

# **HIV/AIDS SECTOR SUBMISSION**

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**Joint HIV/AIDS Sector submission  
on Section 75 of the Children's Bill [B70-2003]**

**Presented to the Portfolio Committee on Social  
Development**

27<sup>th</sup> July 2004

A joint submission of organisations within the Children's Sector working on issues related to HIV/AIDS, including representation from the Children's HIV/AIDS Network, the South African National AIDS Council Children Sector Network, the Children's Institute, the Children in Distress Network, the South African Society for the Prevention of Child Abuse and Neglect, Resources Aimed at the Prevention of Child Abuse and Neglect, the Network Against Child Labour, and the AIDS Law Project.

# 1 Introduction

The HIV/AIDS sector welcomes the opportunity to engage with the Portfolio Committee on the provisions of the Draft Children's Bill.

The AIDS pandemic represents a phenomenon, not unlike that of poverty, which is both causal and symptomatic of so many other vulnerabilities of childhood. Almost every section of the Bill is therefore relevant to children in the context of HIV/AIDS. However, this submission focuses on areas of particular concern to individuals and organisations within the HIV/AIDS sector, and is intended to complement the many other sector submissions that address issues of direct relevance to children living in AIDS affected communities.

The submission focuses on section 75 of the Bill [B70-2003].

## 2 Problem statement

The October 2002 antenatal survey reported that 26.5% of pregnant women were HIV-positive in 2002, and that over 91 000 babies became infected with HIV through mother to child transmission. Based on the results of this survey, official figures released by the Department of Health indicate that an estimated 5.3 million people in South Africa were HIV-positive at the end of 2002<sup>1</sup>.

Recent ASSA model based calculations of the numbers of orphans in South Africa estimate that in July 2003, 990 000 children under 18 had been maternally orphaned and 2.13 million children were paternally orphaned<sup>2</sup>. Projections derived from the same models predict that by 2015 in *the absence of any major treatment intervention or behaviour change*, roughly 3.05 million children under 18 will be maternally orphaned and 4.51 million paternally orphaned, of whom 1.97 million children would be double orphans. This equates to a total of 5.6 million children under the age of 18 having lost one or both parents<sup>3</sup>.

While reliable figures on the numbers of children living in AIDS affected households are not available, an estimated 500 000 children in South Africa currently have a mother who is terminally ill with AIDS<sup>4</sup>.

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<sup>1</sup> Department of Health (2003). National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa: 2002. Pretoria, Directorate: Health Systems Research, Research Coordination and Epidemiology, National Department of Health, South Africa.

<sup>2</sup> These figures refer to children orphaned both by AIDS as well as by other causes.

<sup>3</sup> Meintjes, H., D. Budlender, S. Giese and L. Johnson. (2003). Children 'in need of care' or in need of cash? Questioning social security provisions for orphans in the context of the South African AIDS pandemic. Cape Town, Joint working paper of the Children's Institute and the Centre for Actuarial Research, University of Cape Town.

<sup>4</sup> Meintjes, H., D. Budlender, S. Giese and L. Johnson. (2003). Children 'in need of care' or in need of cash? Questioning social security provisions for orphans in the context of the South African AIDS pandemic. Cape Town, Joint working paper of the Children's Institute and the Centre for Actuarial Research, University of Cape Town.

## Mantoa and her children<sup>5</sup>

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.”

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<sup>5</sup> Giese, S., H. Meintjes, R. Croke, and R. Chamberlain, *Health and Social Services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa: Research Report and Recommendations*. Report submitted to HIV/AIDS directorate, National Department of Health, January 2003. 2003, Children’s Institute, University of Cape Town: Cape Town.

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.

Nationally and internationally, our response to the socio-economic impact of HIV/AIDS on children tends to focus on children who have been orphaned. However, as is illustrated by the narrative above, orphanhood in itself is a process that begins long before the death of a child's caregiver with differently compounded vulnerabilities at different points along this continuum. Research repeatedly demonstrates that the period of a caregiver's terminal illness is one during which children are prone to exacerbated vulnerability – in which caregivers typically face increased struggles to support their children as they become less able to work to earn money and as cash is diverted to health care and treatment.

The 5.3 million South Africans currently living with HIV/AIDS translate into millions of children whose well being is potentially compromised by adult illness and whose protection, care and support need to be ensured through the provisions of the Children's Bill.

### **3 Comments on Tabled Bill [B70-2003]**

#### **3.1 Chapter 1 – Interpretation, objects, application and implementation**

##### **Section 2 - Objects of the Act**

We recommend that the Objects section of the Bill should be amended in order to include an express objective to assist families to care for and protect their children. Chapter 9 of the August 2003 version of the Draft Bill (primary prevention and early intervention) does include this provision, however, to give it prominence, we suggest that it be included in the objects clause as well. Detailed comments on the provisions of Chapter 9 will be included in later submissions related to Section 76 of the Bill.

Suggested redraft:

(2) The objects of this Act are -

- a. To make provision for structures, services and means for promoting the and sound physical, mental, emotional and social development of children;
- b. **To assist families to care for and protect their children**
- c. To utilize, strengthen and develop community structures which provide care and protection for children;
- d. To prevent, as far as possible, any ill-treatment, abuse, neglect, deprivation and exploitation of children;
- e. To provide care, protection and for children who are suffering ill-treatment, abuse, neglect, deprivation or exploitation or who are otherwise in need of care and protection; and
- f. Generally, to promote the well-being of children.

##### **Section 4 – Intersectoral implementation of the Act: a National Policy Framework**

The scale of the HIV/AIDS pandemic and its multifaceted impact on children, families, communities and service providers demands an integrated and collaborative response from all sectors. Responsibility for the care and support of the millions of children who are at risk of being orphaned, who have been orphaned or who are otherwise made vulnerable by HIV/AIDS cannot be borne by one Department. Interdepartmental collaborative programmes and policies are essential in the context of HIV/AIDS.

The collaborative response of the Social Cluster to the impact of HIV/AIDS-related illness and death on children has largely been in the form of the National Integrated Plan for Children Infected and Affected by HIV/AIDS. The overall objective of the

NIP is “to ensure access to an appropriate and effective integrated system of prevention, care and support services for children infected and affected by HIV/AIDS”<sup>6</sup>. Realising the goals of the NIP called for collaborative intersectoral partnerships and mutual support between State services and the non-governmental sector. Attempts at implementing the National Integrated Plan have highlighted the need to clarify the roles and responsibilities of the three sectors, and to put in place measures to maximise the opportunities at the interface between them.

The lessons learnt through this process reinforce the sector wide call for a National Policy Framework that is binding on all government structures with responsibilities for children, and that requires them to plan and budget for these responsibilities.

**Recommendation: That the provisions for an intersectoral National Policy Framework (NPF) be reinstated, to guide the implementation, enforcement and administration of the Act and to ensure that responsibility for the wellbeing of children is shared across relevant Departments.**

### **3.2 Chapter 3 – Children’s Rights**

While the Tabled Bill includes some essential rights, it omits many of those which are critical in the context of HIV/AIDS. In particular,

- Prohibition on unfair discrimination
- The right to social security
- The rights of children with disabilities and chronic illnesses
- The right to social services
- The right to family or alternative care
- The right to education
- The protection of property

**Recommendation: This submission supports the call by the Children’s Institute for the inclusion of a Child Rights Charter in the Children’s Bill that:**

- is comprehensive (includes all relevant<sup>7</sup> rights set out in the UN Convention on the Rights of the Child and the African Charter);
- is binding on all government departments;
- elaborates on the rights in the Constitution using international law adapted to South Africa’s particular circumstances and challenges and supplements where the Constitution is silent;
- obliges all national, provincial and local government departments to:
  - review their legislation, policies and programmes to ensure that the relevant rights are incorporated and adhered to
  - conduct child impact assessments before making decisions with regards to policy, legislative or programme options
  - draw up annual plans showing how they intend to promote and protect children’s rights through their policies, plans, budgets programmes and actions.

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<sup>6</sup> South African Government. (2000). Draft National Integrated Plan For Children Infected And Affected by HIV/AIDS.

<sup>7</sup> Rights that are relevant to the South African context and South Africa’s particular challenges

- report on the implementation of such plans to the Minister of Social Development using prescribed performance indicators
- table the plans and reports in Parliament to be considered by the Joint Monitoring Committee on Children, Youth and Persons with Disabilities.

### **3.3 Chapter 4 - Parental rights and responsibilities**

Section 32 of the current draft of the bill states that:

- (1) A person who has no parental responsibilities and rights in respect of a child but who voluntarily cares for the child either indefinitely, temporarily or partially, including a care-giver who otherwise has no parental responsibilities and rights in respect of a child, must, whilst the child is in that person's care –
  - (a) safeguard the child's health, well-being and development; and
  - (b) protect the child from maltreatment, abuse, neglect, degradation, discrimination, exploitation and any other physical or mental harm or hazards;
- (2) A person referred to in subsection (1) may exercise any parental responsibilities and rights reasonably necessary to comply with subsection (1), including the right to consent to any medical examination or treatment of the child if such consent cannot reasonably be obtained from the parent or primary care-giver of the child."

This section, along with the definition of caregiver, is a significant improvement on current legislative provisions, particularly in the context of HIV/AIDS where many children are currently denied access to treatment because of requirements that parental consent or consent from a legally appointed guardian is required before medical treatment can be administered.

### **3.4 Chapter 8 – Protection of Children**

We were recently informed by the Department of Social Development that they would be making a request to Parliament to include Chapter 8 of the August 2003 draft of the Children's Bill into the Section 75 version of the Bill. In light of this, we have included some brief commentary in this submission on the following provisions in Chapter 8:

Part 3: Protective measures relating to the health of children, and  
 Part 4, sub-section 136: Child headed households.

### 3.4.1 Part 3: Protective measures relating to the health of children

Section 130 outlines conditions under which a child may be tested for HIV and the procedure for obtaining informed consent:

If the child is over the age of 12 years or under the age of 12 years but of sufficient maturity, the child may consent to HIV testing. In the alternative, consent may be given by the child's caregiver or parent, a designated child protection organisation arranging the placement of the child, the superintendent or person in charge of a hospital, or (under certain conditions) a children's court

Pre and post test counselling has to be provided (Section 132)

Section 133 outlines the conditions under which a child's HIV status may be disclosed. Informed consent for disclosure is based on the same principles as consent for testing.

**We support these important provisions but emphasise that they have obvious direct implications for health workers.** It is therefore essential that these provisions are mirrored / cross-referenced in relevant health policy and legislation.

Health workers need adequate training and support in order to provide age appropriate counselling and standardised protocols / tools to determine a child's capacity to consent for HIV testing.

Many health workers are unwilling to treat children who arrive at clinics unaccompanied<sup>8</sup>. In the context of the illness and death that characterize the AIDS pandemic, this situation is likely to arise more frequently. As such, health workers need clear policy guidelines on when and how to treat unaccompanied minors.

The need for intersectoral collaboration around issues pertaining to children is evident throughout the Bill and is highlighted in this chapter. **It is thus imperative that the provisions for an integrated National Policy Framework (or equivalent) be reinstated.**

### 3.4.2 Part 4: Child headed households.

The Bill allows for a provincial head of social development to recognise a household as a child-headed household if –

- (a) the parent or primary care-giver of the household is terminally ill or has died;
- (b) no adult family member is available to provide care for the children in the household; and
- (c) a child has assumed the role of primary care-giver in respect of a child or children in the household.

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<sup>8</sup> Giese S., Meintjes H., Croke R., Chamberlain R. (2003) *Health and Social Services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS – research report and recommendations*. Children's Institute and National Department of Health, Pretoria.



While the sector supports the recognition within the Bill of child headed households (CHH) as a family form in South Africa, there is not yet consensus as to the appropriateness of the definition given some of the potential implications for children and their caregivers. If CHH include households in which the parent or primary caregiver of the household is terminally ill, how would “terminally ill” be defined, and what would the adult caregivers roles / responsibilities be in this household. There were concerns in particular about whether defining such households as child-headed would undermine the role of the ill adult, particularly if s/he were still able to function as a caregiver if provided with the appropriate treatment, care and support.

There was consensus therefore that we need to carefully work through the implications of the proposed definition before finalising it.

Several other issues also need further consideration:

- It is unclear whether the provisions for child headed households are only applicable for those households *recognised* as such by ‘a provincial head of social development’. The procedures for ‘recognising’ a household as child-headed would need to be clearly spelled out so as to ensure that this provision does not create an additional barrier to children attempting to access support.
- Furthermore, research indicates that child headed households, while clearly existing in small numbers, are frequently a transitional/temporary household form<sup>9</sup>, existing for a period for example, just after the death of an adult and prior to other arrangements being made for children’s care. How would this impact on continuity of care and support for the children within these households.
- The SALRC recommended in the draft Bill they submitted to the National DSD that a CHH must function under the general supervision of an adult designated by a child and family court OR an organ of state or NGO. The latest draft has removed the option of a CHH functioning under the supervision of an adult designated by a child and family court. The implications of this are unclear but potentially harmful in instances where a registered NGO is not available and where services to children are being rendered by community based organisations and volunteers (as is so often the case). In effect, the current provision in the draft Bill would exclude these individuals from functioning as mentors for children living without adult caregivers.
- The current provisions for child headed households are limited to facilitating access to social assistance grants with no mention of other forms of support which may be necessary, particularly given the proposed definition of child headed household, which would include households in which a child has assumed responsibility for caring for a sick adult. We therefore suggest that provision be made for the Minister to include in the national policy framework [or equivalent],

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<sup>9</sup> Giese, S., H. Meintjes, R. Croke, and R. Chamberlain, *Health and Social Services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa: Research Report and Recommendations. Report submitted to HIV/AIDS directorate, National Department of Health, January 2003.* 2003, Children's Institute, University of Cape Town: Cape Town.

<sup>10</sup> Lund, F. *Challenging the Development Community to finance Social Assistance.* Presented at Children's Institute seminar series. 2003. Cape Town, 13 October 2003.

a comprehensive and intersectoral strategy aimed at identifying, assisting and promoting the best interests of children living in child headed households.

- The vulnerability of children living in “youth” headed households (where the oldest person is 18-21 years) is not addressed in the Bill. Research suggests that children living in households where the only/oldest adult is younger than 21 years frequently face the same challenges as children living in child headed households. There is a call within the sector for recognition of these households as households in need of special support.

### **Suggested redrafts and additional provisions**

**136.** (2) A child-headed household must function under the general supervision of an adult designated by ~~organ of state or non-governmental organisation~~ –

- (a) An organ of state or non-governmental organisation determined by the provincial head of social development; or
- (b) ~~designated by~~ a children’s court.

(3) The ~~organ of state or non-governmental organisation~~ adult person referred to in subsection (2) –

- (a) may collect and administer for the child-headed household any social security grant or other grant or assistance to which the household is entitled; and
- (b) is accountable to the provincial department of social development, or the children’s court, or to another organ of state or a non-governmental organisation designated by the provincial head of social development, for the administration of any money received on behalf of the household.

(4) The ~~organ of state or non-governmental organisation~~ adult referred to in subsection (2) may not take any decisions concerning such household and the children in the household without consulting –

- (a) the child at the head of the household; and
- (b) given the age, maturity and stage of development of the other children, also those other children.

(5) The child heading the household may take all day-to-day decisions relating to the household and the children in the household as if that child was an adult primary care-giver.

(6) A child-headed household may not be excluded from any aid, relief or other programme for poor households provided by an organ of state in the national, provincial or local sphere of government solely by reason of the fact that the household is headed by a child.

(7) The Minister must include in the national policy framework [or equivalent], a comprehensive and intersectoral strategy aimed at identifying, assisting and promoting the best interests of children living in child headed households.

### **3.5 Chapter 10 – Child in need of Care and Protection and Chapter 12 – Children in alternative care**

Section 150 includes as a category of children in need of care and protection, children who have been orphaned. Following a court process, children who are found in need of care and protection may be placed in various “alternative care” options, including: court ordered kinship care, foster care, care in a child and youth care centre and temporary safe care.

While there are many orphans who, as a result of abuse, neglect, abandonment or exploitation, are in need of care and protection by the State, the vast majority of children who have been orphaned are cared for by extended family and kinship networks. For most of these children, the primary support required is financial, with good ongoing monitoring systems to ensure that their needs are being met. When reviewing provisions for children who have been orphaned, the distinction therefore needs to be made between:

- i. Children requiring the state to intervene in their care arrangements because they are at risk of abuse, neglect or exploitation. This is frequently associated with a court process, the placement of a child in alternative care and the provision of a cash grant / subsidy – the formal child protection system.
- ii. Children who are being cared for in kinship / extended family networks and who simply require financial support / poverty relief in order to maintain their current care arrangements.

The legislation needs to make adequate provision for this second category of children without requiring all these children to go through the formal child protection system.

The current provisions of the Bill fail to fully recognise and support informal care arrangements which by far accommodate the vast majority of orphans. Without adequate alternative provisions for children who have been orphaned (and other vulnerable children), the only avenue available to caregivers for accessing support will be the formal child protection system.

Failing the full extension of the child support grant to all children, it is likely therefore that the provisions within the Bill will lead to massive pressure on the courts and

social workers to process court ordered kinship or foster care, the majority of applicants applying simply to access some form of poverty relief. There are several likely consequences:

- The processing of foster care / court ordered kinship care placements for orphans will consume an inordinate amount of social workers' time, allowing them to reach far fewer children than they otherwise might and significantly impacting on their ability to deliver other much-needed services.
- The focus on processing foster care / kinship care placements (which are not an option for biological parents) means that there is little / no support for children in the care of their (sick) biological parents.
- The focus on court ordered care for orphans will create further bottlenecks in an already overburdened system and reduce the effectiveness of the foster care system to meet the needs of children who require the state to intervene in their care arrangements, eg. children who have been abused, neglected or who require temporary removal from their families while family re-unification services are delivered.
- If courts remain the gatekeepers to state support, then we will continue to discriminate against children and caregivers in rural and poorly resourced areas where children's courts are often inaccessible.

It is essential therefore that we strengthen the supplementary provisions for children who are in the informal care of relatives (or others) and for children in the care of their own biological parents. The current provisions create perverse incentives for poor children to live with caregivers who are not their biological parents, and provide little if any support to biological parents to care for their own children. This completely contradicts the principles enshrined in the South African Constitution, the White Paper for Social Development and the draft Children's Bill, where family preservation is accorded highest priority.

We argue that, in addition to an effective formal child protection system, the best way of ensuring blanket *financial* provisions for all vulnerable children is the full and immediate extension of the Child Support Grant, with additional needs met through the provision of free basic services and special grants.

**In line with this, we call for a provision within the Children's Bill to allow for amendments to the Social Assistance Act which, as it stands, fails to adequately address the needs of children in the context of HIV/AIDS.**