The challenge lies in implementing policy

SONJA GIESE and HELEN MEINTJES, of the HIV/AIDS Programme, Children's Institute, UCT,[1] examine the government's response to the care and support of children in the context of HIV/AIDS in South Africa.

> *What I realise, when I was young, death was not spoken of daily - today four or more people are buried daily. People who are buried are mostly parents who leave behind children, more in number and more in suffering ... (When I was growing up) there were orphans, but not like today. Today we have orphans and today we don't have food. It is clearer than in the past.*
>
> *Ma Makwea, Limpopo Province*

South Africa currently has over 6 million people infected with HIV – the greatest population of HIV-positive individuals of any country in Africa (Bradshaw, Johnson *et al*. 2002). The majority of these individuals are young adults between the ages of 15 and 49-years. Adult HIV-related infection, illness and death have a direct impact on child well-being in South Africa and on the realisation of children's basic rights to survival, development and protection.

Between 1 January and 31 December 2002, an estimated 89 000 children (around 7.5% of the total number of children born during this period) were infected with HIV through mother-to-child transmission, either at birth or through breastfeeding (Dorrington, Bradshaw *et al*. 2002). Due in part to the compounding dynamics of HIV/AIDS, poverty and malnutrition, most of these children will die before their 5th birthday (Bradshaw, Johnson *et al*. 2002). During the same period, approximately 150 000 children lost their mothers to AIDS, bringing the total number of 'maternal' orphans in South Africa to almost 1 million children.

Children's experiences of orphanhood related to a terminal illness such as HIV/AIDS, begin long before the death of a caregiver, however, and many hundreds of thousands of children are made vulnerable by virtue of the fact that they live with, and frequently assume responsibility for the care of, sick adults and other children. Furthermore, in heavily HIV/AIDS affected communities, the majority of which exist in conditions of poverty, the impact of HIV/AIDS is experienced collectively. In these communities, informal networks of neighbourhood support are essential for survival. However, with high rates of morbidity and mortality of relatively young adults, increasing dependency ratios (with the young and the very old assuming greater responsibility for care), and decreasing income-earning capacity, these informal networks of care and support are weakened, and all children are rendered more vulnerable.

Initial responses to the impact of HIV/AIDS on South Africans were focused on the role of health services and concentrated on prevention and on the clinical care of people living with HIV/AIDS. The exponential growth of the pandemic and its multi-faceted impact on the lives of adults and children necessitates a broader response, however, and the roles of various government departments have begun to evolve accordingly.

The Policy

The National Integrated Plan

An important development in addressing the HIV/AIDS epidemic was the drafting of the HIV/AIDS and STD Strategic Plan for South Africa (2000-2005). This plan is intended to guide South Africa's response to the HIV/AIDS pandemic through four

key priority areas: prevention; treatment, care and support; legal and human rights; and research, monitoring and evaluation.

The goals for the treatment, care and support component of the strategy are particularly relevant to children. They are to:

- provide treatment, care and support services in health care facilities;
- provide adequate treatment, care and support activities in communities; and
- develop and expand the provision of care to children and orphans.[2]

Within this overarching strategy, each department is encouraged to develop their own strategic and operational plans. The primary response from the Social Cluster, in terms of children, was the development of the National Integrated Plan for Children Infected and Affected by HIV/AIDS (NIP). The NIP was initiated at a meeting of the Directors General of the national Departments of Health, Education, Social Development and Finance in December 1999, 'to ensure access to an appropriate and effective integrated system of prevention, care and support services for children infected and affected by HIV/AIDS' (South African Government 2000).

The three core components of the NIP are a Lifeskills programme (delivered predominantly by the Department of Education), voluntary counselling and testing (VCT) (delivered through the Department of Health) and home- and community-based care and support (HCBCS) programmes, responsibility for which is jointly shared by the departments of Health and Social Development.

The budget associated with the NIP is made available to provinces in the form of conditional grants and weighted according to an equitable share formula, with the most affected provinces receiving a greater proportion of the funds (Streak 2001; Marshall 2002). In line with the government's stated focus on prevention (South African Government 2000), the early budgets for the NIP reflect a heavy emphasis on prevention programmes, with the bulk of spending devoted to Lifeskills and, to a lesser extent, VCT, and a low priority for HCBCS. However, over the last few years these priorities have shifted somewhat, with increased proportions of the budget dedicated to providing HCBCS to HIV/AIDS affected households (Marshall 2002) and more specifically, to addressing the needs of 'orphans and other vulnerable children' (Department of Health 2003). In addition to increasing the share of the budget dedicated to care and support activities, increases in the total budgets for the NIP between 2000–2005 – particularly in 2002/3 when the global amount for the NIP increased by 130% – indicate a positive degree of commitment to addressing the impact of HIV/AIDS on children. Furthermore, there appears to be an improvement in fund usage, with less of the underspending that characterised the NIP's early years. The DSD, for example, reports a 90% spending of the conditional grants for HCBCS for the 2002/2003 financial year (Department of Social Development 2003) compared with 57% in the 2001/2002 financial year (Marshall 2002).

At present, much of the burden of care for vulnerable children falls on poor women, in poor households, in poor communities.

While recent announcements and policy statements suggest that the Department of Education is reviewing its role in providing care and support to vulnerable learners, to date the department's activities have been limited almost exclusively to the provision of lifeskills education through schools. Care and support services have been primarily the responsibility of Social Development and, to a lesser extent, Health. The focus of our discussion will, therefore, be on the roles of the Departments of Health and Social Development in the implementation of the NIP and related activities, with an emphasis on the government's home- and community-based care and support initiatives. Issues related to prevention of HIV transmission and to the treatment of HIV-infected children and caregivers will be discussed elsewhere in this edition of ChildrenFIRST pp50–55.

Home- and community-based care and support

A core response in South Africa and elsewhere in Southern Africa, to supporting households affected by HIV/AIDS is HCBCS. This term is used by the Departments of Health and Social Development to emphasise the 'integrated nature of the government's response', bringing 'home-based care' (traditionally a health function) and 'community-based

care and support' (a social development function) together. The term is defined by government as 'the care/services that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities'. According to departmental documents, the intention of the HCBCS programme is to 'ensure that persons who are infected and affected by HIV/AIDS have access to integrated services that address their basic needs for food, shelter, education, health care, family or alternative care and protection from abuse and maltreatment' (Department of Social Development 2001).

In this regard, the programme aims to (Mabetoa and De Beer 2002):

- ensure access to care and follow-up for children and families through a functional referral system;
- integrate a comprehensive care plan into the informal, non-formal and formal health and social development system;
- empower the family/community to take care of their own health and welfare";
- reduce unnecessary visits and admissions to health facilities; and
- ensure that children and families who are affected by HIV/AIDS have access to social development services in the community'.

The HCBCS business plan for 2002/2003 defines the roles for the Departments of Health and Social Development in the support of children affected by HIV/AIDS, either through direct service delivery by the state (the exception) or through the financial and professional support of organisations rendering these services. The table below provides an overview of the various responsibilities of the two departments as outlined in departmental documents.

Table 1: Overview of Department of Social Development and Department of Health responsibilities in relation to the care and support of children affected by HIV/AIDS

Core common functions	DSD specific functions	DOH specific functions
■ identifying community needs and resources	■ community mobilisation around HIV/AIDS	■ provision of basic home-based care supplies (such as gloves, aprons and basic medicines) to home-based carers
■ facilitating networking and referrals between key role-players	■ providing information and education on available services and social security grants	■ conducting home visits to assess care needs (including the need for physical and emotional support)
■ provision of material assistance in the form of food, clothing, and shelter	■ the early identification of vulnerable children and families	■ training and supporting caregivers
■ poverty alleviation	■ finding and monitoring alternative placements for children where necessary (including foster care, adoption and residential care)	■ developing care plans and providing care
■ providing counselling and emotional support	■ establishing child care committees within communities	■ providing DOTS supervision
■ monitoring and supervising home/community based carers	■ training trainers, families, communities, caregivers and professionals	■ ensuring links between home-based carers and health facilities.
■ funding of non-governmental organisations delivering HCBCS services.	■ establishing poverty alleviation programmes in highly impacted communities	
	■ ensuring grant accessibility, including access to the CSG, FCG, CDG and the adult DG.	

Compiled from Mabetoa (2002) and Department of Social Development (2001)

The National Departments of Health and Social Development have outlined a number of proposed models for home- and community-based care programmes, to guide non-governmental, community-based and faith-based organisations and provincial departments rendering these services on the ground (Department of Social Development 2001; Fox, Fawcett *et al*. 2002). The intention is that these models be adapted in different contexts, in order to accommodate the economic and social diversity of communities. While the role of the state differs in these various models, the emphasis within each is on home- and community-based carers having access to professional support, primarily in the form of health workers and social workers. The departments further recommend that home- and community-based carers operate in teams. The teams should comprise of a full-time team manager/co-ordinator (preferably a senior professional nurse or senior social worker); a child and youth care worker; a professional nurse working part-time; and home- and community-based carers, each of whom should receive payment/stipends (Department of Social Development 2001).

Various departmental documents emphasise that, while the HCBCS programme stresses the role of 'communities' in meeting their own needs, it 'does not imply shifting the burden to communities' (Department of Social Development 2001). In spite of this, however, the majority of organisations providing HCBCS services are based within the non-governmental sector and include NGOs, CBOs and faith-based organisations, many of which rely on unpaid/poorly paid local volunteers to deliver services. These organisations typically offer a range of services from very health-focused home-based care (often targeting sick adults primarily) to the provision of material support, counselling, food parcels, and the payment of school fees. The role of the state with regards HCBCS is, therefore, largely the support (financially and through capacity building) of non-governmental organisations rendering services directly to children and affected households. "HCBCS teams are set up at local level with an understanding that the districts will offer professional support where needed," explained a national representative of the Department of Health, "Many of our HCBCS programmes are run by NGOs. The involvement of Health is the provision of professional assistance, supervision of caregivers and provision of home-based care supplies, ... and financial resources for the operation of these programmes." Similarly, the Department of Social Development's Business Plan recognises the need and 'makes provision' for social workers as key role-players in the local teams that implement and monitor HCBCS services.

The Practice

Problems of accessing state support for HCBCS services

A core component of government's strategy in addressing the impact of HIV/AIDS on children is the provision of professional and financial support to home- and community-based care organisations working within the non-governmental sector. State service providers, however, frequently lack the capacity, infrastructure, resources and/or inclination to provide this support (Clarke and Strachan 2000; Desmond and Gow 2000; Schneider and Russell 2000; Giese, Meintjes *et al*. 2003).

In reality, state social workers spend most of their time on social security related issues; they seldom have the time or resources to provide support to other service providers. Similarly, very few NGOs enjoy a collaborative and supportive relationship with local health facility staff, despite the obvious benefits of sustaining these collaborative partnerships (Giese, Meintjes *et al*. 2003).

Despite increased allocations to the budget for conditional grants, accessing government funding for HCBCS services is frequently as fraught with challenges as accessing professional support. In conducting our research, we were unable to determine the total number or proportion of NGOs providing HCBCS services that receive state funding. However, a recent rapid appraisal conducted by the Departments of Health and Social Development of HCBCS services in South Africa (Swartz, Mbalo *et al*. 2001) identified 466 such organisations, of which less than 30% reported receiving any funding from the state. Our research

further documented the extensive difficulties experienced by NGOs when attempting to access state funding, frequently resulting in compromised, disrupted, or discontinued services. "The emphasis is so much on the NGO sector to support vulnerable children," said the manager of an NGO in Durban, "but then I always question whether we have the necessary infrastructure – we need funding to ensure service provision." More recently-established organisations complain of several problems, including the complexities of meeting the demands of government funding proposal formats; the fact that state funding schedules make programme planning and commitments impossible; and that in some instances, organisations are provided with no feedback from provincial departments long after applications for funding are submitted (Giese, Meintjes *et al*. 2003).

Further challenges to implementing the NIP

While there appears to be some progress with the implementation of the NIP, several major challenges that undermine the potential effectiveness of the plan remain. Firstly, collecting reliable information on the programmes and achievements of the NIP is an almost impossible task.[3] The various documents, presentations and government representatives that were consulted often reported different (and at times contradictory) information. The need for transparency and civil society involvement in the implementation of the strategy was further evident from the wider consultations with representatives of NGOs, which revealed that very few organisations are aware of progress made with respect to the NIP and of how to access its support.

Secondly, while numerous government plans and strategies, including the NIP, advocate for a 'collaborative response', there is very little evidence of real partnerships in practice, particularly between government departments. It is essential that the state seeks additional mechanisms, through programme design and resource allocation, to facilitate, encourage and reward effective collaboration at all levels. The value of collaboration is highlighted repeatedly in examples of 'good practice' that emerge from organisations working on the ground. The common denominator among almost all services that appear to be most effective in meeting the needs of vulnerable children is that they function in collaborative partnerships with other service providers.

While the term 'orphans and vulnerable children (OVC)' is frequently used in government documents related to the NIP, the reality is that much of the emphasis of the government's response to the impact of HIV/AIDS on children focuses on those who have been orphaned. While we are not undermining the very real vulnerability of this group of children, in the present stage of the pandemic, we face an equally large and immediate service need which is often neglected – that of supporting the large numbers of children living with, and often caring for, terminally ill adults.

Need for poverty alleviation mechanisms

Not surprisingly, the overwhelming majority of needs expressed and prioritised by children experiencing orphanhood, are poverty related ones that are shared by many other children in South Africa. Given this, and the fact that the impact of HIV/AIDS is felt collectively, a response to the needs of HIV/AIDS affected children should be grounded within a national poverty reduction strategy, aimed at addressing the needs of all poor children. The state's existing mechanisms for poverty relief and emergency relief of distress are grossly inadequate. An urgent extension of existing poverty alleviation mechanisms is needed, together with improved administrative systems, to ensure accessibility to all vulnerable children, including those living with sick adults and children who have been orphaned.

Reliance on the poor to care for the poor

Across all sectors, capacity constraints severely restrict service delivery to vulnerable children and their families. We have already noted how the lack of capacity of health workers and social workers is a barrier to providing professional support to organisations rendering HCBCS services. Capacity related issues present one of the greatest challenges to effectively addressing the needs of children in the context of

HIV/AIDS in South Africa. At present, much of the burden of care for vulnerable children falls on poor women, in poor households, in poor communities. With increasing morbidity and mortality related to HIV/AIDS, this dependency on the poor to care for the poor is unsustainable and, in a country like South Africa, unethical and inequitable.

Numerous government documents, including the NIP, 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. While the sharing of burdens and resources within communities and between households is an important coping strategy in many communities, the burden of increased poverty and HIV/AIDS is changing household form and weakening this 'social safety net'.

While we are not advocating an approach that takes us away from the notions of 'community care' and 'social mobilisation', there is an urgent need for a comprehensive response from government. Substantially more financial and professional resources need to be made available to strengthen the 'social safety net' and to increase the capacity of formal and informal services, in order to ensure their sustainability over the full course of the pandemic and its impact on children, the worst of which remains to be felt.

From policy to practice…

Since 1994, the response to the socio-economic challenges facing South Africans has been characterised by massive policy and legislative reform. Much of what needs to be done is already in place in policy. The challenge lies in implementing these policies and strategies and in monitoring and evaluating their appropriateness and effectiveness in the context of the HIV/AIDS pandemic and the myriad of other factors rendering children in South Africa vulnerable.

There is an urgent need for a comprehensive response from government. Substantially more financial and professional resources need to be made available.

Department of Social Development

Recent initiatives towards the provision of care and support to children in the context of HIV/AIDS

In 2002, the National AIDS and Children Task Team (NACTT) was reconstituted as the National Action Committee for Children Affected by HIV/AIDS (NACCA), with the aim of ensuring co-ordination between all stakeholders and promoting active collaboration to improve service delivery. The team includes representatives from all relevant government departments, international development agencies and some national NGOs.

In June 2002, the Department of Social Development, in collaboration with the Nelson Mandela Children's Fund facilitated a national conference entitled 'A call to co-ordinated action for children affected by HIV/AIDS'. The conference proposed the establishment of a co-ordinating structure, to bring together governmental and non-governmental role players at various levels, in order to strengthen and consolidate service delivery to children in the context of HIV/AIDS (Department of Social Development, Save the Children Alliance, *et al*. 2002). The meeting culminated in a plan of action to 'protect the rights of children who are infected and affected by HIV/AIDS and to ensure that the rights of children to food, shelter, social services and grants, education, health, counselling, alternative care, protection and non-discrimination are protected' (Department of Social Development 2003). The plan includes a strategy for a national capacity development process to facilitate community involvement in the identification, care and support of orphans and other vulnerable children, to create community, district, provincial and national databases, and to fast track the process for accessing social grants and other essential services. According to the department, the plan is in the initial stages of implementation.

Following this conference, NACCA was tasked with developing action plans for seven strategic areas, namely housing, education and recreation, food security, training and capacity building, database and communication, care and support, and social security and placements. An 8th task team is responsible for ensuring co-ordination and

information sharing from national to local levels. The task team plans will be presented to NACCA in 2003 (Smart 2003).

Together with Save the Children (UK), the Department of Social Development commissioned the Children's Institute to research and develop a national directory of services for children infected/affected by HIV/AIDS – the department is now responsible for updating and maintaining the directory which is available in hard copy and electronically at www.childaidsservices.org.

In 2002, the department developed national guidelines for social services for children infected/affected by HIV/AIDS. These guidelines are intended for use by service providers and government officials working with children and their caregivers.

The Circles of Support initiative was also launched in 2002 and aims to reduce stigma and discrimination against children affected by HIV/AIDS and to encourage and increase community support for vulnerable children.

The Department of Social Development set as one of their targets for the HCBCS programme the support/establishment of 300 HCBCS projects by March 2003 (Mabetoa 2002; Mabetoa and De Beer 2002). This target was reached and the department reports that it currently supports 341 HCBCS programmes (it is unclear whether this support is purely financial or includes professional support) (Department of Social Development 2003). They also include, under their achievements for the 2002/2003 financial year, the training of 1604 volunteers, establishment of 41 child care forums and 85 support groups for people living with HIV/AIDS and the appointment of provincial HCBCS co-ordinators (Mabetoa 2002; Department of Social Development 2003).

The department recently announced the extension of the Child Support Grant to children under the age of 14-years but stated that this extension would be progressively implemented over a period of three years. The department has also announced its intention to extend the Foster Grant to children who have been orphaned. Both the progressive implementation of the CSG and the use of the FCG as a poverty alleviation mechanism are problematic (Giese, Meintjes *et al* 2003).

Department of Health

Recent initiatives towards the provision of care and support to children in the context of HIV/AIDS

In September 2002, the Department of Health facilitated the first national HCBC conference. The objectives of the conference were to develop a coherent HCBC response, agree on steps to scale up the delivery of home-based care services, increase the involvement of people living with HIV/AIDS, and consolidate networking between organisations providing home- and community-based care and support services. An important resolution of the meeting was that care, support and counselling for children form essential components of HCBCS (Smart 2003). The recommendations from the conference are 'currently being pursued' and similar conferences are planned provincially (Department of Health 2003).

A rapid appraisal of HCBC programmes was conducted in 2002. The appraisal identified 466 HCBCS programmes in place nationally, assisting approximately 370 000 people. A second appraisal is currently underway.

The Department of Health's achievements with respect to HCBCS include the distribution of 10 000 'home-based care manuals', the training of 2000 home-based carers and 180 'master trainers' nationally, and the appointment of provincial HCBCS co-ordinators (joint Health and Social Development posts).

The Department of Health, in collaboration with the Department of Social Development, commissioned the Children's Institute, UCT, to research and develop a set of

recommendations for health, education and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS. The recommendations were presented to the Department of Health in January 2003 and have been accepted. However, the document has not yet been endorsed for distribution.

To strengthen collaboration between various services and to identify gaps in service delivery, the Social Cluster has contracted the Health Systems Trust to map HIV/AIDS related services at sub-district level.

The South African National AIDS Council (SANAC) is the highest body advising government on all matters related to HIV/AIDS. The SANAC Secretariat (housed within the Department of Health) recently announced its intention to include a children's sector representative on the Council. This is an important development for the children's sector and an opportunity to put children's issues at the forefront of the national response to the HIV/AIDS pandemic. ■

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Footnotes

1. This paper is an adaptation of sections of Giese, S., H. Meintjes, R. Croke & 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.
2. The term 'orphan' is not defined in the document.
3. Many thanks to Louise Vis for assisting with collecting and collating information on the NIP.