Recommendations for health and social services for orphans and other vulnerable children in the contexts of HIV/AIDS in SA

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Background

South Africa has a population of approximately 46.6 million people, of whom 6.5 million are estimated to be HIV-positive. Of direct significance to children is the fact that in South Africa an estimated 3.2 million women of childbearing age (15 to 49) were living with HIV/AIDS in July 2002. Approximately 204 000 children lost a mother in the year 2002 alone - 73% of them as a result of AIDS. As of July 2002 an estimated total of 885 000 children under the age of 18 years in South Africa had lost a mother. This figure is expected to peak at over 2 million by 2010 (Dorrington, Bradshaw et al. 2002).

In August 2001 the Children's Institute was awarded a tender from the National Department of Health to develop a set of recommendations to support and inform an appropriate health, social services and education response to the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa. The project was designed as a multi-site qualitative research project, based in 6 research sites across 5 of South Africa's 9 provinces, namely Eastern Cape, Free State, KwaZulu-Natal, Limpopo Province, and Western Cape. Information was collected through a combination of child participatory research activities, interviews, focus group discussions and observation. Research participants in the study included children who had been orphaned and children living with sick caregivers, caregivers themselves, teachers, health workers, social workers, home based carers and other service providers who were found to contribute in some way to the well-being and/or vulnerability of the children. The research sought to explore and understand the life experiences of these children and to collect information about the factors that impact positively or negatively on support-seeking behaviour, access to services and support, and service delivery. The research report and recommendations were completed over a period of 16 months and were submitted to the National Department of Health at the end of January 2003. This article provides a brief overview of what can be found in the document.[1]

A window on the world of children and caregivers in contexts of HIV/AIDS and poverty

The research documents describes orphanhood as a process that begins long before the death of a child's caregiver, with differently compounded vulnerabilities at different points along this continuum.

The case studies and narratives that characterise the research report attempt to capture and to express the experiences of children and their caregivers, and to articulate the complexity of the challenges to service access and delivery within the contexts of HIV/AIDS and widespread poverty. The research reiterates how the impact of HIV/AIDS and orphanhood on children is compounded in contexts of poverty, where illness and death exacerbate existing household challenges. Not surprisingly, the overwhelming majority of needs expressed by research participants, and those that were prioritised by children themselves, were poverty related, and ones shared by many other children in South Africa who are not experiencing orphanhood.

Recommendations for a service response

The stage of the pandemic in South Africa in 2003 is such that the majority of HIV infected people (75%) are in stage 1 and 2 of disease progression (Dorrington, Bradshaw et al. 2002). The implications of this for

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1. The document has not yet been released by the Department for formal distribution.

The following is an extract from one of the case studies that appear in the research report.

Mantoa and her children

Mantoa – aged somewhere in her forties, but looking much older – lives in a dusty village in Limpopo Province, 1 and a half hour's journey from the nearest town. She has 8 vibrant but skinny 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 have 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. 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.

(All names have been changed.)
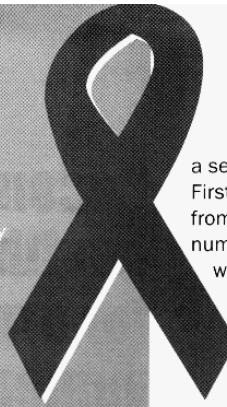
a service response are two-fold. Firstly, the country is 7 years away from experiencing the peak in the number of orphans, and well-grounded strategies and interventions put in place now will lay the foundation for a response that can grow with the size of the orphan population. Secondly, we face an equally large and more immediate service need which is often neglected, that of supporting the large numbers of children currently living with, and often caring for, terminally ill adults and other children.

Since 1994, the SA Government has made exceptional progress in recognising the special needs and rights of children, by ratifying and endorsing global treaties and covenants and by developing national laws, policies and programmes aimed at realising the rights of children to survival, protection, development and participation. Juxtaposing the existing policy and legislative framework against the research findings highlights several key issues.

Firstly, fundamental documents and programmes – including the National Programme of Action for Children, the National Integrated Plan for Children Infected and Affected by HIV/AIDS, the National HIV/AIDS and STD Strategic Plan for South Africa (2000-2005), and the White papers for Education and Social Welfare, among others – emphasise, and create structures to promote collaborative partnerships. While the research found little evidence of these partnerships in practice, the importance of adopting and facilitating a collaborative approach to addressing the needs of children was well illustrated. The one common denominator among service providers across the sites who appeared to be most effective in rallying resources and in addressing the needs of vulnerable children was their success in establishing and maintaining collaborative partnerships with other service

providers. This success factor was as true for services in poorly resourced areas as those in areas that are relatively well resourced. Our research therefore strongly supports the government's commitment to collaboration and urges the state to seek mechanisms, through programme design and resource allocation, to facilitate, encourage and reward approaches to service delivery that foster true collaboration.

Secondly, numerous laws, programmes, policies and strategies developed since 1994 advocate for an approach to welfare and development that is built around the notions of social mobilisation, community development and community- based care and responsibility.

These notions were well reflected in practice in the research sites, where responsibility for the care of the sick and the vulnerable fell predominantly within the domains of households, neighbourhoods, and community based organisations. However, in AIDS-affected communities, where inter-household dependency is common and where levels of mortality are rapidly increasing, the burden of exacerbated poverty and HIV/AIDS is felt collectively. As is reflected in the narratives and case studies throughout the report, and extensively documented elsewhere, the "social safety net" of "community care" is weakening. The reliance on the very young and the very old (poor women in particular) to care for and support each other, while at the same time nursing the sick, is increasing.

While this research does not advocate for an approach that takes us away from the notions of community care and social mobilisation, it does highlight the urgent need for a response that:

※ Makes substantially more financial and professional resources available to ensure the sustainability of

the "social safety net" over the full course of the pandemic and its impact on children, the worst of which remains to be felt;

※ strengthens and supplements the support systems that are already in place, and makes optimum use of opportunities for the identification and support of vulnerable children through existing formal and informal service delivery; and

※ is integrated into a service response to the needs of all vulnerable children in South Africa and grounded within a comprehensive national poverty reduction strategy.

And finally, while there is room for legislative and policy reform in the service response to orphans and other vulnerable children, the existing policy and legislative framework provides for many of their needs. The immediate priority in terms of a course of action lies in the effective implementation of these policies, towards the full realisation of the shared vision of government and civil society to "Put Children First".

Towards this end, the document contains a set of core and detailed recommendations for consideration by the relevant Government Departments and the non-governmental sector and ultimately, for a service response that promotes the realisation of children's basic rights to survival, protection, development and participation — in a context of HIV/AIDS and poverty. For more information on this research, or for a copy of the research report and recommendations, please contact *sonja@rmh.uct.ac.za* or *helenm@rmh.uct.ac.za*

Bibliography

Dorrington, R., D. Bradshaw, et al. (2002). *HIV/AIDS Profile* In The Provinces of South Africa: Indicators For 2002. Cape Town, Centre for Actuarial Research, University of Cape Town.