

## **ADDRESSING THE IMPACT OF HIV/AIDS ON CHILDREN IN SOUTH AFRICA – PRIORITIES FOR FUNDERS AND DEVELOPMENT AGENCIES**

Compiled by Helen Meintjes and Sonja Giese  
University of Cape Town, March 2004

This briefing paper is structured into two parts. Part A provides a brief overview of orphan numbers and what we know about the living circumstances of children growing up in the context of HIV/AIDS in South Africa. Part B of the paper provides a set of key recommendations to guide funders in responding to the impact of HIV/AIDS on children.

## Part A) Background to the issue:

### Definitions and projections of orphanhood [1, 2]:

1. For the purposes of enumeration, international practice has been to define orphans according to three categories:
  - Maternal orphans: children under the age of 15/18 who have lost their mother
  - Paternal orphans: children under the age of 15/18 who have lost their father
  - Double orphans: children under the age of 15/18 who have lost both parents

The reason for the different age cut-offs has to do with the way in which national surveys worldwide have tended to collect data in 5 year age-cohorts, thus making it simpler to estimate numbers of children under 15. However in line with the UNCRC definition of a child being under the age of 18, in the last year or two, national and international projections have tended to shift their focus to include children up to the age of 18.

2. Because standard estimates and projections regarding orphan numbers are broken into these three categories, figures always need to be read with care for two key reasons:
  - It is clear from these categories that not all children enumerated as ‘orphans’ are necessarily without any biological parent to care for them (c/f 3 below).
  - Some models (including those produced by Actuarial Society of South Africa (ASSA) and very widely used in South Africa) calculate maternal orphan figures to include all children who have lost their mothers, including those who have lost their fathers, and do similarly with respect to paternal orphans. ie. in both instances, maternal and paternal orphan estimates include those who are double orphans.
3. 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. Of these children, 190 000 were double orphans, resulting in a total estimate of 2.93 million children under 18 who had lost one or both parents.

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 [3 and pers. comm Leigh Johnson, CARE].

These figures refer to children orphaned both by AIDS as well as by other causes.

4. Contrary to widespread belief, the majority of children orphaned by AIDS are not HIV-positive.

## Where are these children living? With whom?

In considering these estimates and defining an appropriate response, it is crucial to consider the living contexts of children in South Africa generally as well as those who have been orphaned:

1. There is a long history in South Africa of children – and especially children living in circumstances of poverty – not being constantly parented by either one or both of their biological parents, and living with other adults as caregivers for at least periods of their lives (i.e. living with ‘social’ rather than biological parents). This continues to be the case, both for children who face orphanhood *as well as those who do not*. Children frequently experience a sequence of different caregivers, and many children are brought up without paternal figures, or live in different households to their biological siblings [4].

For example, 2002 General Household Survey (GHS) data indicates that of the almost 15 million children under 18 whose parents were recorded as *alive*, only 45% were living with both parents at the time of the survey, while 36% were living with their mother and not their father, 3 % with their father and not their mother, and 17% were living with neither parent. The majority of those children not resident with their parent(s) were resident with relatives [5].

2. Similarly, the majority of children who are orphaned (maternal, paternal, or double) are cared for by their relatives. Because of the characteristically non-nuclear nature of South African households, in many instances children remain in their homes upon the death of their parent(s), with a continuum of care provided by other adults with whom they are resident at the time [3, 4]
3. There are interesting differences between the care arrangements for paternal and maternal orphans. GHS data from 2002 suggests that about  $\frac{3}{4}$  of children whose fathers have died, live with their mothers (71%). But less than one third of children whose mothers have died live with their fathers (27%). In the main, maternal orphans live with other relatives [5].
4. Only very small numbers of orphaned children find themselves living without any resident adult caregiver in so-called ‘child headed households’ or on the streets. GHS data suggests that less than 1% of children in South Africa (orphaned or otherwise) were resident in child headed households in June 2002 [5] (This figure should be treated with caution considering the small sample of child headed households surveyed in the GHS). Systematic investigation in several countries (including in some of those where the HIV/AIDS pandemic is more advanced than in South Africa) have similarly confirmed that child-headed households are rare [6, 7]. Important to note is that research indicates that child headed households, while clearly existing in small numbers, are frequently a transitional/temporary household form [4, 8], existing for a period for example, just after the death of an adult and prior to other arrangements being made for children’s care.
5. To date no reliable evidence exists to support the frequent claim that orphans are likely to find themselves living on the streets [9].

To summarise: research demonstrates how – contrary to popular perception – the majority of children who have been orphaned in South Africa are *not* without adult care, support, supervision or socialisation [4, 9], or necessarily without positive adult role models [9].

## **What is wrong with an approach to HIV/AIDS that focuses on orphans?**

To date, both internationally and nationally, much of the attention paid to children's vulnerability as a result of the AIDS pandemic has focused on providing support to orphans. What is wrong with this approach? [4, 10]

1. 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.

While we are about 13 years away from the peak in the number of orphans in South Africa, we are currently faced with vast numbers of children whose care is compromised by virtue of the fact that they live in households with sick adults. Consider the current statistics of in excess of 5 million South Africans currently living with HIV/AIDS, and how this translates into millions of children whose care is potentially compromised by adult illness.

2. There is vast overlap between the difficult experiences faced by children who have been orphaned (by AIDS or any other cause) and the majority of poor children in South Africa. Children living with impoverished parents are documented to struggle similarly from hunger, inability to pay school fees or to buy school uniforms and with access to health services. In general it is the *poverty* of orphans that is addressed by programmes targeting orphans. Yet this is a state shared by millions of other children in SA (between 60 – 70 % of children in South Africa [11] ).
3. At neighbourhood level, orphanhood (as defined internationally) is not necessarily considered to be a primary indicator of children's vulnerability. Other indicators which have been recorded by research as local level priority concerns include children living in poverty, children who have been abused, children who live on the streets, children born to teenage mothers, children living households where there is alcohol abuse, among many others.
4. In AIDS-affected communities, where levels of mortality are increasing, it is not only those who are 'directly' affected by HIV/AIDS who bear the burden of the illness and death that characterises the AIDS pandemic. Poverty is amplified way

- beyond those whom it directly afflicts, as whole neighbourhoods face increased demands on ‘informal’ networks of support to provide for those who need help.
5. Anecdotal evidence indicates that directing material resources to children who have been orphaned to the exclusion of other children can in some instances place orphans at *increased* risk in neighbourhoods where there is a high degree of poverty and unemployment.

In other words, responses to the impact of AIDS on children which focus on providing support only to children who have been orphaned fail to take into account the multitudes of other children whose vulnerability is similarly increased in the context of the AIDS pandemic. As a result they raise questions of equity and appropriateness.

### **A note on residential care facilities:**

1. A common response to increasing numbers of orphans in South Africa is the establishment of residential facilities/ ‘orphanages’. This response is based in part on incorrect assumptions about the circumstances of children who have been orphaned.
2. Research documents a number of important issues to consider with regard to institutional care for children
  - It is generally not ideal for children in the long term, frequently affecting children’s developmental outcomes [12].
  - Children and caregivers are generally reluctant to resort to this form of care, but in some instances consent to it because families are unable to provide for the children adequately themselves [4, 12]. This emphasises the pressing need for improved poverty alleviation mechanisms and support for households [4].
  - Children raised in institutions are left with no ‘home’ upon reaching the age of 18, the cut-off age for which most residential facilities.
  - Institutions are prohibitively expensive to run. For the same costs, far more children can be supported within communities than children in residential care.
  - Residential facilities/institutions established specifically for orphans, or ‘AIDS orphans’ risk increasing the stigma and discrimination associated with HIV/AIDS [4], in particular where these are set up as ‘villages’ that operate separately from surrounding communities.
  - There are important lessons to be learned from failed responses to children living on the streets in the 1980s and 1990s, particularly considering these responses were based in similar assumptions and predictions to those being made about the circumstances of orphans. Evidence indicates clearly that the glut of institutions that emerged out of an international focus on ‘street children’ during this time period were an inappropriate and unsustainable response [9].

## Part B) Some key recommendations for addressing the impact of HIV/AIDS on children's lives in South Africa

Programmes aimed at addressing the impact of HIV/AIDS on children need to be sensitive to local contexts and to local understandings of vulnerability, taking into account issues of representivity, sustainability and equity. It is therefore difficult to prescribe a national response that is meaningful and appropriate in all contexts. However, our research with children, families and service providers across the country [4] suggests that the following might be useful approaches/principles to apply when considering how best to address children's vulnerability in the context of HIV/AIDS in South Africa.

1. When considering the impact of HIV/AIDS on children, *there is a need to move beyond a focus purely on children who have lost biological parents*. Support should be targeted with caution. If the funder's priority is to support children made vulnerable by HIV/AIDS, then targeting of neighbourhoods heavily affected by HIV/AIDS could be a first step, followed by less HIV specific (and community determined) targeting at the level of individual households/organisations. By strengthening services and support for *all* children living in areas of high HIV prevalence, you will create a safety net that captures those made vulnerable by HIV/AIDS that has as its foundation considerations of equity and sustainability.
2. *Support for communities* – who, as evidenced above, are providing care and support for the majority of children made vulnerable by HIV/AIDS – will be key to successfully tackling the impact of the epidemic on children in South Africa. Donors and programmes need to focus their energies in this direction.
3. In order to respond equitably and minimise any risk to increasing beneficiaries' vulnerability, programmes should *target 'categories of need'* rather than categories of children. In other words, if a programme aims to provide poverty relief it should target poor children, if it is to provide bereavement support then children who have lost people who are important to them (or who are in the process of it) should be targeted etc.
4. Given the scale of the pandemic and the reality of resource limitations, we need to look to *maximising opportunities* within existing services to identify and support vulnerable children. Many service providers come into contact with children or caregivers without utilising this contact as an opportunity to identify children who may be potentially vulnerable. Consider for example, the crucial identification role that the formal health services and home-based care services are well placed to play if sufficiently alert to children's vulnerability.
5. In particular, there is a lot of potential to explore the *role of schools* as nodes of care and support for vulnerable children. South Africa has a network of over 28 000 schools reaching approximately 11.5 million children. The education system is one which is centred on children and committed in principle to child wellbeing and development. Schools are relatively accessible to children and families and children spend a significant proportion of their time, over a period of several years, at school. There are several activities well suited to the school environment, many of which need not be facilitated by school staff themselves, for example:



- School based nutrition programmes
  - School based information services
  - Networking and referral systems
  - NGO service delivery through schools
  - Health services through schools
  - Life skills programmes
  - Counselling programmes
  - Peer support groups
  - Pre-school/day care programmes
  - After school care programmes...etc.
6. *Poverty alleviation* is an essential component of our response to addressing the impact of HIV/AIDS on children. Ensuring that children and their families are able to access to food, clothing, school equipment, etc on an ongoing basis forms one component of this kind of relief. Funders can also help to address poverty through providing assistance to families trying to access state grants, and support for organisations lobbying for appropriate and sufficient social security provisions for children. Access to social security grants not only helps ensure that children are fed and clothed, but also assists caregivers to find and create employment opportunities for themselves.
  7. Community-based organisations responding to the AIDS pandemic frequently struggle to access sufficient funds to support their workers, and rely heavily on *volunteers* to carry out much of their work. This is not only unsustainable, but also inappropriate considering the majority of voluntary workers live in poverty themselves. Disproportionate amounts of funding tend to go into the building of infrastructure for example, while organisations struggle to keep running with minimal funding. Donors could play a key role in ensuring sustained support to children by providing funds to local CBOs, NGOs and FBOs specifically for staff salaries and stipends.
  8. Funders are in a position to assist with strengthening communities and community based responses to HIV/AIDS through facilitating collaboration. Funding can be directed in such a way so as to foster collaboration, rather than competition. As an example, criteria for funding could include the existence of a functional management committee/child care committee made up of appropriate local representatives.
  9. Many of the organisations that have grown out of local initiative to support children in the context of HIV/AIDS lack effective fund-raising, financial management, programme management (etc) skills, and would benefit from mentoring or capacity-building programmes to strengthen these aspects of their projects. This will be critical in ensuring for the growth and sustainability of organisations, and for a sustained and expanding response to the pandemic.
  10. In certain contexts there is a role for residential care facilities for children, particularly in the form of small group homes (i.e. caregiver/s caring for small groups of children within households) situated within communities. However, institutionalisation of children should be avoided as far as is possible, and within the best interests of the child.

*For more detailed recommendations, see Giese S, Meintjes H, Croke R and R Chamberlain (2003) 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. Children's Institute, University of Cape Town.*

### **Reference list**

1. Johnson, L. and R. Dorrington, *The Impact of AIDS on Orphanhood in South Africa: A Quantitative Analysis*. 2001, Centre for Actuarial Research (CARE), University of Cape Town.
2. Johnson, L. and R. Dorrington, *The Demographic and Epidemiological Impact of HIV/AIDS Treatment and Prevention Programmes: an Evaluation Based on the ASSA2000 Model*. 2002, Centre for Actuarial Research (CARE), University of Cape Town: Cape Town.
3. Meintjes, H., D. Budlender, S. Giese, and L. Johnson, *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*. 2003, Joint working paper of the Children's Institute and the Centre for Actuarial Research, University of Cape Town: Cape Town.
4. 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.
5. Budlender, D. and H. Meintjes. *Children's family/household context in contemporary South Africa*. Presented at *Workshop on the provisions for Parental Rights and Responsibilities in the Children's Bill*. 2004. Children's Institute, Cape Town, 24 February 2004.
6. Ainsworth, M., S. Ghosh, and I. Semali, *The impact of adult deaths on household composition in Kagera Region, Tanzania*. 1995, Development Research Group, World Bank: Geneva.
7. Gilborn, L.Z., R. Nyonyintono, R. Kabumbuli, and G. Jagwe-Wadda, *Making a Difference for Children Affected by AIDS: Baseline Findings from Operations Research in Uganda*. 2001, The Population Council.
8. Lund, F. *Challenging the Development Community to finance Social Assistance*. Presented at *Children's Institute seminar series*. 2003. Cape Town, 13 October 2003.
9. Bray, R., *Predicting the social consequences of orphanhood in South Africa*. African Journal of AIDS Research, 2004. **2**(1): p. 39-55.
10. Meintjes, H., S. Giese, R. Croke, and R. Chamberlain. *Conceptualising children's vulnerability in the context of HIV/AIDS: Considerations for policy and programmes*. Presented at *SA National HIV/AIDS conference*. 2003. Durban, 4-6 August 2003.
11. Leatt, A., *Reaching out to children: an analysis of the first six months of the extension of the Child Support Grant in South Africa*. 2003, Children's Institute working paper: Cape Town.
12. Tolfree, D., *Roofs and Roots - The Care of Separated Children in the developing world*. 2002, Save the Children UK Position on Residential Care.