

***“My neighbour tries to help, but she too is in need”***  
**Reflecting on realities as we work towards**  
**a world fit for children.**

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## **1. Defining a world fit for children**

May 2002 saw World leaders participating in the United Nations General Assembly special session on children. Heads of state and government representatives reaffirmed their commitment to the Convention on the Rights of the Child and to completing the unfinished agenda of the World Summit for children.

Member states called for a global movement towards “a world fit for children” (UNICEF, 2002), and upheld their commitment to a set of core principles and objectives (listed below). Each is mirrored in some form in the SA Constitution:

1. Put children first: In all actions concerning the child, the best interests of the child shall be a primary consideration
2. Eradicate poverty: break the cycle of poverty within a single generation
3. Eliminate the worst forms of child labour
4. End all forms of discrimination affecting children
5. Fight infectious diseases, tackle major causes of malnutrition, and nurture children in a safe environment that enables them to be physically healthy, mentally alert, emotionally secure, socially competent and able to learn.
6. Ensure that every child has access to and completes primary education that is free, compulsory and of good quality.
7. Protect children from harm and exploitation
8. Protect children and families from the devastating impact of HIV/AIDS
9. Respect the right of children to express themselves and to participate in all matters affecting them, in accordance with their age and maturity.

In line with these principles, the General Assembly adopted a plan of action, including a strategy dedicated to addressing the impact of HIV/AIDS on children:

“To combat the devastating impact of HIV/AIDS on children, we resolve to take urgent and aggressive action...” (UNICEF, 2002:79). As part of this strategy, member states are called on to: “By 2003, develop and by 2005 implement national policies and strategies to build and strengthen governmental, family and community capacity to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS...” These have come to be known as National OVC policies.

In keeping with our commitment as a signatory of the Convention, South Africa is in the process of finalising the requisite national “OVC policy”. In addition, the most

important piece of child-related legislation in SA, the Child Care Act (1983), is currently under review and will be replaced by a more comprehensive Children's Act.

It has often been said that key to the realisation of children's rights is the need for children and caregivers to know their rights and to be aware of the mechanisms that exist to enforce their enactment. This paper is written on the premise that it is at the very least of equal importance for law makers and implementers to know the realities of the children for whom the rights and laws are drafted.

Reflecting on the experiences of children and caregivers in heavily AIDS-affected communities, this paper highlights key issues for consideration by the State and civil society in the drafting of policies and legislation designed to mitigate the impact of HIV/AIDS on children<sup>1</sup>.

The paper draws primarily on a qualitative research project conducted by the Children's Institute between 2001 and 2003 (Giese, Meintjes, Croke, & Chamberlain, 2003), in collaboration with the national Departments of Health and Social Development. The research investigated the experiences of children who had been orphaned<sup>2</sup> and children at risk of being orphaned (i.e. children in the care of an HIV-positive or terminally ill caregiver<sup>3</sup>). Research participants included children and their caregivers (within 118 households<sup>4</sup>) and 80 service provider agencies (including schools) within 6 sites across 5 of South Africa's 9 provinces.

The next section begins with two narratives – life stories that typify the experiences of so many households within AIDS-affected neighbourhoods. These narratives illustrate the startling gap between rights and realities –even in a country like SA, with a constitution to surpass all others, a section of the bill of rights dedicated to children and a plethora of laws, policies and strategies that were developed with the best interests of the child at heart.

The paper then goes on to discuss some of the key issues that emerge from the narratives and the implications of these for an appropriate and adequate policy and programme response.

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<sup>1</sup> Note that this paper does not consider the particular needs of HIV-positive children

<sup>2</sup> Defined as a child who has no surviving parent caring for him or her after one of them has died (South African Law Reform Commission, 2003)

<sup>3</sup> Defined as both the person(s) in the household responsible for providing care to a co-resident child or sick adult or negotiating care on their behalf and/or to the interview respondent. Note that very often more than one person is responsible for care. The researchers aimed to interview at least one of the caregivers primarily responsible for the welfare of the children in the households.

<sup>4</sup> Defined as a group of co-resident people. For the purposes of this research a person is considered to be co-resident if he/she is present more than 3 nights of the week. Note that households are fluid, with the movement of both people and resources across space.

## 2. A window on the world of children and caregivers in the context of HIV/AIDS and poverty

### # 1. Mantoa and her children

Mantoa – aged somewhere in her forties, but looking much older – lives in a dusty village in Limpopo Province, one and a half hour's journey from the nearest town. She has 8 vibrant though undernourished children, the youngest 6 of whom live with her: Thabo (14), Solomon (12), Wunda (10), Lefa and Refiloe (8), and Thabang (2). Her eldest daughter lives with her mother's sister, and her second born with her mother, some distance away.

The children's father is not contributing to their maintenance, having thrown Mantoa and the 3 youngest children out of his house in 1999 in order to live with another woman. Thabo and Solomon followed a year later, complaining that their father's new wife didn't feed them when he wasn't there.

The household is desperately poor. Thabo and Solomon earn the only income – R100 a month for herding a neighbour's cattle each day. Although Thabang is eligible for a Child Support Grant, he doesn't receive one because he has no birth certificate and Mantoa was left without an ID after a shack fire. Because she knows documents are required, she hasn't approached social services for help in this regard. A local erratically-funded faith-based organisation provides the household with a small food parcel once a month, when they have them available.

When we met her and her children, Mantoa was frail and ill with AIDS. Her youngest child Thabang had also tested HIV-positive and is a weak, sickly child whose breathing is laboured and wheezing. Both had spent stretches of time in hospital, but had been back at home for a while. Their treatment for TB is DOTS monitored by a home-based care volunteer from one of the local NGOs. Mantoa struggles to maintain her treatment because sometimes there is no food in the house and taking the medication on an empty stomach makes her feel ill.

The local clinic staff has treated her well, she says. Thabo echoes her sentiments. He describes how once he took his brother Lefa there. "He was complaining of headaches and chest pain, and my mother was at home sick. She couldn't go". Once the clinic nurse had identified that the boys were Mantoa's children, she helped out but only, Mantoa said, because the nurse knew that she was sick. Mantoa describes how recently the clinic staff arranged for her to go to hospital by ambulance so she didn't have to pay – without this help she couldn't imagine how she would have got there. But she was unable to keep a subsequent appointment for a check-up for Thabang at the hospital because she didn't have any money to spare for transport.

While their mother was in hospital for a month, the children lived alone. An uncle who lives nearby popped in to check on them every now and again, although he is unemployed and was unable to provide much material support. Thabo describes proudly how he cooks for everyone when his mother is sick. (Solomon laughs at his brother, teasing how at first they could hardly eat his meals, but that they've improved with practice!) Thabo

says they coped all right, but “the fact that she left sick made my heart worry”. Solomon agrees, “Yes, our hearts were sad.”

When food runs out – as it frequently does, Mantoa says – she hates having to beg her mother or the neighbours for help. Her mother is already supporting a number of others on her meagre farmworker salary. Mantoa describes how she never knows how her neighbours will respond, only that they gossip about her when she’s gone. “They don’t say anything to me”, she says, “but the stiffness of their body [language] says a lot. I feel very uncomfortable”. When she is well, she “gets something out of the ground – maize, vegetables, fruit,” and sometimes the boys go fishing in a nearby dam. “Sometimes they’re lucky”, she smiles gently, “but mostly there is nothing”.

Thabo and Solomon are not at school. So far it has been too costly for anyone to travel to the area where they were previously attending school in order to get transfer letters, without which the local school refuses to accept them. Besides, the boys say, “they would chase us away without the fees”.

Wunda, Lefa and Refiloe are attending, although at one point they were all suspended because their fees of R50 each hadn’t been paid. Mantoa visited the principal and pretended that she would pay soon, and so the children were allowed back. Mantoa doesn’t know how long it will be before the principal expels them again. She still hadn’t managed to muster the R150 total required, and described with despair how the school was now also insisting that children wear uniforms.

She worries in particular about her children going hungry when she’s hospitalised. The rest, she is calmer about – they can manage the rest of the household chores, she says with some resignation. After herding cattle, Thabo and Solomon fetch water from the nearby standpipe every day (although they say that the supply is irregular; when it is not working they walk about 30 minutes to a well), collect wood and do much of the clothes washing. Says Thabo, “Some boys feel like cooking is a girl’s thing, and going to fetch water is a girl’s thing. But we don’t worry, we just do it”. Eight-year-old Refiloe washes all the dishes.

## **# 2. Nomsa Ntsikanye and Jabulile, Ayanda and Zandile**

Nomsa Ntsikanye’s shack in Cato Crest, KwaZulu, bears testimony to better times. Three large rooms are furnished with Bradlows’ purchases – a dining room table, a sideboard, a lounge suite... She’s paid attention to her yard too in the past, and it’s full of plants. She is no longer able to tend them.

Nomsa is 34 and lives with her 2 children, Ayanda (11) and Zandile (3), and her sister’s daughter Jabulile (14) who moved from rural KwaZulu after the death of her mother in 2001.

“It is nice staying with my aunt,” says Jabulile, “She is kind to me. She treats me like her own child”. Besides, she adds, “life in the rural area was not very interesting”. She enjoys attending a better school than she was able to in the past, and being able to use the local library. She is also able to be involved in lots of fun activities, “like when there is Miss Cato Crest, I go to register my name”. She adds that she didn’t like the life she led with her mother because she used to leave her on her own regularly while she “went to stay

with men she did not know. She only came back home when she started being sick”.

She likes staying with her aunt, she reiterates, only now she is also very sick. Nomsa says she has TB. She lost her job as a security guard because she was missing work too regularly. She was too weak to work anyway, she said. Since then, the household has been relying on the money she had saved “but it is finished now”, and they rely exclusively on her UIF payments of R380 per month, although these will terminate shortly. “I don’t know what I’ll do when it is finished”, she lamented. “I’d like to be able to do something to help myself but I cannot work”. Jabulile worries too. Most of the time, she says, Nomsa is bedridden and unable to walk. “She was a healthy strong woman”, she adds, “Now I do not believe it when I look at the bony aunt who looks so different from the aunt I knew”.

Jabulile describes how “many times we don’t have food to eat. At times we live without food for up to 3 days at a time. When the food is finished we don’t eat at all. This disturbs me at school because I can’t cope with an empty stomach. My main worry”, she added, “is when Zandile cries for food. I feel desperate, I don’t know what to do to help him”. Sometimes in these instances, Nomsa begs the neighbours to give Zandile something small. But speaking with Jabulile we understand how difficult it is for Nomsa to do this. “She does not like the neighbours to know that she is struggling, explains Jabulile, adding that the neighbours gossip and say that her aunt has AIDS.

The lack of food in the house also complicates Nomsa’s TB treatment: she cannot afford to eat the food the doctor recommended - kidneys, milk, juice, and mince meat. On an empty stomach, her TB medicine makes her vomit and she has stopped taking it. Says Jabulile, “When there is food in the family, everyone is happy, but when food is finished, nobody talks.”

“My aunt struggles a lot,” Jabulile continues. She hasn’t either been able to pay Ayanda’s and her school fees. “The teachers keep asking for fees and for uniform. It’s very painful because I can’t explain my situation to my teachers”. On a separate occasion Nomsa adds that the teachers keep nagging for her to provide Jabulile with a school uniform but “*angazi ukuthi bathi ngiyithathephi*” (“I don’t know where they expect me to get it from”). The children also don’t have all the stationery they require at school, and have to borrow from other children. Recently Jabulile’s class teacher helped her out by giving her an exercise book. Ayanda, who attends a different school, was initially denied a report at the end of last year because he hadn’t paid his fees. But at the beginning of the 2002 school year, the feisty child went to the principal himself and explained his situation to her, and he was immediately permitted to continue.

Since her aunt became ill, Jabulile has carried the bulk of the domestic chores as well as of child care. Jabulile cooks food “if there is any”, cleans the house, bathes Zandile, and nurses her aunt. Sometimes she misses school so that she can care for Nomsa on especially bad days. On good days Nomsa does some of the housework.

It is a heavy load. “Sometimes I talk to myself, asking God why am I in this problem”, Jabulile says. “I wish there was someone to help me”. However, she adds, her relatives no longer come around since Nomsa has been so ill.

Jabulile never talks about her mother, but Nomsa often notices her deep in thought.

The household has not received much formal service support. Once they received a food parcel, but the community health worker never brought any again. Nomsa feels embarrassed to ask for more. "There's nothing I can do", she said gently, "this is an act of a person who is being generous". She doesn't like the treatment she's received so far at the local clinic, and resists returning. She's aware that she could apply for a foster grant for Jabulile but, she said, she hasn't had the strength to get to the social workers. And she avoids attending church because people "keep looking" at her. "Christians!" she exclaimed, "they have a lot of time to gossip!"

### **3. Key issues for consideration**

#### **3.1 Care arrangements and household form**

HIV/AIDS is a relatively new addition to the myriad of factors that shape household form and function in South Africa and, in many respects, the devastation caused by the pandemic is a result of the compounded impact of HIV on already poor and marginalised households.

The research illustrated how siblings are frequently split between two or more households and many households are multi-generational or 'skip' generations, with grandparents caring for their grandchildren in the absence/death of their immediate offspring. Some children are resident in so-called child headed households (i.e. households in which there are no resident adults), and in households in which the only adults are young adult siblings / older youth. Despite the fact that a lot of attention is directed at child headed households, their actual numbers remain relatively low. The vulnerability of children in these households is however frequently compounded by a lack of access to basic services and support, including social security.

The research demonstrates that it is common for orphans to be resident in households alongside the biological children of residents and with other informally cared for children (whose biological parents were alive but lived elsewhere).

Importantly, orphaned children who participated in the study were virtually all in the care of their relatives. In only 3 of 87 participating households that included orphans were the children and their caregivers not related by kinship. In 33 of the remaining 84 households, children were living with their grandmothers.

A discussion about children in the care of relatives would be incomplete without reference to the role that grandparents are playing.

“Although I may not live for a long time,” said Moremadi Makwea, elderly caregiver to 3 young grandchildren in Tzaneen, “I pray that God could spare me enough time to see them grow up and be established into getting employment, and then I think I will die happy.”

As observed in other studies in Africa (Ferreira & Brodrick, 2001; Ferreira, Keikelame, & Mosaval, 2001; Steinberg et al., 2002; UNFPA & The Population and Family Study Center, 2002) grandparents in particular are shouldering much of the burden of care for children in AIDS affected communities. Apart from those households in which grandmothers bore primary responsibility for the care of resident children, many more of the households in our study were supported financially and with food by grandmothers who lived elsewhere.

Importantly, care arrangements for children (whether orphaned or not) who were living with people other than their biological parents were almost always “informal” i.e. without having gone through a legal placement process. Out of 243 potentially eligible children, only 15 children (in 8 households) had been formally fostered through a child and family court. In addition, only two instances of legal adoption of children were documented.

### **3.2 Recognising the process of orphanhood**

Historically, programmes and policies aimed at addressing the impact of HIV/AIDS on children have tended to focus on children who have been orphaned, targeting services and support at children after the death of their biological parent(s). Much of the literature (and even the discussion at this conference) therefore looks at the needs of orphans in the care of relatives / neighbours or living in child headed households. More recently however, there has been recognition of the fact that, in the case of AIDS-related orphaning, the vulnerability of children is likely to begin long before the death of a child's caregiver.

Given the South African context, in which ARVs are not currently available to the majority of people who need them and where large numbers of people are unemployed or reliant on erratic, part-time, or temporary work (without sick leave or related benefits), prolonged and repeated bouts of AIDS-related illness can have severe consequences for households. In the rural research sites in particular, where food security was commonly dependent on an ability to work the land, capacity to carry out physical labour was critical. The lengthy periods of illness and concurrent inability to work therefore place many children at risk long before the death of their caregivers.

As would be expected, it is not uncommon for more than one member of a household to be HIV-positive. Many households therefore experience the illness and death of multiple members, with consequences each time, including reduced income-earning capacity, increased dependency ratios, costs related to health care and funerals, and the concurrent movement of individuals into and out of the household to reduce burdens of care and/or contribute to household income.

### **3.3 Mobility**

The movement of individuals between households is an important coping strategy in the context of poverty and AIDS. Children and adults came and went in search of work, educational opportunities, to receive care and support, or to provide care or domestic labour to relatives needing assistance. While mobility between households is by no means a new phenomenon, it does appear that HIV/AIDS will increasingly play a part in shaping its pattern and form.

We would argue that sensitivity to these processes and patterns of mobility are key to a successful and appropriate policy and programme response to orphans and other children affected by the illness and death of adults.

### **3.4 Poverty**

Poverty-related experiences were at the forefront of participating children's and caregivers' concerns. Almost every child prioritised hunger as their greatest concern. Many of the children, caregivers and teachers spoke about the way in which hunger affects children's school attendance and their abilities to concentrate while at school. Many children spoke about missing school as a result of having to engage in income-earning activities of different kinds.

“... it is not the same as it was 2 years ago – most of the time when I am in class, teachers will be teaching but I find myself being absent minded ... I think about the biggest problems we have. We can't find food and I have my siblings to worry about - I worry about how we are going to get food...”

Goodness, 16 years old

Other poverty-related struggles for households included: struggles to pay school fees, lack of school uniforms, clothing and other material possessions, inadequate housing, difficulty accessing water and not having money for transport or health care when sick. Research participants spoke about how these concerns had been exacerbated with the onset of illness or death of a caregiver or breadwinner, including those who were not resident in the household but were providing much needed support.

### **3.5 Household interdependency**

Critical to any discussion on the impact of HIV/AIDS on children is a recognition of the interdependency of households in poor neighbourhoods in South Africa. Two thirds of the 118 participating households in our study indicated that they received material support of one kind or another from at least one other household. This extra-household support, a phenomenon which is well documented elsewhere (Sogaula et al., 2002; Spiegel, 1995), took various forms, from financial support to sharing of food (and food gardens) and maintenance payments, payment of children's school fees, payment of electricity, and purchasing of school uniforms/shoes.

By implication then, in AIDS-affected communities, where levels of mortality are increasing, the burden of exacerbated poverty and increased numbers of children in need of care is felt collectively. As increasing numbers of households are affected by the illness and death of the HIV/AIDS pandemic, it is inevitable that informal networks of inter-household support will be stretched and weakened. Mechanisms to support vulnerable children must first and foremost seek to strengthen these community networks.

### **3.6 Children as economic contributors**

“The children are hungry, they will end up doing these things trying to get something to eat. You find that most of them, with the money they get from the streets, they can even buy bread at home, because the parents are not working and everyone is fending for him or herself.”

School teacher, Cato Crest

Like other children living in contexts of poverty, many of the children who participated in the study were either currently, or had previously been, engaged in income-earning or subsistence activities. In a number of instances – such as that of Mantoa described in the earlier narrative – the children were the only household members who brought money into the house.

In some instances children's work activities benefited them directly – for example where they worked specifically in return for school fees, food or material resources – but for the most part their activities benefited their households collectively. Children did not necessarily work for cash incomes but also in exchange for the opportunity to attend school and for food. Activities ranged from regular cattle and goat herding in rural areas (the task of many young boys), assisting with planting and ploughing fields (usually the domain of older children), and domestic work and child care, to more erratic jobs such as collecting and selling firewood, collecting water, mending shoes, repairing bicycles, or simply begging. Children's descriptions of their responsibilities frequently illustrated an increased need for them to be involved in work as a result of a caregiver's illness or death.

What is perhaps most striking about the child participants' discourse regarding the work that they do was the way in which they valued opportunities to obtain paid work, and how they viewed their own role in earning money as central to the way they could and must survive.

The following quotes were taken from recordings of a group 'resource mapping' activity, during which children discussed ways in which their lives could be improved:

- "If only we could get piece work after school".
- "When we're hungry or needing things, we go to ask for piece work from the neighbours - we collect firewood to sell to them."
- "The only solution to hunger is finding a job"
- "Working in the fields is important because it is easier to help yourself than to wait for other people to help you."
- "We don't even know *where is* government. Besides, the government takes a very long time to help people".

This issue raises important considerations for policy. In the absence of adequate support from the state, the role of children as economic contributors to households challenges the very concept of "best interests". When these activities help to sustain households, feed and clothe children, and enable children to continue their education - and the alternative to working is starvation - the concept of "best interests" becomes a relative one. When do the negative effects of child work outweigh the impact on children of experiencing desperate hunger and witnessing the suffering of other household members?

### 3.7 Children as caregivers

Children's roles as caregivers to the sickly, the elderly and the very young stood out clearly and repeatedly throughout the study.

When her mother became ill, Mariam (11) was launched into taking care of her on an almost full-time basis. She also took on responsibility for cooking, cleaning, and collecting wood and water. Consequently Mariam stopped attending school almost altogether. "If I didn't sleep much the night before because of my mother, I wouldn't go to school the next day", she explained. Besides, she added, school is "very difficult – most of the time I can't concentrate – I think about what is happening at home". She was haunted by fears of her mother's death. "Sometimes I would come back and find my mother lying there with her eyes wide open..."

While all of the children who participated in the research bravely accepted these responsibilities, a number commented on their struggles and personal sacrifices. In each instance, aspects of the children's lives were being compromised.

- In many of the households, at least one of the children was not attending school or was only attending erratically because of caregiving duties<sup>5</sup>.
- Many of the children were also very distressed by seeing and being responsible for a caregiver who was ill. In the absence of any alternatives, children were taking on onerous responsibilities that plunged them into having to make difficult decisions (such as how to deal with particular instances of illness, or at what

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<sup>5</sup>Steinberg et al. (2002) documented 1 in 5 young caregivers spending school/study time caring for a sick person. Usually these were girls, raising the possibility of broad-based under-schooling of girls.

stage to call for professional medical help), and to negotiate their way through caring for the very sick.

- As has been documented elsewhere, (Burman, 1996; Steinberg et al., 2002; USAID, UNAIDS, & UNICEF, 2000), the burden of care most often fell with girl children. Throughout the study, key caregivers, both adults and children, were primarily women. In the case of children there were many examples of the oldest female children becoming those responsible for the care of whoever required it and girls were frequently moved to stay with sick relatives so as to provide care.
- The contexts of care for these children were often distressing. In particular, where there was limited access to water, sanitation, toilet facilities and washing materials.
- Without access to basic resources such as gloves and disinfectant, the children's ability to care for sick adults appropriately was made more difficult and their exposure to opportunistic infections increased.
- On the whole, participant children who were providing care to sickly or elderly household members were provided with little external support, mostly because of the lack of co-operation between child-focused services and the mostly adult focused home based care services.

### **3.8 Succession planning**

There was little evidence of succession planning by sick adults on behalf of their children. Where planning for children did occur in the research sites, it generally entailed requests from caregivers asking relatives or friends to take care of their children after they had died and, in a few instances, transferring child support grants where children were eligible. Wills were seldom written<sup>6</sup>, and in some cases where deceased family had written a will the wishes expressed within it were ignored. The research documented a few examples of neighbours and relatives aggressively trying to claim the estates of children living without adults and poaching material possessions or pressurising surviving children into selling their inheritance to meet the costs of funeral arrangements.

In the case of one group of children living alone, their abusive uncle had plundered their father's death benefits while at the same time claiming 5 foster grants every month for the children, even though only one was resident in his homestead. Of an original amount of R64 000 in death benefits, there remained only R94 in the account at the time of the research. When one of the children challenged his uncle, he faced frightening threats of violence, and was warned that if he didn't stop causing trouble he was "going to kill him".

In the absence of recourse to justice, the wishes of biological parents and the 'best interests' of their children were frequently ignored.

### **3.9 Children's role in decision making**

Considering the ways in which the children repeatedly demonstrated their agency and resilience in coping with the difficulties of their everyday lives, and the amount of responsibility so many children assumed in relation to the care of the sick, it is ironic that children were often left in the dark about the reasons for the illness and death around them. There was also a general absence of discussion with children about plans for their care and no instances were documented in this study of children being provided the opportunity of identifying their preferences for care.

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<sup>6</sup> This has been similarly observed by researchers elsewhere in Southern and East Africa. See for example (Ali, 1998), (Gilborn, Nyonyintono, Kabumbuli, & Jagwe-Wadda, 2001).

When asked during a group activity who they thought should make decisions about care arrangements after the death of a child's parents, 14-year-old Sifiso confidently said that the children should decide where they will stay. Zamandelu (16) agreed: "Yes, because they are the ones who are going to feel the pain when the choice is not right."

### **3.10 Abuse and exploitation**

The plenary speaker yesterday spoke extensively about the abuse of children within communities, and particularly after the loss of a mother. Our research documented both positive and negative experiences of children living with relatives, as well as instances of children made extremely vulnerable while in the care of their own biological parents. While the research did not look in any detail at the issue of institutional care (children's homes / orphanages), there is a substantial body of literature on the pitfalls of this form of care too. Given the variability in children's experiences of a range of care options, it is clear that we need to recognise the importance of not viewing any one option as *the* panacea in the context of HIV/AIDS.

Many of the children who participated in the study were safely and happily living with caregivers other than their biological parents. On the other hand, many children described suffering various degrees of discriminatory treatment or exploitation at the hands of caregivers who were not their biological parents. Some children who lived with relatives or neighbours complained that they were treated differently to the other children "who belong to the house" – that they had less access to household resources and that they had to carry out more of the daily domestic tasks.

Similarly, experiences of abuse and exploitation by biological parents were reported. One service provider substantiated her concerns about child abuse in the area with a horrifying anecdote. She gave as an example that of a 12-year-old girl who was in the process of being married off to the man who had raped her. Her mother said she had been 'spoilt' by the rapist, and was organising the *lobola* payment. When the organisation approached the child's mother, it had apparently not occurred to her to report the rape to the police or to the Child Protection Unit.

Children's experiences clearly demonstrate the need to ensure appropriate and accessible protection mechanisms for all children. The research highlights the absence of avenues for children to access support or recourse to justice in contexts of exploitation and abuse. Not only were services largely inaccessible, but the poor follow up meant that children who reported abuse were frequently placed at greater risk.

Debating the incidence of abuse among orphans in relation to other children is beside the point. It is crucial that appropriate, accessible protection mechanisms be set in place for all children who find themselves in need of support because of the actions / lack thereof of any adults - whether their biological parents, other relatives or neighbours.

## **4. Summary and recommendations**

### **4.1 Two key considerations in designing a policy and programme response**

In communities where HIV/AIDS and poverty are rife, research participants across the sites reiterated two important issues, recognition of which is critical to the design and implementation of laws, policies and programmes.

The first is that, contrary to the stereotypical image of the African “AIDS orphan”, not all children who have lost biological parents are destitute. Failure to recognise this point effectively disregards the incredible effort on the part of poor individuals, communities and community-based organisations in South Africa. Many of the caregivers we spoke to were reluctant to even call the children in their care orphans – because the word is so frequently associated with being unloved and uncared for.

The second issue is that in AIDS-affected communities, it is not just those children directly affected by the illness or death of a caregiver that experience poverty and hunger.

“For me, in Ingwavuma there is a problem because people are not working. There are no job opportunities. There are no factories. So people are not working here ... You find that even if the father is there, that the children are suffering. With the father and the mother there ... Definitely I can't say that orphans, only the orphans, are needy. Sometimes you can find an orphan who is living better than a child who has parents. Orphan or no orphan, it's just the same. They are needy, all of them...”

Sbongile Kuzwayo, a school principal in Ingwavuma

## **4.2 Recognising household form and care arrangements in South Africa**

- The multiple different relationships which characterise households challenge any stereotype of a nuclear family as a standard household form.
- The fact that orphans are so frequently resident in households with other poor children (who were not orphans) highlights the inappropriateness of a response that targets only children who have lost biological parents.
- The informal nature of care arrangements and the mobility of children between households raise pertinent questions for legislation regarding parental rights and responsibilities and issues of guardianship.
- The reciprocal relationship between children and the elderly needs further consideration
- The limited support available to biological parents to care for their own children is a major gap within current policy, as is the absence of support for children caring for their terminally ill parents (or other relatives).
- Although widely considered to be an anomalous household form, where appropriate, legislation needs to ensure access to services and financial support for children living in so-called child headed households / youth headed households.

## **4.3 The role of the education system**

“Early in the morning as teachers and pupils gather for morning prayers and announcements, those children whose fees are outstanding are told to go back home to collect the outstanding fees. It seems to me like schools are punishing pupils for being poor. It seems like if you are poor then you also lose the right to an education.”

Eighteen-year-old Sibongile Mlilo, Umzimkulu

- Despite the fact that South Africa's legislative framework makes provision for free basic education through the school fee exemption process, some children who participated in this research were unable to access schooling. While recognising the cost and complexity of its implementation, we nonetheless would argue that the provision of universal, free education is a crucial component of a response to widespread poverty and to addressing the impact of HIV/AIDS on children.
- As has been stated earlier, school attendance was also impacted upon by children's hunger, by their caregiving duties, by children working during school hours or by emotional difficulties..amongst other factors. Given the range of challenges facing children in AIDS-affected and poor communities in South Africa, opportunities within schools for the identification and support of vulnerable learners need to be further explored and better utilised. These include for example extending school based health services and nutrition programmes and improving networking and collaboration with other service providers.

#### **4.4 Strengthening the child protection system**

- Abuse prevention and early intervention services (including the provision of post-exposure prophylaxis to rape survivors) and accessible recourse to justice for children who have been abused need to be strengthened. The research findings are unequivocal in demonstrating that improved human resource capacity is fundamental if the Department of Social Development wishes to meaningfully address the needs of vulnerable children in South Africa. Across every research site service provision was hindered by a lack of human capacity, and social workers were unable to fulfil a number of their designated roles. In particular, social workers were not able to provide sufficient child protection and early intervention services and played no role in addressing the large and growing need for psychosocial support.
- Linked to this is the widespread application of the Foster Grant as a poverty alleviation mechanism. Social workers across the sites were inundated with requests to process foster care placements because the foster care grant represented the only viable income support for many poor households. Providing foster grants to all children in South Africa who are already orphaned or who will be orphaned in the future would be an impossible – and inappropriate - task, not least because it will undermine the much needed child protection system, of which foster care is a critical component.

#### **4.5 Addressing poverty**

- The severe poverty that characterises the lives of children and caregivers who participated in this study highlights the important role that social security benefits can and must play in supporting vulnerable children in South Africa. While significant improvements have been made, the current social security system remains problematic. Many poor children are not eligible for the child support grant (the primary poverty alleviation mechanism for children) and many of those who are eligible are unable to access the grant. The research demonstrates how difficulties of access to grants are exacerbated by the HIV/AIDS pandemic – particularly for children who are subjected to the loss of multiple caregivers, orphans who do not have the identify number or death certificate of their biological parents, and children who live alone.
- A related concern is that of child labour. In a context where HIV/AIDS is amplifying households' and communities' poverty, children need to earn incomes.

The answer is not necessarily to ban children from working, since this would further marginalise poor households. Rather, poor households and neighbourhoods need support in order to improve their living circumstances so that children's work need not be relied on for survival.

- Widespread, non-targeted poverty relief is therefore an essential component of a response to the needs of children in the context of HIV/AIDS and our research supports the call for the Child Support Grant to be increased and extended beyond those it currently reaches and that administrative procedures are further amended so as to accommodate children who do not have the necessary documents and to prevent grants being stopped on the death of a child's caregiver.

#### **4.6 Supporting a collaborative response**

- Importantly, most of the support to children in the sites was provided by community based and non-governmental organisations, many of whom relied on volunteers and were unable to access financial support from the state. It is imperative that these organisations receive the support they need - either from or with the help of the State.
- And finally, it is impossible for the Departments of Health, Education and Social Development to ensure appropriate and adequate support for children in the context of HIV/AIDS, without improved collaboration between these departments and others. The broad-based needs of the children who participated in this study clearly demonstrates that in order to effectively address their experiences, a truly multi-departmental, cross-tiered integrated response on the part of the South African government is required.

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