them because they were afraid of being infected with TB and how their children's friends might stop playing with them.

The younger children in the study showed the most fear around HIV and AIDS, especially in the play exercise with the toys. In three of the groups, when the children were told that one of the toys were sick, they moved their own toys away, saying they did not want to mix with the 'sick toy' and even that they would 'beat her'. However when the toy feigned sadness or loneliness, the children were quick to relent and come back to join together again.

Several adults in the community had seen or known about stigma directed against teachers by pupils, when the teacher fell sick.

*"School, if it is the teachers then the pupils would not want to be close to them. They would be afraid of his looks".* (health worker, rural)

Towards the end of the workshops, after a lot of discussion about stigma, children were asked about ways of changing or challenging stigma related to HIV and AIDS. Many had practical suggestions and showed sympathy towards people living with HIV (see recommendations). Like many others, when children are conscious of the hurt caused by stigma, they seem committed to fighting it.

<sup>12</sup> In the household sub-study (see Bond et al 2003), it is evident that when parents fall ill with TB, children play a central role both in care giving and income-generation.



### Some children did not experience stigma

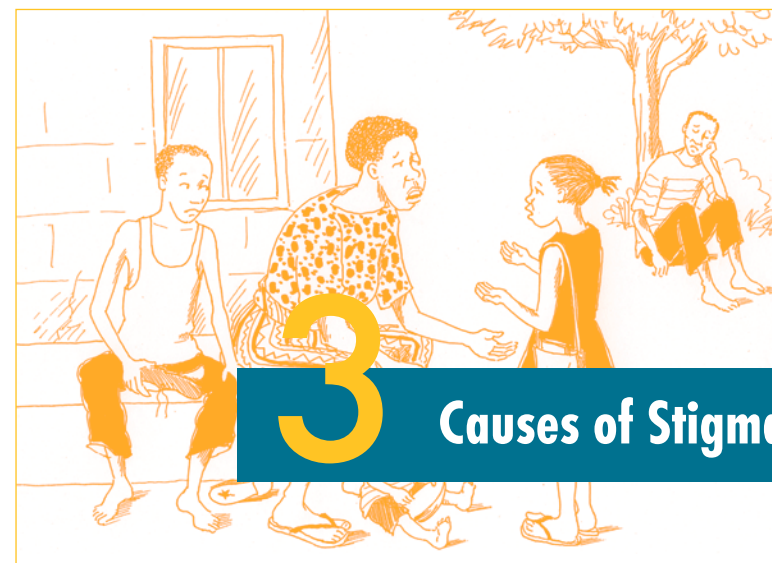
Not all the orphans experienced stigma at home. Some children experienced difficulties, mainly caused by poverty but these problems were unrelated to stigma. One 13-year-old boy told of how his parents had died of TB and he now lived alone with his grandfather. To make ends meet he helps out with repairs at a carpentry workshop. He says when they give him money, he is happy because he can buy clothes and food for his grandfather.

#### Box 4: Just one of the family

Angela is 11 years old and lives with her aunt and 5 cousins. Two of her other cousins are double orphans like Angela. Angela's mother died when she was 7 years old.

Angela says that she is treated like the other children in their family - they all do chores around the house, to help their auntie while she works at the market.

On Sundays they go to church together. Angela describes her family as one where 'we are all happy'. (see cover picture)



## 3 Causes of Stigma

Below is a brief outline of some of the causes of stigma against children. The focus of this study was the way in which children experience stigma and how they cope with its impact and many of the causes of stigma against children are the same as those for stigma against adults. For a fuller discussion of the causes, see the main country report (Bond et al 2003).

### Poverty and burden

*"Maybe due to the economy which is biting and so it's hard for people to keep orphans"*  
(15 year old boy, community school group, urban)

One of the main causes of the stigma perpetrated against children, particularly orphans, is poverty and its impact on family life. Although children have reported feeling stigmatised when they are forced to leave education, or not given enough food, there is a general consensus that poverty instigates these events and what the orphans experience is reflected in the fact, not just that they are orphans, but that they are orphans in a poor society. Barnett (1992) writes about perpetual poverty and how it impacts on family life. The stress caused by a continual lack of resources, may result in both physical neglect and emotional neglect of the children.

### Fear of Contagion

Lack of in-depth knowledge and popular knowledge and fears about the transmission of HIV fuels stigma. Stigma against children living with HIV/AIDS is usually bound up with misconceptions

or exaggerated concerns about transmission of the virus, reflected in instructions given to children not to play, sit, share cups with children associated with HIV.

Fear of association with people living with HIV and AIDS is transferred in some families onto children whose parents die. The idea of becoming somehow 'polluted' by contact with children, leads to secondary stigma, where adults believe, not only that the children inherit HIV, but even the 'immoral' behaviour associated with it.

*"In the village they call them outcast - maybe the parents used to misbehave so that they may think that they also contract the disease from their parents. So they will try by all means to avoid those orphans".*  
(secondary school girls, rural)

### Past Relationships

The relationship that the new guardians had with a child's parents before they died can also affect the way an orphan is treated. If there was a poor or distant relationship with the deceased parent, this may be projected onto the children.

*"They say to the children that their parents never used to behave - hence they will suffer 'we will not help you'"* (young women, rural)

If guardians were close to the dead parents, and there was no overt judging or moralising about their behaviour, orphans are more likely to be welcomed and treated well.



*'In this house there is a sick person and the owner of the house doesn't care for the sick person but the small child is very merciful, by taking care of the sick one. The sick person is suspected to be HIV positive or have TB'*

Girl, aged 13, Street Children, urban

Other children talked about, or drew pictures of incidents where kindness was shown to people who were sick with HIV or TB, showing that not everyone automatically discriminates.

One boy even seemed puzzled by the idea of stigma. He said 'We are keeping two orphans at home and they are treated as family'. Another girl told of how she lives with her auntie and cousins, and they are all one family.

### Values

Children and teenagers are often regarded as unruly, out of control, lacking moral values and presenting a threat to society by their elders in the community. Along with women, youth have become a focus of blame for the transmission of HIV (see Nyblade et al 2003, Bond et al 2003). If stigma is about social control then it is most apparent in the prejudice against street children. Many people view street children as thieves, petty criminals and gangsters. When people express prejudice and judgements against street children they may be expressing an underlying collective fear of the 'uncontrollable' – children without parents, without guidance, sanctions, responsibilities or belonging.



#### The Spiral of stigma, children and HIV:

Stigma can increase children's vulnerability to becoming infected with HIV. Many adults in the community described how the death of a child's parents can lead to the child being neglected and the likelihood of the child becoming involved in risky sex.

*"It feels as if you are not part of the family and you will be forced to start misbehaving [having sex] in order to find some money and earn a living and once you are infected they won't accept you back into the family".*

(young man, urban)

*"Although the only problem they are facing, they can also be abused. You know when you are sending a child to go and sell corn, the customer might be someone who is not interested in buying the corn but to abuse that person that is all and the risk comes in".*

(Project Manager, male, rural)

Where poverty is a factor, guardians may even collude or encourage risky sexual behaviour.

*"Orphans are in a difficult situation where they need our comfort or sympathy. If a widow is keeping a lot of orphans, she will allow them to be promiscuous in order to survive economically. Its not that people don't want to keep those children its just that our economy is bad in the sense that she has 3 children and to add on other children it becomes a problem".*

(elders, urban)

Figure 2 (over page) conveys, against a background of extreme poverty and gender inequality, how parents illness and death, less parenting, the burden of care, material and emotional deprivation and the pressure to survive feed the stigma of being an orphan and lack of self worth **and** increase the likelihood of both taking risks and being infected with HIV. Taking risks and being HIV-positive are moreover associated with deeper stigmas (the stigma of being on the street, selling sex and the stigma of being infected with HIV).

#### The psychosocial impact of stigma:

A child's progression through basic developmental stages is jeopardised if consistent love and care from a parent or guardian are not present. Development is also jeopardised if HIV and AIDS cause social isolation, stigma and discrimination or otherwise disrupts normality.

As well as the impact on a child's self-esteem and sense of worth, stigma has other consequences on a child's well being. Children's emotional needs include love, security, encouragement, motivation, care, self-esteem, confidence, trust and security, a sense of belonging, guidance and understanding. Children need to be heard and need to express their feelings.

By definition stigma makes a person feel different from other people or discredited, in the eyes of their peers. This affects a child's social interactions, their sense of belonging and identity. A child who is stigmatised may be deprived of support and guidance

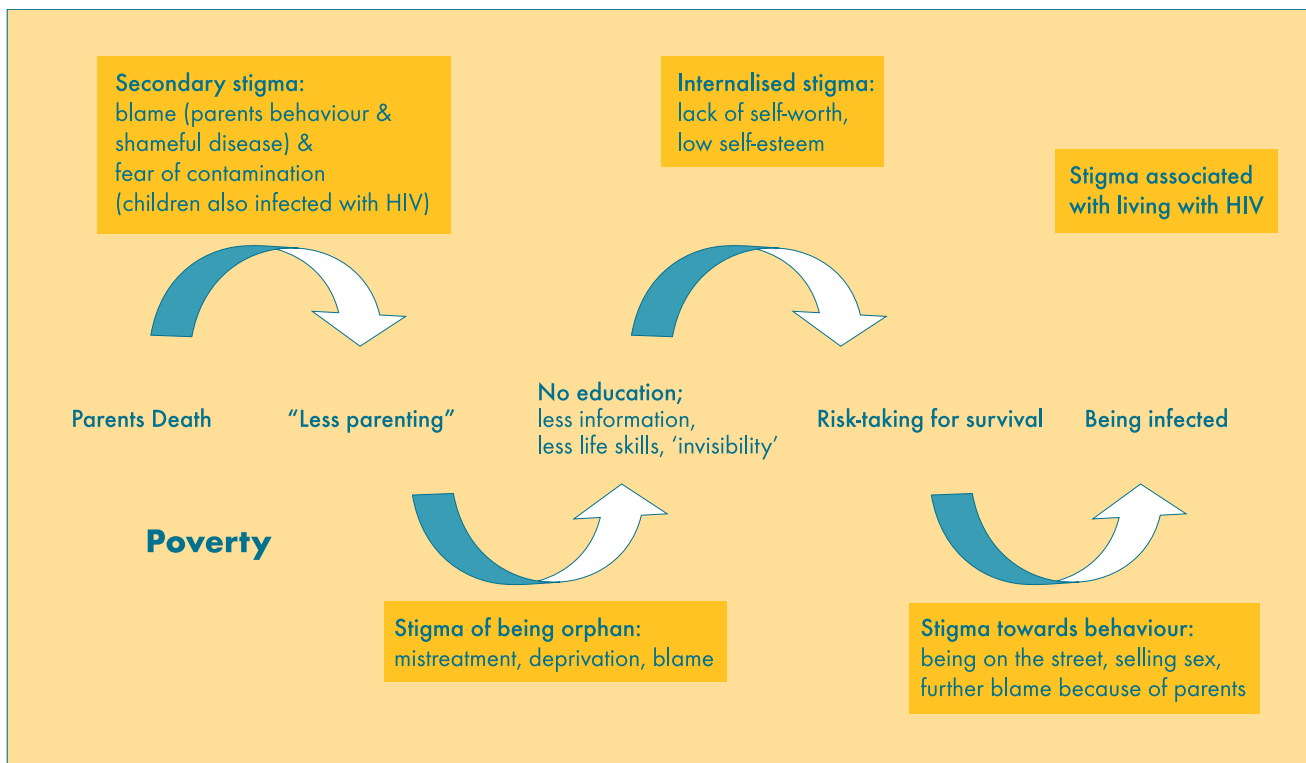


Figure 2: The Spiral of Stigma And Risk-Taking

from adults and peers and will find it difficult to learn life skills - emotional skills, assertiveness, relationship skills, decision-making and problem-solving skills. This in turn means that coping skills to meet the challenges of life are limited.

**Internalised Stigma:**

Children who experience prolonged or sustained stigma internalise the messages of worthlessness and rejection behind the stigma, which impact on their sense of identity and self-worth. Accepting the blame for their parents' death or their orphan hood, can lead to feelings of guilt and shame. One boy said, "I should not have been born", (14 year old, Street children, urban) and another, 'It's my fault because I don't have parents'. (10 year old, Treatment group, rural) Many of the children showed signs of being withdrawn and isolated, and some found it difficult to interact with others.

**Depression:**

Many children reported that they feel sad. They cry a lot. They think about their parents a lot. Children who have lost a parent obviously miss them and wish they were alive. When orphans are mistreated, rebuked or deprived of basic needs, they feel the absence of their parents all the more. They tend to idealize the dead parents and believe, as one girl in Choma said, "if my parents were alive, I would not be suffering" (School attenders, rural)

Children's psychosocial difficulties are often compounded by silence. In many cultures it is taboo to discuss an impending death for fear of making it happen. If a family fears stigma, they may deny illness is linked to HIV and AIDS or to forbid discussion. In this climate, a child's anxieties and fears are not acknowledged or discussed. After a parent's death, grief is compounded if siblings are separated, or guardians fail to provide nurturing care.

The lack of care, love and support in the new home - or in the new school - pushes children back to their dead parents. This does not help the children to let go of the experience of the death and start adapting to a new life. In the long run stigma and rejection can lead to depression. Adults in the community often identified the psychosocial impact on orphans.

*"It is bad to see these children see their parents sick. Even us old people, you hear that your mother is dead or father is dead-it is bad"* (retired man, rural)

Feelings of isolation and loneliness contribute to children's depression. Children become withdrawn and interact less with others. One 15-year-old boy said he just keeps quiet, which may lead him to be withdrawn and unable to show any emotions as he grows up. Likewise, one of the boys living with HIV

said that when they laugh at him too much, he 'just sleeps'.

In extreme cases, depression that is not acknowledged might lead to suicidal feelings and ideas. Five of the children in the study mentioned during the individual interviews that they had at different times thought about suicide. During the fieldwork in Choma, a story was told about a secondary school boy at boarding school, who was living with HIV, who had recently committed suicide. He left a note saying "I can't bear the way people look at me".

**Box 5: All Alone**

Bernadette is 10 years old and lives in Southern Province with her older brother. Her parents died 2 years ago - first her mother, then her father.

Bernadette says that she feels lonely most of the time. She does not attend school as there is no money for school fees and she is often sick. This means she has few friends.

Bernadette has never talked to anyone about her parents' death. She thinks about her mother all the time and misses her so much.

She says, "People are treated badly at school and at home. I feel like I want to cry and I see myself as different from others. I think I am treated badly because I'm sick and I am always crying. I feel lonely all the time".

**Identity:**

Stigma impedes the development of a child's identity. As children grow and develop, they will identify with the parent or guardian in the family who later serve as role models. Children will incorporate family history, culture, memories and experiences into their identity. They learn from older siblings and elders in the family.

If a child's main experiences in a family or community are isolation, ridicule, shunning and abuse, the child's self image and self-identity will be distorted. This was particularly evident among some of the non-school going children, who showed less confidence and were more withdrawn in group activities.

**Sense of trust in adults:**

Children who are stigmatised grow up finding it difficult to trust adults and to believe that others can help them. When children experience adults as abusive, harsh, frightening and unsympathetic, they will learn that it is safer not to trust them and it is better to find ways of coping alone.

If children cannot trust adults, this will leave a long-term impact. As the child grows up they will find it difficult to form attachments and adult relationships.



## 5 How Children Cope With Stigma

During the workshop, and in individual interviews, the children were asked how they cope with stigma and difficult situations, or what they do when they feel upset, lonely or isolated. The strength of children's resilience is remarkable. Children who are affected by loss, sickness and stigma can bounce back with some support and loving care. Most of the children had found their own strategies for coping with the pain of stigma. These included turning to religion, talking to friends, sharing their feelings and fantasising about revenge and consolation. Some of the children moved from households where they were being mistreated.

### Leaving Home

Sometimes when children continually experience abuse and punishment they chose to leave home.

*"I was being mistreated, chased from the home all the time- that's how I started going to town, to do piece work in order to get food"*  
(15 year old boy, out of school group, urban)

Some children find other relatives to stay with, others are removed by relatives who recognise they are being abused and others move to the street, where inevitably they will face dangers and mistreatment of a different kind. In the Community School Group, out of the eight orphans who recalled being mistreated by the relatives they stayed with, five of them moved - four moved to (or were removed by) other relatives and one moved onto the streets.

### Turning to God/Prayer:

Religion and spirituality seemed to be a major source of strength for many children. Several children said that they pray when they feel sad. One boy said he 'prays and forgives and forgets' when his stepfather is mistreating him. Another said that he tells himself that his family 'don't know what they are doing' as he prays.

Children said that God helps them to think about forgiving, and even helping the guardians in the future, who are mistreating them now. With the exception of two children - one whom talked about a priest who is thin and is being ridiculed and the other who talked about gossiping among the congregation about a sick member - most children talked about the church as a source of support and an agency that can help to educate the community to reduce stigma for children.

The songs ("I trust my mother in heaven - I know that she cares for me", "Jesus' love is forever", "There is no one like Jesus") chosen by the children during the workshop, often illustrated the hope that they feel as a result of their belief in God and the strength that their faith gives them to cope with adversity. Their relationship with God is an important source of support for the children. They often attach their hopes for the future and a better life to their belief. Religion and faith are a significant source of strength.

### Turning to Friends:

Some children said that they turn to friends when they are mistreated or if they need help. One of the



*'This is a church where people are praying, never minding who is next to them, whether they have HIV or not'*

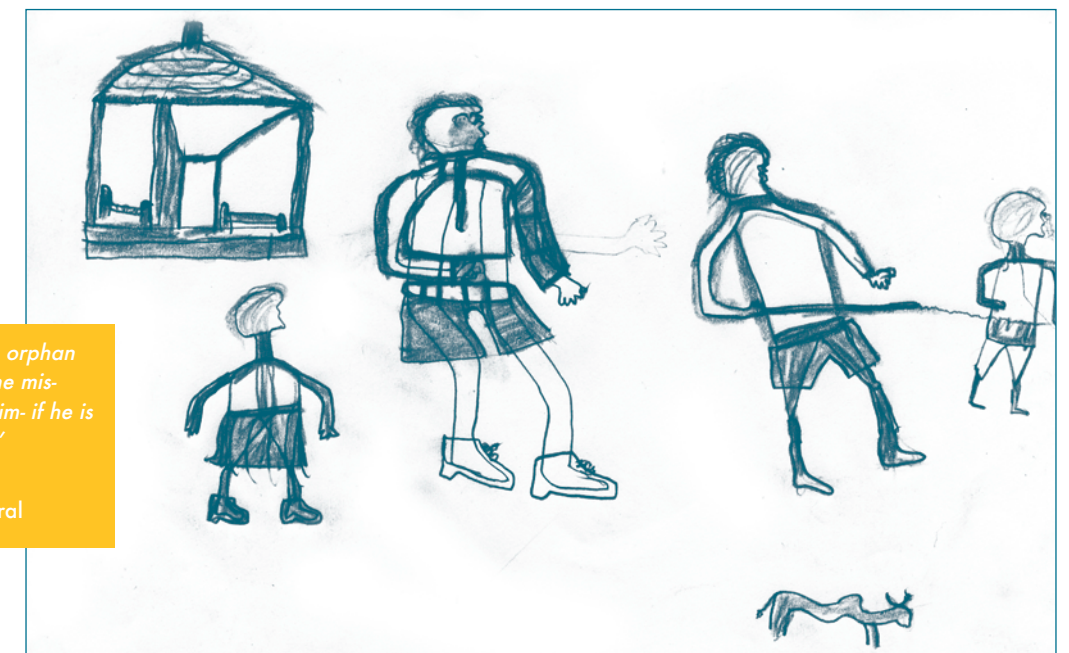
Girl aged 9,  
Out of School Group, urban

songs chosen by the group of out of school children was a Nyanja song whose meaning is 'coming together and showing love to each other'. Children have faith in one another and feel more able to cope with stigma if they can count on their peers for support and love.

One boy, Austen, drew his picture to show how his friend is mistreated. He wrote underneath 'when he is beaten I go and comfort him'. One of the orphans who was being badly mistreated at home, when asked if he talked to anyone about his situation, replied "I do, a friend of mine who keeps secrets". One of the girls from the same group said that she goes to her friends if she needs to talk to someone.

*The stepmother sends an orphan to go and herd cattle. She mistreats the child. I know him- if he is beaten I go and comfort'*

Boy aged 13  
Out of School Group, rural



When asked how children can help to fight stigma, again and again, children said *we must help our friends*. In the drama by the street children, an orphan boy is left without food at home, and is given so much work, he cannot go to school. One of his friends comes to see him, and helps with the chores. Later he brings him food, saved from his own meal. There were many similar recollections of helping friends out.

### Expressing feelings:

The hurt and damage that stigma causes is alleviated when children talk about their feelings or express them directly. Once feelings are expressed,

they no longer hurt the child so much. In the study, many of the children had different ways of expressing their feelings. One girl always talks to her mother if she feels upset, one of the boys talks to his father, another said that she

talks to 'Aunty Bertha' at Kara Choma, and then she 'feels fine'.

Even if children said they did not talk to anyone, they could still acknowledge that they felt angry or hurt, which can be the beginning of learning to express feelings.

Expressing anger through aggression can be a powerful way for children to cope with stigma, as long as no harm is inflicted on anyone, and guardians understand the child's actions. In one of the play

exercises, the young children insult and beat the doll who is an orphan - maybe recreating their own painful situation. The doll fights back, turning passivity into action, as the children try to master the painful experience and become less powerless.

Two girls reported that they sometimes fight back if they are insulted:

*"I cry, and sometimes I beat".*

(girl, 8 years old, out of school, urban)

*"When people insult me I can get angry and beat him"*

(girl, 9 years, Street children, rural)

Expressing anger can be empowering, if children are supported to find appropriate ways in which to do so.

### Fantasies of 'revenge':

Stories and imagination can play an important role in deflecting feelings of anger, and fantasies of revenge support some children to cope with stigma. One child told the story of a stepmother who pushes a child into the ditch. The child is saved and in the end the stepmother is pushed into the ditch. She begs the child for help but the child refuses, reminding her of how she used to treat him. Believing that the people who mistreat children will suffer in the

end can help a child cope with discrimination and stigma.

A drama sketch performed by the children from the Community School group in Lusaka had the theme of an orphan who is mistreated, runs away and becomes rich. He then forgives the uncle who used to mistreat him and who now asks him for financial help. The forgiveness portrays generosity on the child's behalf, and, imagining an abusive guardian in trouble may serve as an outlet for feelings of anger and revenge. Seeing himself in that orphan in the story gives him strength. The children said that the message from the story is *"Never mistreat the orphans, because they are the future of tomorrow."*

Many children believe that if you are not given food and are badly treated, you will one day grow rich. This belief is reflected in stories like Cinderella, whose theme was echoed in the story made up by the children, to use in the workshops. This belief in a 'happy ending' can be good consolation to tolerate a painful situation.

Imagining oneself into a strong position can support resilience and the will to survive whatever adversity presents itself. One of the girls living with HIV told a story of a sick girl who recovers, becomes a nun and helps other sick children.



## Recommendations For Programmatic Responses

The findings from the study show the extent of the damage caused to children by stigma and the need for action to reduce the stigma they face. Generations of children growing up without adequate love and support and lacking in education, life skills and trust in adults, will lead to further increases in HIV infection, as well as numerous children feeling marginalized from society.

Programmatic Responses need to enhance the capacity of families to cope with orphans, special services for orphans and ensure that all children in Zambia go to school.

### 1. Children's suggestions for combating stigma

Throughout the workshops and particularly during the individual interviews, the children were asked for ideas of how they could help children (or adults) who are being stigmatized. The children showed sympathy, understanding and willingness to help and came up with many ideas.

- Sharing feelings - *"I can help by talking to them [sick children]"* (non-school attenders, urban)
- Understanding children - *"I think the best way to stop people from treating children badly is to educate them on the importance of a child in the home. If people would know that this child they are abusing in future is going to help them, they wouldn't even think of abusing that child"* (street children, urban)
- Comforting - *"When he is beaten I go and comfort him";*(School-attenders, urban) *"I can help my friend who is upset, I invite her to play and tell her to forget about everything"* (non-school attenders, rural)
- Support to go to school - *"I would like to help my friends with pencils and books"* (Treatment group, rural)
- No risk of casual transmission - *"I can tell them, AIDS doesn't come through being together"* (Community School, urban)
- Challenge mistreatment - *"I can tell others to stop mistreating"; "To advise whoever is looking after the orphans not to mistreat them but treat them as their own children"* (community school, urban)
- Care for people living with HIV and AIDS - *"I feel like taking care of a person who is HIV positive"* (School attenders, urban)
- Get support from NGOs - *"I can take her to NGOs where they offer counselling on child abuse"* (Street children, urban)
- Practical support - *"If someone is suffering I can get that person on the bicycle and take him to the clinic"* (non-school attenders, rural)



*'A child whose parents died and the relatives grabbed the property. The child was kept by one of the relatives, highly mistreated, but the orphan grew up and became rich'*

Boy, aged 10,  
School-attenders, rural

## 2. Education on HIV and AIDS for children and adults

The findings from the study show that many adults and children continue to have misconceptions about the transmission of HIV, even if they have basic knowledge. These misconceptions can lead to stigma. New and creative ways of teaching about HIV and AIDS need to be developed. Information about Parent and Mother to Child Transmission needs to be extended to the wider community. Both children and adults need safe spaces where they can discuss fears, beliefs and taboos openly.

Children especially are open to learning and eager to know the 'facts'. As shown in the study workshops, once children have information, they can understand the harm that stigma causes and can play a key role in challenging myths perpetrated by misinformed adults. For example, during one of the follow-up visits to the children, a teenage girl told us that after the first workshop, she had challenged her mother about her treatment of a neighbour's child who had TB. The mother had responded by changing her behaviour.

Children, especially those not attending school, need greater information about preventing HIV, since stigma increases their vulnerability to risk-taking.

## 3. Anti-stigma education

Anti-stigma education and action could also contribute greatly to reducing stigma and discrimination against children living with HIV/AIDS. During the study, we found that once we talked about stigma to both adults and children, awareness and understanding automatically increased. Evidence is growing to show that once people - both adults and children - become aware of the hurt and pain that stigma causes, they are less likely to stigmatise (Bond et al 2003).

Anti-stigma education could also create awareness about the abuse of power - how guardians, teachers, children can exploit or play on an orphan's lack of power and their own position of dominance. As one of the schoolboys in Chilalantambo pointed out - 'We didn't apply to be orphans'.

Incorporating anti-stigma education into training programmes for professionals like teachers, health-workers, counsellors, home-based carers, social workers would be a big step on the road to tackling stigma. These groups can then play a role in educating pupils, parents and families to further reduce stigma in communities.

The development of an anti-stigma 'Toolkit' Training Resource (Kidd 2003) as a result of the wider stigma research is one of the resources that will be available for this type of intervention.

## 4. Free education and greater material support for families coping with HIV/AIDS

Since poverty has been identified as a major contributor to stigma, any measures that help to reduce family stress and economic hardship would help to reduce stigma and discrimination, particularly against orphans. Poverty is usually the main reason why many orphans do not attend school. This report recommends that urgent action be taken to make free education a reality for all children. Current government policy supports free primary education in Zambia, but many children are still facing hurdles in attending school because of the need for school uniforms, books and PTA fees.

Social and material support to families who are caring for orphans and other vulnerable children would lighten the economic burdens of taking in extra family members. Poverty-reduction programmes should support families affected by HIV, in order to reduce the stress on households. Families are the primary social safety nets for orphaned and vulnerable children and their capacities must be strengthened to minimise the deprivation of orphans and the migration onto the streets.

## 5. Psychosocial support for children

The research has shown that most children long for greater emotional support to help them deal with difficult life situations like the sickness and death of their parents, moving to a new family or learning to cope with living with HIV. Children with HIV can also be helped to cope with stigma they experience.

With the introduction of Voluntary Counselling and Testing (in HIV services), counselling is now commonplace in Zambia (especially in the urban areas) and there are many trained counsellors in the country. Linking counsellors to schools, churches and community groups could facilitate counselling sessions and support groups for orphans.

Schools and communities can play a big role in acknowledging the need for this support and creating time and space for children to meet with counsellors or appropriate professionals. Greater emotional support will enable children to achieve higher educational results and enhance their identity.

In agencies and NGOs who work with children, more resources can be allocated to ensure that children's emotional needs are met. Counselling services like Kara can work in partnership with others to ensure that child and youth-friendly services are made accessible and more widely available.

## 6. Psychosocial support for guardians

Greater psychosocial support for guardians could also play a key role in reducing stigma and supporting children. If guardians and other family members are given emotional support - a chance to acknowledge and share the burdens they carry, the grief and loss that they have faced and the difficulties of incorporating the new children into their family, then they may be less likely to blame the orphans for the family problems and have a greater understanding of their emotional needs.

Self-help support groups in communities, as well as groups facilitated by trained counsellors, would be one way of providing guardians with an opportunity to share their stresses and emotional needs. Awareness campaigns, encouraging guardians to seek psychosocial support, through health services and counselling centres would also be effective measures to ensuring guardians are better supported and stigma is reduced.

## 7. Involvement of the church and faith-based organisations in reducing stigma

Faith and religion were seen as major sources of strength and encouragement for the children. The

church is generally seen as a place of support and has played an important role in providing care and support to families affected with HIV/AIDS, through home-based care groups.

However, sometimes people use the church as a place for gossiping and excluding certain members and its moral discourse can be used to justify HIV and AIDS related stigma.

The church can play an important role in leading the fight against stigma and discrimination, in creating discussions and forums and support groups, where openness and acceptance are preached and practiced and stigma is actively discouraged.

## 8. Give attention to how gender roles make a difference

In many circumstances, girls face greater stigma than boys, and girl orphans are more vulnerable to sexual abuse and exploitation. They are even less likely to go to school because of expectations around working in the house, caring for siblings and selling at the market.

Stigma reduction programmes need to take account of the difference that gender makes, and work with boys and girls, men and women to redress the inequalities and find community solutions to the support the empowerment of girls and young women.

## 9. Participation of children in development of services

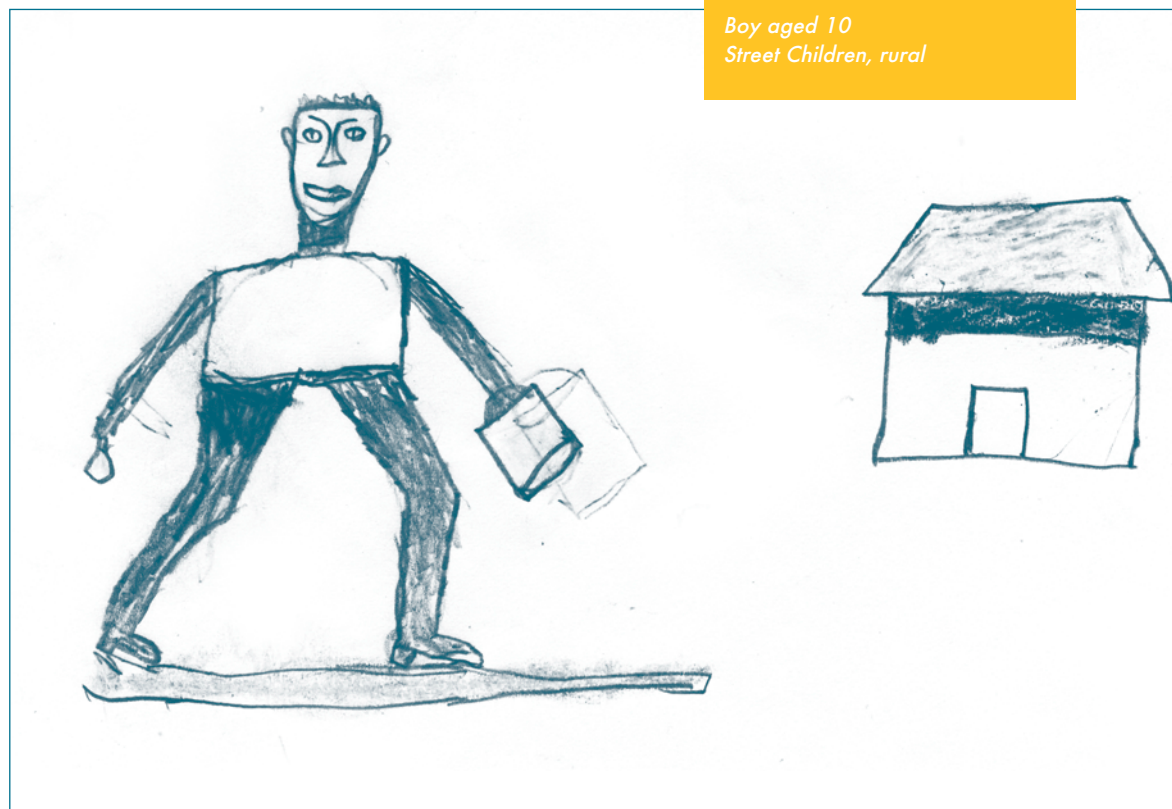
One of our greatest lessons from carrying out this study, was learning just how much children have to say, if they are asked, and how wise their words and clear their perceptions can be, even on difficult topics like stigma. Children know what they need, what can help and support them and what would make a difference in their lives. Any organisations which target the needs of children need to ensure that children's views are included in the planning, development and evaluation of its programmes.

These recommendations need to be considered in the context of HIV and AIDS in Zambia, where few people have access to medical treatments and many prevention messages are hampered by the impact of poverty on those most at risk.

One of the most obvious ways of helping children to avoid stigma is to support parents who are affected by HIV. Increasing access to treatment for opportunistic infections and anti-retrovirals (ARVs) would undoubtedly be a significant factor in prolonging lives and preventing orphan hood for thousands of children. As would preventing new infections in parents who do not have HIV.

*'A street kid is from selling at the market. He is happy because he has made some money'*

*Boy aged 10  
Street Children, rural*



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## Appendix 1

### Mary's Story

#### Story to be told in the Group session (Children and Stigma)

Hello children,

Do you like stories?

Today I am going to tell you a story of one girl who lives in Zambia, even in Lusaka.

Her name is Mary. Do you know how old she is? She is in grade VI at one of the school in the compound.

What's the girl's name?

Mary lives with her aunt Elizabeth who is Mary's mother's sister.

Mary's mother died when she was in grade IV and father died even earlier when she was in grade II. Do you know any word for Mary? A child who loses both mother and father?

Mary has one cousin Rita, this aunt's daughter who also is 13 years old.

Children what's the name of Mary's cousin?

Yes Rita. Now Rita also studies in the same grade. Do you remember which grade Mary is in? Yes grade VI

Even though Mary and Rita were studying in same grade, Mary was in different school; the community school while Rita was in Government school.

Mary had to do lot of housework before she goes to school and even after she comes back from school. She does not have anytime left to do homework. She does not have anytime to play with Rita or any other children outside, as she is always kept busy in the house, cooking, washing, sweeping and so on.

When Mary came to stay with her aunt after her mother died, Rita was friend to her. But aunt Elizabeth told Rita in private, she should not play or mix with Mary.

Do you know why the aunt said this to Rita?

Even Rita was called by aunt Elizabeth "baby" even though both Rita and Mary were equal in age and grades.

Her aunt never gave Mary enough to eat. Aunt Elizabeth would serve her the last. Sometimes, Aunt Elizabeth would send her out to do some work. When she came back, the food was finished. So Mary would have to go hungry.

Poor Mary, she was miserable most of the time.

Mary's uncle, and Rita's father, was loving to both the girls, but Mary was afraid to tell him about too much work or about not enough to eat. Her aunt can even beat Mary if she told her uncle.

In school also she had only one good friend. The other children did not play with her. One day she wanted to sit on the swing. When she reached the swing two girls came and pushed her away. And shouted "don't come here. We don't want to be sick like your dad!" Poor Mary, she did not know what made her father to die. She did hear that the father was taking some medicine for T.B.

Mary felt so lonely. She thought that there was nobody in the world who cared about her. She missed her Mama and Daddy so much; she wished that they could still be with her.

She ran to the class and started sobbing. Her class teacher was passing by the class. She heard the sound of crying. She peeped inside and saw Mary crying so hard. She tried to comfort Mary, sat near her, held her hand and asked why she was crying? Mary could not stop crying - she had never felt so upset and lonely.

After some time she managed to tell the teacher what had happened in the playground, that other children did not let her sit on the swing. That no one would play with her. That she felt as though she had no friends and no one she could talk to. Again tears came in her eyes.

The teacher was very loving and told her that she would talk to the other children. Mary asked the teacher "Can other children die by playing with me?"

The teacher laughed and said, "Of Course not".

Mary: "Then why are they saying like this to me?"

Teacher: "Maybe because they think you have T.B. and they will get it from you."

Mary and her teacher talked like this for a long time. Mary told her how things were at home and how much she missed her mother and father.

After a while, the teacher asked, "Would you like to tell your story in the class?"

At first Mary was frightened to share her story. She thought that the other children might laugh at her and call her more bad names.

When teacher said that this would help the class to understand about TB and HIV/AIDS, Mary finally agreed.

The teacher also visited her home and had a discussion with Aunt Elizabeth. And this really made a difference.

Mary saw that her aunt now at least gives her some porridge in the morning before she goes to school and asks her to join with them when they eat their meals. Now Mary can concentrate at school and learns what teacher is teaching her in the class. She is happy and the other children play with her. She even has a best friend called Jason.

And at home Rita and Mary are friends again.

#### MARY'S STORY - QUESTIONS

1. Do you know anyone like Mary?
2. What was happening to Mary (or the other child you know)?
3. Take some time to explain the word Stigma and the concept by asking them to give examples from the story.
4. Why did the other children not want to play with Mary?
5. How can this sort of treatment affect your friends?
6. Have any of you here had any similar experiences?
7. Would you like to share anything else with us? (Introduce the principle of confidentiality and assure that we will never give your name to anyone)



## Appendix 2

### Questions for individual semi-structured interview

#### 1. (Asking for permission)

- Is it OK for me to ask you some questions about yourself?
- You might want to tell me some things that you didn't say in the group.
- If there is anything I ask you that you don't want to talk about- just tell me. This is up to you.
- We need to record what you say for our study, but we won't be telling anyone that these are your answers.
- Please feel free with me.

Start by looking at the picture (either what they have drawn or one of the stigma pictures)

#### Experiences/Impact/Well-being

1. Do you know anyone who you think has HIV/AIDS? (Add if needed: Do you know any child whose Mother or Father is sick with HIV?)

2. Do you know anyone who you think has TB? (Add if needed: Do you know any child whose Mother or Father is sick with TB?)

- If YES: Can you tell me about them?

Prompts: How do you feel about them? Do you think they are different from other people- in what way?

- If NO: What do you know about HIV/AIDS? (Or Do you think children can have HIV?)

#### 3. ONLY FOR CHILDREN ON TREATMENT GROUP

Do you know if you have TB or HIV?

- If YES: Do you know how you got it? How does it affect you? How do you feel about yourself? Have you ever been called bad names by anybody? Have you ever been teased by others?

Can I ask you some questions about the medicines that you are taking?

Is the medicine helping you to feel better? Are you having any problems with it? How do you feel about taking it?

- If NO: next question

#### 4. (a) Do you stay with your parents?

- If YES: do you know any children who are orphans? What do you think about them?

• If NO: Who do you stay with and why? How do you feel about yourself?

- Prompts: Do you think about being an orphan? Do you know what happened to your parents? How are things at home?

(b) What about children whose parents are HIV positive- how are they treated?

If badly: Who treats them like this

- Others in the family?  Teachers ?
- People in the community ?
- Other children?  Clinic workers?
- Others? \_\_\_\_\_

#### 5. We talked about stigma a lot in the group (make sure they understand this)- have you ever experienced stigma?

- If YES: Can you tell me about this?

Prompts: Has anyone ever called you a bad name? How do they treat you? Do you feel different from other people? Do you know why people treat you like this? Have you experienced stigma in different places like at school, at home, on the streets, in church?

- If NO: Do you know anyone who has?

Prompts: What are the names people use to hurt someone? Do you think that person is different to you? How do you feel about someone who has TB or HIV/AIDS?

#### Coping with Stigma

#### 6. What do you do to feel better when you feel upset?

7. (i) Do you talk about this to anyone? At home /school / church?

(ii) Do you know anyone who you would like to help you?

(iii) What kind of help would you like?

(iv) How would you help someone who was being stigmatised or treated badly?

(v) How can we stop people treating children badly like this?

#### Closure

Is there anything else you would like to tell me?

How are you feeling now?

Do you want to ask any questions?

If you feel upset later on- who will you talk to?

We will come back and visit you in 2 weeks time to say hello- if you would like to talk to one of us or another counsellor- we can arrange it.