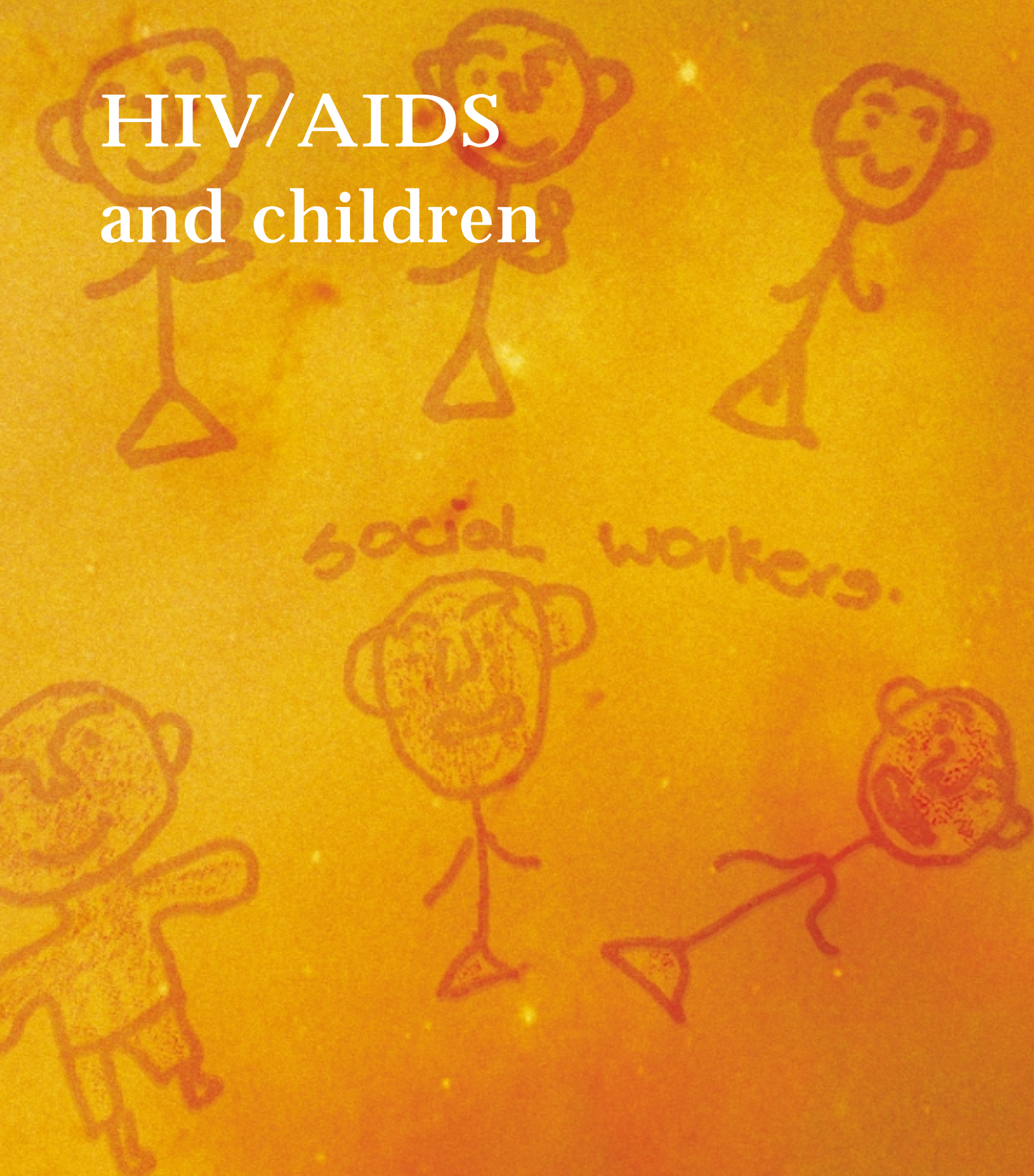# HIV/AIDS
and children

Introduction

According to the *General Household Survey 2004*, there are just over 18 million children living in South Africa. Of these, 260,000 children under the age of 15 years are HIV infected, making it the fastest growing chronic infectious disease amongst children. Research indicates that this figure is growing. The Actuarial Society of South Africa estimates that, in 2000, the rate of HIV infection amongst children was 1.0% and it almost doubled to 1.7% in 2005. The infection rate, as well as the infection growth, is much higher in children under five compared to older children – thus requiring greater efforts to reduce the transmission of HIV from mothers to their children. While these statistics only focus on infected children, many more are affected by the HIV/AIDS pandemic – therefore highlighting the need for a holistic and comprehensive response across all levels of government and civil society.

It is against this background that the emphasis of this first edition of the *South African Child Gauge* is on children in the context of the HIV/AIDS pandemic in South Africa. While there are numerous critical issues that could have been highlighted, the issues featured in this edition are those that have most recently received significant attention from both the government and civil society. These issues are also the focus of research at the Children's Institute, which has enabled us to draw on the most recent data and work in these areas. The four issues discussed in this section are: antiretroviral (ARV) roll-out for children; social security for children in the context of HIV/AIDS; the transformation of schools to be nodes of care and support for vulnerable children; and the involvement of children as active participants in law-making processes that affect them.

The first section, *Children and antiretroviral roll-out: Towards a comprehensive approach*, critically analyses the South African government's *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa.* It is argued in this section that firstly, the plan does not adequately address children's general health rights and needs; and secondly, it does not meet the specific health needs of children with HIV. The authors call for the implementation of a more holistic and comprehensive approach for children infected with HIV (beyond simply administering ARVs) and for the widening of the parameters of care at policy, service delivery and advocacy levels.

The second section, *Social security for children in the time of HIV/AIDS: The (mis)use of foster care?* argues that the most equitable, accessible and appropriate mechanism for supporting children in the context of the AIDS pandemic would be through the extension of the Child Support Grant to all children and for the removal of the means test that restricts children's access to grants. The authors recommend that more children be brought into the social security 'safety net' not only on the basis of their orphan status but rather on the basis of their poverty levels and need.

Schools as nodes of care and support for children affected by HIV, AIDS and poverty examines the role that schools can play as a vehicle of service delivery to vulnerable children. This section calls for increased collaboration between different sectors and service providers; the mainstreaming of services to meet the needs of those most affected; and the integration of service delivery at the school site.

The final section, *Heroes in the context of vulnerability: The participation of children in the Children's Bill*, reminds us of the importance of facilitating children's rights to participate in processes that affect them, especially in the context of poverty and HIV/AIDS. The lessons learnt from the *Dikwankwetla* project reinforce children's agency and their abilities to participate in law-making processes, and show how this, in turn, assists law-makers to make informed decisions.

Children and antiretroviral roll-out: Towards a comprehensive approach

Maylene Shung-King (Children's Institute) and Paul Roux (School of Child and Adolescent Health, University of Cape Town)

In November 2003 the South African government, represented by the Department of Health, approved an *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa*. This plan addresses a range of health issues for adults and children living with HIV and/or AIDS, including implementing the roll-out of antiretrovirals (ARVs) to those who meet certain criteria.

An ideal plan for the comprehensive care, management and treatment of HIV and AIDS must meet all the needs of affected persons. In order to assess whether the South African plan satisfies this onerous requirement, we first need to consider the world in which HIV-positive and HIV-affected children live. This section starts by briefly describing the circumstances of children – worldwide, in Africa and in South Africa. We show the close linkage between poverty and ill-health in general and indicate the specific interrelationships between poverty, malnutrition, HIV and AIDS. We consider lessons learnt from the ARV roll-out elsewhere in Africa. We then examine the South African government's national plan and make certain recommendations for action.

This section focuses on the following questions:

- What do we know about children, poverty and HIV infection?
- What constitutes the vicious cycle of poverty and HIV/AIDS?
- How do we reduce the occurrence of HIV infection in young children?
- What are the specific health needs of children with HIV infection?
- What are the considerations for ensuring adequate access to ARVs?
- What are some obstacles to accessing ARV treatment?
- What is the South African government's response to the health care needs of children with HIV infection?
- What key areas in the comprehensive plan need review?
- What is currently happening in South Africa with the ARV roll-out as it relates to children?
- What are the key concerns regarding current ARV provision to children?
- What are our recommendations?

What do we know about children, poverty and HIV infection?

Poverty throughout the world

There are about 2.2 billion children in the world. About 1 billion of these children live in poverty:

- 640 million children do not have adequate shelter;
- 500 million children do not have access to sanitation;
- 400 million children do not have access to safe water;
- 90 million children are severely deprived of food;
- 270 million children do not have access to health care services, or have access to ineffective services.

HIV/AIDS throughout the world and in Africa

By 2004:

- 42 million people throughout the world were living with HIV; 6.3 million of these people were newly infected;
- 20 million people had died of AIDS; 4 million of these were children.

During 2004, half a million children throughout the world became infected with HIV. Currently, 2.2 million African children are living with HIV and/or AIDS.

HIV/AIDS in South Africa

According to a 2004 report by the Medical Research Council of South Africa:

- Just over 5 million South Africans out of a total of 46 million were HIV positive. It is estimated that 500,000 of these people were sick and in need of ARVs.
- About 245,000 children were infected with HIV. It is estimated that 50,000 of these children were sick and needed access to treatment.
- Some 37,000 children were infected with HIV at or around birth (this is called vertical transmission) and 26,000 were infected through breastfeeding.
- Between a quarter to a third of those children who were vertically infected died before they reached one year of age.
- Only about two-thirds of HIV-infected infants survive into early childhood.

What constitutes the vicious cycle of poverty and HIV/AIDS?

There are many factors that result in, and complicate, the HIV pandemic and its consequences. One of the most critical factors is poverty.

Poverty deepens the effects of HIV/AIDS on households and HIV/AIDS in turn aggravates already existing poverty. In urban areas, affected households with at least one person living with HIV or AIDS experience a serious drop in household income. In rural communities, agricultural activity and output decrease. In general, households directly affected by the pandemic are poorer than those not directly affected.

In South Africa we have a double crisis because the rate of HIV infection is rising alongside a rising unemployment rate. There is a growing gap between the employed and the unemployed. Research by Professor Nicoli Nattrass at the University of Cape Town shows that, in certain areas, 73% of adults in HIV-affected households receive a Disability Grant. These grants make up 56% of the total income of these households. HIV-positive adults qualify for a Disability Grant when their CD4+ counts fall below 200 (established through a blood test that indicates the extent to which HIV has damaged the body's immune system).

With the national ARV roll-out, more and more adults will gain access to ARVs and their health status will improve. This will result in their Disability Grants being cancelled because the current system of grants assumes that adults will gain employment once their illness is under control. This is of course not true in a situation where unemployment figures are so high and, therefore, improved health does not guarantee that the HIV-positive adult will find work. Thus, the adult with access to ARVs faces a future of poverty. This is a disincentive to adherence to ARVs and, should the person lose the grant, future poverty is likely to lead to future disease.

Malnutrition and HIV/AIDS: A further spiral in the vicious cycle

Poverty and malnutrition are intertwined and both affect child survival. In developing countries, improved nutrition is both a humanitarian and an economic priority. A sustainable reduction in poverty requires political will, stability and economic policies that focus on creating employment. This is a long, slow process and there is no guarantee that it will adequately improve the income of the poorest. So there is also a need for other, more

immediate interventions which focus on living conditions and which specifically take children into account.

Throughout Africa the following short-term strategies are being trialed:

■ School-based feeding programmes which target school-age children.

■ Subsidies on basic commodities, like food and services, including the provision of clean water, power supply and agricultural inputs.

■ Providing children with nutritional supplements, such as Vitamin A, selenium, zinc and other 'alternative' food supplements.

■ Creating employment opportunities, which is particularly important for women who bear much of the burden of food provision and for the care of orphans and HIV-affected family members.

Generally, the most effective strategies and policies are those which help individual families to access food and financial aid, preferably through job creation.

Given that HIV/AIDS is compounding the general ill-health effects of poverty, it is important to reflect on what the comprehensive health care needs are of children with HIV infection. In the light of the devastating effects of HIV/AIDS, the first priority – and the most significant response – is the prevention of childhood HIV infection. There are many mechanisms for preventing the disease in adults, but we need to look at how to prevent the disease in young children when adults have already contracted HIV.

How do we reduce the occurrence of HIV infection in young children?

Around the world, almost two-thirds of new infections that occur in children are through mother-to-child transmission (MTCT). It therefore makes sense to target MTCT as the first area of prevention. Interventions to reduce MTCT infection depend on a readily accessible health care system and an efficient and friendly prevention of mother-to-child transmission (PMTCT) programme.

In some smaller rural communities where the risk of infection amongst women runs high, women do not readily go for voluntary counselling and testing because of the fear of stigma. There is an urgent need for a focused drive to help pregnant women counter the fear of stigma and to emphasise the benefits of PMTCT to the next generation.

Although more and more pregnant women are being tested for HIV, the rate of testing is overall not at its optimum. This means that many opportunities for prevention of MTCT are missed because HIV infection remains undetected and women and their infants do not receive PMTCT. The result is that large numbers of children will continue to be infected at the time of birth.

What are the specific health needs of children with HIV infection?

Where children do contract HIV, it is important to understand what responses are required to address their health needs best.

Children with HIV infection have the same general health needs as children without HIV infection. In addition to their general health needs, they also have a range of needs that are specific to being HIV infected. In addition, the HIV infection makes their general health needs more complex and varied.

Nutrition: The majority of children in South Africa live in extreme poverty and are malnourished. Malnutrition in HIV-infected children can speed up the progression to AIDS. Therefore an effective intervention must include food- and nutrition-based programmes for HIV-infected children and their families. It also needs to be responsive to the nutritional status of HIV-infected children, which changes as they gain access to ARVs. For example, the Paediatric HIV/AIDS Service at Groote Schuur Hospital in Cape Town has noted that, before starting ARVs, 40% of children who attended the clinic weighed far below the average for their age as opposed to those children receiving ARVs, of whom fewer than 4% were underweight for their age. They concluded that this was the result of a combination of interventions including the national feeding scheme for under-weight children, a comprehensive health care package, access to available grants (including Disability Grants), and an NGO-driven income generation project for mothers and caregivers.

Medication: Children with HIV infection need preventive and treatment medicines for HIV-related infections, including access to ARVs. Medication with ARVs requires an infrastructure to manage screening, to monitor treatment, side effects and adverse events – including the development of resistance – and to promote adherence.

Education: Adherence support requires ongoing patient and caregiver education. Life-skills programmes must be in place to support children before and after their caregivers disclose their HIV status to them.

Palliative or home-based care: Families infected and affected by HIV need support in coping with comfort care, end-of-life care, estate planning and other matters related to death and dying.

Preventive services: Pre-school children with HIV and AIDS also need routine preventive services, including vaccinations. They need ready access to dental care, as they are prone to dental caries and periodontal disease.

Psychosocial support: Children who are HIV infected have specific emotional, psychological and social needs. These include help with pre-test counselling for HIV testing, disclosure of the diagnosis to the child, disclosure to others, and adherence support. School-going children need support in dealing with the side-effects of drugs, absence from school for health care visits and possible stigmatisation by peers. Life-skills programmes and support groups are useful adjuncts to individual counselling.

Care for children experiencing orphanhood: There is an increasing number of children who are experiencing orphanhood due to HIV/AIDS, who live with terminally ill parents, primary caregivers or elderly relatives, or who live on their own. These children need special help in accessing adequate health care services.

Bearing in mind these comprehensive health needs of children, the table below outlines a model for a comprehensive health service response that is child-specific and child-orientated, and capable of meeting the needs of children with HIV infection.

Table 1: A proposed comprehensive service for children with HIV infection

Comprehensive health care includes care that covers a range of health needs	General needs of children	Specific needs of children with HIV infection
Health promotion	This refers to all efforts to promote good health in all children and their families through health facilities, the school health system, and other interventions.	This includes: ■ primary prevention; ■ prevention of disease progression; ■ nutritional support and advice; ■ voluntary counselling and testing services; and ■ specially trained counsellors for children and adolescents.
Primary prevention	This refers to: ■ all preventive programmes aimed at young children, including immunisation, developmental screening and growth monitoring and nutritional support; and ■ specific services for adolescents that are essential, such as adolescent-friendly clinics.	This includes interventions such as: ■ the prevention of MTCT; ■ post-exposure prophylaxis (ARVs for children who have been sexually abused and are at risk of HIV infection); and ■ specific adolescent-friendly services and school-based programmes relating to the prevention of HIV.

Comprehensive health care includes care that covers a range of health needs	General needs of children	Specific needs of children with HIV infection
Secondary prevention	This refers to measures that prevent an existing condition from getting worse.	This includes interventions such as: ■ access to ARVs; ■ prevention of opportunistic infections such as Pneumocystic Pneumonia, commonly known as Pneumocystic Carinii Pneumonia (PCP), TB, etc.; and ■ nutritional support.
Curative care	This includes: ■ intensive treatment for conditions not specifically related to their HIV infection; ■ critical care services for all children that experience life-threatening acute illnesses; ■ ongoing and continuous care services; ■ supportive services for adolescents; ■ a good referral network so that children can be referred up or down levels of care; ■ clear communication between health professionals at different facilities and levels; and ■ patient-held records detailing relevant information.	This includes: ■ treatment of opportunistic infections, such as TB, pneumonia and gastroenteritis; ■ other disease-specific interventions; ■ the whole range of health services available for children with any other chronic health condition; ■ adolescent-friendly services and adult health care services that can respond to their physical, emotional and psychological needs; and ■ solid and well-structured networks that help achieve patient confidence and ensure continuity of care. Inconsistent and unreliable services will result in poor adherence to ARVs. Ideally every child on ARVs and his/her parents/caregivers should have a healthy and supportive relationship with the multidisciplinary 'team'.
Palliative or home-based care and support	This refers to care that makes children as comfortable as possible when they reach their terminal illness.	Children and their families with end-stage AIDS require ongoing terminal care and support at home.
Support to parents/ caregivers of children	Parents and caregivers of children need support and information on child care, access to appropriate health care and social service support	This includes: ■ support in care of HIV-infected infants; ■ support regarding managing confidentiality; ■ liaison with schools; ■ management of their own disease; and ■ HIV-infected parents/caregivers also having access to the necessary treatment for themselves.
Support from other sectors	Intersectoral support from social services, education and other services for orphans, vulnerable children and children living in poverty.	This includes: ■ liaison between health care, education, social development, housing, NGOs and CBOs to develop comprehensive care plans for individual school-based programmes for HIV-affected children. ■ The government is still deciding on a specific grant for children that have become care-dependent – those who have reached Stage 3 or 4 of their disease.

So far we have highlighted the range of health needs of children with HIV infection, and have said that the sole provision of ARVs is not a sufficient response to the pandemic. It is now necessary to reflect on what is required when providing ARVs to children, given that this is an important and complex component of their total care.

The provision of ARVs is complicated. The World Health Organisation and UNAIDS proposed a package of care, prevention and support services that must be in place before ARVs can be introduced. This includes:

- HIV testing and counselling;
- trained and certified staff to prescribe ARVs and to follow up on patients;
- an uninterrupted supply of ARVs;
- a secure and confidential patient record system;
- support to ensure that the patient takes the medication; and
- community mobilisation and education on ARVs.

Although ARVs are available and are becoming more and more affordable, this treatment is often out of reach for the African child. Few African countries have accessible, free ARV programmes that run within their public service health systems. Most sub-Saharan treatment programmes rely on external funding from global agencies and other donors.

A comprehensive health care package can improve child health, prolong life and delay the need for ARVs. Where children enjoy continuous and ongoing access to appropriate health care, mothers begin to change their perceptions of their children – they no longer see them as having a terminal or life-threatening disease, but as having a chronic or long-term illness which can be appropriately managed. Researchers have noticed that mothers play differently with their children when they believe that they have the future they once thought was lost to them. This change in perception has important and holistic effects on the well-being of the child.

An inadequate health care infrastructure, which lacks a comprehensive health care package, has a critical and costly affect on the child and the family. The health of each affected child deteriorates more rapidly and children die sooner. This is the case in Africa, as already inadequate resources are being stretched to breaking point by the new, great and intensive demand imposed by the HIV/AIDS pandemic.

For children who do need ARVs, access to this medication improves their health and quality of life and reduces the need for costly in-patient hospital care. This will enable hospitals to use their resources more efficiently because children on ARVs need fewer and shorter admissions. Beds are therefore more freely available to all acutely ill children whether or not they are HIV infected.

Furthermore, treatment sites must be improved to get the best out of existing facilities, systems of care and patient flow to ARV treatment. This will ensure that the maximum number of infected children gain access to ongoing and appropriate care, closer to their homes. Many initiatives in Africa are helping treatment sites to improve their systems of care through operational research, bottom-up improvement of systems, collaborative networks, local ownership and transfer of knowledge.

Screening children's need for ARV treatment

At present, in South Africa, children with HIV and AIDS are only being identified once they have already fallen seriously ill. This situation could be improved by early diagnosis of the infection in children who are suspected to have HIV, and by instituting appropriate preventative and therapeutic management early on in the course of illness. Much of this work will fall to nurses in community health centres. At present, many nurses are uncertain of their skills and abilities to perform this screening and unsure of how to refer suspected cases for further management.

Once a child is known to be HIV positive, regular CD4+ counts are necessary to monitor the child's immune status. Taking blood from a child's vein can be technically difficult. There is a need to develop technology that will permit CD4+ counts to be done on blood collected by heel- or finger-prick.

Problems with size, taste, dose of medication

Worldwide, there are obstacles to administering ARVs to children. These include calculating and administering the correct doses of medication, the taste of some ARVs and the lack of a useful range of pill sizes for children. Health workers have had to work out innovative techniques to help children swallow large pills or to help caregivers mask their unpleasant flavours. Ultimately, drug manufacturers need to produce a

range of pill sizes for each of the ARVs that will allow paediatric clinicians to prescribe increasing doses to match the needs of their growing patients.

Adhering to treatment

Adherence to ARV treatment is as good in Africa as anywhere else. The child's adherence depends on the caregiver's commitment. Adherence practices are complex and influenced by many factors. Only some of these factors can be changed through the training and education of caregivers.

It is clear that the death of the mother and joint care from surviving relatives is a threat to adherence. Comprehensive care for the child therefore requires close attention to maternal health. The fact that maternal and child health is so closely linked argues for a family medicine approach to health care for HIV and AIDS.

Poverty too contributes to poor adherence. Adherence to a regular medication schedule requires a well-regulated life. Poverty makes life difficult to regulate.

Children without adult caregivers might find themselves in a difficult position, as the current criteria require children to have at least one responsible adult who cares for them before they are put on the ARV treatment programme. In addition, good adherence in children requires that a motivated caregiver ensures that the child gets his/her medication on a daily basis and in the correct dosage. For children to take this level of responsibility for younger siblings might be difficult, depending on the age of the older children in the household, as well as their living conditions.

Creating partnerships in response to the HIV/AIDS pandemic

NGOs and faith-based organisations (FBOs) carry the bulk of the HIV-related burden in Africa. In the pre-ARV era, organisations such as The AIDS Support Organisation (TASO) in Uganda developed extensive community-based programmes, supporting tens of thousands of families. Other organisations, such as Mildmay – which established a network of hospices in sub-Saharan Africa – contributed to a network of care.

In the era of ARV access, the flexibility and creativity of NGOs have enabled them to establish original and ground-breaking treatment programmes in response to the local, 'grassroots' conditions in which they work. However, the future success of these programmes depends on efficient, sufficient and prompt partnership between these NGOs and government.

Throughout Africa, the public health clinic operates at 'grassroots' level – exactly the place where practice needs to be examined, considered and improved. These clinics can be used to provide comprehensive health care services to caregivers, children and their communities, including training, counselling, life-skills programmes, and other interventions. They can also be used as a venue for partnerships across sectors to initiate appropriate projects to deal with the burdens of poverty and disease. The clinic is also the appropriate platform for research into appropriate vaccine regimens for HIV-positive children, both before and after access to ARVs.

Treatment centres, primary health care services and NGOs need to work together with national governments and international donor organisations to address health care and poverty relief throughout Africa to treat and support children with HIV/AIDS, and to help their caregivers and communities become self-sufficient.

With this in mind, we now focus specifically on the South African government's response to children infected with HIV.

What is the South African government's response to the health care needs of children with HIV infection?

The South African Constitution guarantees all children, including children with HIV infection, the right to basic health care and basic health care services. These rights are also found in various international documents and treaties to which South Africa is a party.

The government's plan for the comprehensive care, management and treatment for HIV and AIDS focuses narrowly on the roll-out of ARV treatment. It does not particularly focus on children or consider children's comprehensive health needs. However, the government has commissioned guidelines that provide much more specific direction for the comprehensive management of HIV-infected children. These guidelines will supplement the ARV roll-out plan. The task team that developed the guidelines was co-ordinated by Dr Tammy Meyers and is referred to as the 'Meyers guidelines' for the purposes of this article. Our critique of the government's current plan thus incorporates a critique of the Meyers guidelines.

Child-oriented counselling and testing

The government's national plan says that prevention counselling, as well as voluntary counselling and testing (VCT) should be available. The plan does not recognise that in most cases parents are not disclosing the diagnosis of HIV and AIDS to the child. The plan does not include a provision for life-skills programmes for such children to prepare them for disclosure, nor does it provide guidelines to prepare families to make the disclosure to the child. The plan does not say how the specific counselling needs of children with HIV infection should be addressed. Counselling for children needs to be age-appropriate and counsellors need specific training on how to cope with children that are old enough to understand issues related to their HIV status.

Research conducted by the Children's Institute at six sites across five provinces in South Africa found that health workers and counsellors are not comfortable in counselling and supporting children. This is a crucial part of holistic care of HIV-infected children and needs to be addressed urgently. The government needs to develop clear guidelines on when and how children should be counselled about issues such as HIV status, disclosure and confidentiality.

The national plan sets out specific directions on when to test and which tests to use for children. The complexities around HIV testing in young babies and children are inadequately covered. This is addressed more comprehensively in the Meyers guidelines, which hopefully will be taken into consideration at ARV sites.

The plan also does not give direction on how to address HIV diagnosis where children have no adult caregivers; in homeless children; or where children are in informal care where no one has the legal authority to give consent on their behalf.

ARV provision

The plan clearly outlines the different medicines available to treat children but is less clear on the specific difficulties of diagnosing HIV in children. It recommends that there must be "at least one responsible person capable of administering the child's medication", but it does not take into account how difficult this can be. No mention is made of the special considerations that need to be taken into account when preparing and providing ARVs to children. For example, no

attention is paid to trying to make medicines for children less complex to take so that adherence is easier; or to the need to develop drugs that do not rely on fridges for storage, especially in a country where large sections of the population do not have access to electricity.

Monitoring of children on ARVs

Children on ARVs need regular monitoring of varying kinds, for example monitoring of the HIV disease, of the safety of the ARVs, of their growth and development while on treatment, of how drug dosages need to be adjusted as they grow and develop, and of adverse drug side effects, amongst others. The plan does not give specific attention to these issues.

Drug availability

The plan implies that ARVs – and medicines to treat general infections, opportunistic infections and HIV-related complications – must be available at specific facilities. However it does not recognise the complexities of administering and storing some of the drugs.

Staff and human resources

One of the greatest challenges for ARV roll-out to children is to ensure that there are enough appropriately trained staff. The plan does consider the need for health workers to be trained on how to manage children on ARVs. It focuses narrowly on staff training in dealing with the medical aspects only. The Meyers guidelines, on the other hand, recommend that health workers at all levels must have more holistic knowledge and experience to ensure that children's comprehensive health care needs are met. However, both the plan and the Meyers guidelines do not adequately consider the need for other 'players' to be involved in the multidisciplinary team beyond the formal health sector – the need for CBOs and FBOs, lay counsellors, schools, amongst others.

Roles of different levels of care, referral and continuity of care

The plan clearly outlines the roles and responsibilities of the different levels of care. However it does not discuss co-ordination between ARV services for children and other relevant policies and services, such as services to children with other chronic conditions. There is an urgent need for collaboration and co-ordination within the Department of Health, between

other government departments, and between other sectors that impact on children with HIV infection.

Adherence – making sure the drugs are taken

The plan looks at the area of adherence from the point of view of the patient being able to take responsibility for his or her own adherence. It does not address children who need to rely on adults to help them with their adherence. Good adherence can be promoted by ensuring consistent support of children with HIV infection and their families/caregivers and ensuring continuity of care. Ideally, every child on ARVs and his/her caregiver should develop a healthy relationship with a specific care-providing team. This team should be led by a health worker who would be responsible for co-ordinating and monitoring the ARVs and the interdisciplinary services at all levels of health care.

From the discussion above it is clear that the plan does give consideration to children. However, this is done in a medical and technical manner and does not adequately consider the comprehensive needs of children. Two key interventions that are not adequately addressed are reducing HIV infection in adults and the prevention of mother-to-child transmissions. Both these interventions would have the greatest effect on reducing HIV in children.

What is currently happening in South Africa with the ARV roll-out as it relates to children?

ARV roll-out is taking place much slower than anticipated by the government. There are far fewer sites providing ARVs for children than for adults. Recent figures released by the Treatment Action Campaign in June 2005 indicate that close to 5,000 children are on treatment, while it is estimated that at least 50,000 children are in need of treatment. This means that only about 10% of children currently requiring treatment are getting it. This figure varies greatly from province to province, with some provinces having less than 1% and others having close to 17% of children on treatment. Most of the sites where children are on treatment are donor-funded. It seems that the major barrier to implementation is that ARVs for children are not available in some parts of the country. However, research and evaluation needs to be done to identify the exact problems with implementation.

What are the key concerns regarding current ARV provision to children?

ARV roll-out is a complex and long-term intervention which needs a well-functioning service infrastructure at all levels. At present, service providers at different levels of care have identified a number of problems at treatment sites which are creating a barrier to roll-out, such as:

General service capacity: Throughout South Africa, there are many paediatric ARV treatment sites and clinics that are trying to identify and enroll infected children and to deliver ARVs to them as fast and as efficiently as possible. Primary level facilities are currently ill-equipped. There are similar concerns about secondary level facilities. There are not enough health care professionals who are trained or skilled in screening and identifying children in need of HIV testing or in providing HIV care and ARVs. Most facilities are understaffed and cannot cope with the large number of patients requiring screening, testing and assessment for ARVs. Starting and managing large numbers of children on ARVs would require a large increase in resources.

Currently, the demand for ARVs far exceeds the supply of services. Even where care is available, it is far too centralised.

Co-ordination of services: Current services for HIV-infected children and adults are not family- or child- and caregiver-oriented. There is a need for co-ordination between different programmes in the Department of Health, between different disciplines in health facilities and across sectors. To quote one example: due to a vertical approach to care delivery, there is resistance at primary care level to the idea that ARV treatment sites should manage TB in their own patients.

Disclosure, confidentiality and consent: Current services do not address non-disclosure to children and there are few treatment sites that offer life-skills programmes or children's support groups. Children, like adults, need a lot of emotional support in dealing with the potential stigma of having HIV infection. This support is currently not available. Closely associated with this is the issue of confidentiality and consent for testing and treatment. Currently there is no agreement about how to deal with these issues.

Selecting children to receive treatment: The plan does not give any guidance on how service providers should prioritise who should be enrolled onto the programme. This means

that no clear priority is given to children above adults, or women above men. Each site uses slightly different criteria over and above the minimum requirements for enrolment. As resources are so limited it is inevitable that roll-out will initially focus on children that are very ill. As indicated above, attention should be given to a systematic approach that will screen and test children before they become ill. Children should gain programmatic access to ARVs based on the monitoring of CD4+ counts.

Adherence difficulties: Pharmaceutical companies should pay specific attention to developing child-friendly medication, with tablet and capsule sizes that permit an early switch from syrups. This would simplify treatment, reduce the number of doses and improve adherence support and monitoring.

The treatment and care of HIV-infected children in residential care facilities: Children in children's homes who have chronic health conditions such as HIV are not adequately catered for by the State. In formal residential care, no extra subsidy is given for children with chronic health conditions, even though there are additional medical and transport expenses. In informal facilities, caregivers struggle to cope with the varying needs of children and struggle to access treatment such as ARVs. This is complicated by the fact that caregivers cannot legally give consent for testing and treatment.

Material support to affected families: Poverty is a major factor in the progression of HIV and AIDS, contributing to malnutrition, poor hygiene, unsafe water, poor access to health care and non-adherence. A neglected element of comprehensive health care is the need to improve the overall public health infrastructure and social support in the form of facilitated access to grants, the development of new forms of social grants, and application for state-supported housing. Assistance in access to state-funded care and the creation of income-generating opportunities for affected families are as important as any other facet of health care.

What are our recommendations?

Our main recommendation is to reduce HIV infection in adults and to prevent mother-to-child transmissions. Both these interventions would have the greatest effect of reducing HIV infection in children.

Our other recommendations are related to policy, service delivery and advocacy.

At policy level

- All policies and plans that have implications for children must have a specific section catering for children's specific needs, and must be drawn up by child experts. In addition, different policy and planning initiatives for children must be co-ordinated within government departments and between other sectors.
- The current draft policy framework for children with chronic health conditions must be officially accepted and implemented.
- The following gaps in the plan and the Meyers guidelines must be addressed: monitoring, adherence, accessing and providing ARVs.
- The government must address the critical shortage of nurses to meet urgent needs, particularly to implement screening, diagnosis and monitoring of HIV and AIDS, at the primary health care level.
- The government must acknowledge the critical consequences of poverty that impact on HIV-affected families. It must develop policy to facilitate and support public-private income-generating projects aimed at alleviating poverty amongst HIV-affected families as part of comprehensive health care.
- The government must reassess the regulation of Disability Grants for adults and children with HIV and AIDS.

At service delivery level

- The overall health care infrastructure, especially at primary level, must be strengthened, otherwise ARVs and other HIV-specific programmes will be difficult to implement successfully. Chronic and critical care services for children are particularly neglected. Emphasis must be placed on the specific needs of children when increasing the number of ARV sites, as well as on the training of staff and providing other essential resources.
- The government must develop clear guidelines on age- and development-appropriate practices for counselling, disclosure and confidentiality in children.
- The government must develop clear guidelines on how to prioritise among eligible children and how to standardise practices across sites.
- Children living in especially difficult circumstances who require HIV treatment and support must receive special attention and support.
- Family medicine should be promoted as a model of care to sustain the health of caregivers and children alike.

- Pharmaceutical companies that develop medicines for children must pay specific attention to improvements that would enhance adherence in children.
- There should be, at clinic level, a new focus on support towards the material needs of affected families through the provision of information on and the facilitation of access to grants, state-supported housing and feeding schemes.

At advocacy level

Watchdog bodies must monitor the care and support of children with HIV infection and must advocate for and facilitate possible ways of strengthening social service provision to children.

In conclusion: Children's health rights in general and in particular the rights of children with HIV have not yet been met. Their basic general health care needs and their specific HIV-related needs have not been adequately addressed. Given the large number of children that are already HIV infected, we need to implement a comprehensive package of care for children infected with HIV. This requires political will from all government departments, careful planning, and a consciousness on the part of policy-makers, planners and implementers of the special needs of children.

Sources

This section has drawn extensively on the following discussion paper:

Shung-King M & Zampoli M (2004) *Antiretroviral roll-out in South Africa: Where do children feature?* Cape Town: Children's Institute & Save the Children Sweden.

Other sources used in this section:

Bobat R, Coovadia H, Moodley D & Coutsoudis A (1999) Mortality in a cohort of children born to HIV-1 infected women from Durban, South Africa. *South African Medical Journal*, (89): 646-8.

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Social security for children in the time of HIV/AIDS: The (mis)use of foster care?

Helen Meintjes (Children's Institute), Debbie Budlender (Centre for Actuarial Research),
Sonja Giese (Absolute Return for Kids) and Leigh Johnson (Centre for Actuarial Research)
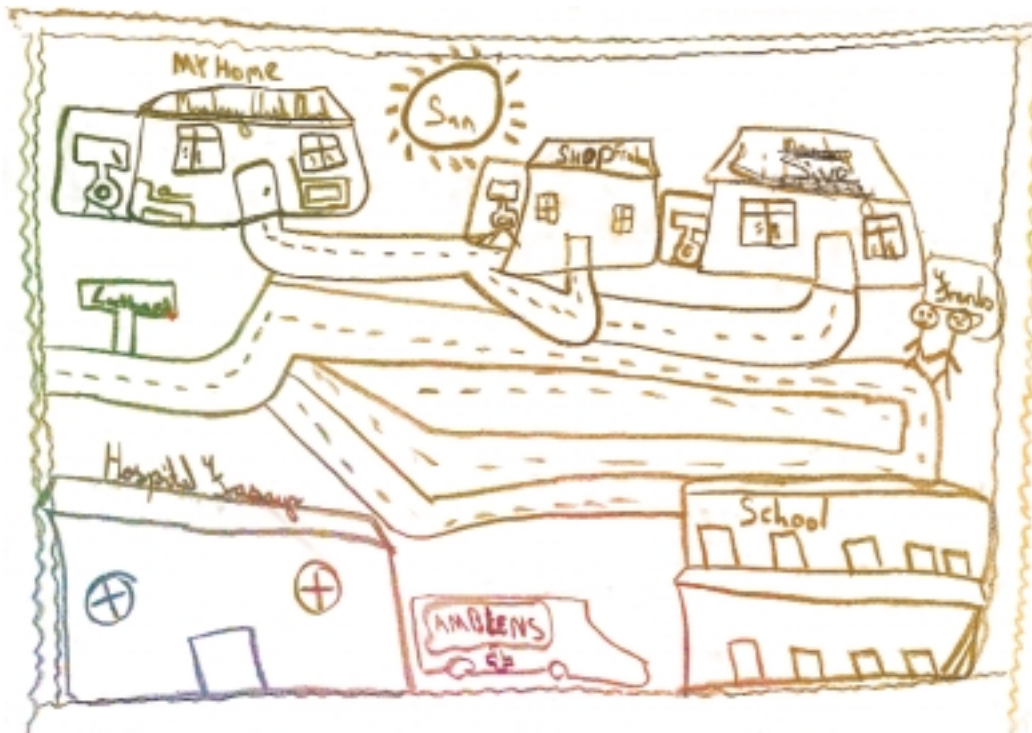
It is estimated that over 10 million children under the age of 18 years in South Africa live in poverty. The AIDS pandemic can only exacerbate the circumstances of these children. In this context, appropriate social security provisioning can play a critical role in supporting poor children and their households through the pandemic.

To date, foster care placements and grants have been viewed as a key intervention in addressing the needs of children in the context of AIDS. The South African government encourages people taking care of orphans to make use of the foster care system to access financial support. This section critically considers this approach.

This section focuses on the following questions:

■ What are the current and proposed social security provisions for children in South Africa?

■ What are the implications of the ongoing implementation of the current provisions – how practical, effective, equitable and appropriate are they?

■ What are the comparative costs of different social security scenarios?

■ What are our conclusions and recommendations?

The current provisions

We focus on two of the cash grants that are currently legislated for children – the Child Support Grant (CSG) and the Foster Care Grant (FCG).

The Child Support Grant: The purpose of the CSG is poverty alleviation. Under the regulations to the Social Assistance Act 59 of 1992, the caregivers of poor children under the age of 14 years are, in 2005, eligible for a CSG of R180 per month. Any 'primary caregiver' of a child under 14 years old can apply to the Department of Social Development for this grant. The department will assess whether or not the caregiver qualifies in terms of a means test, which is based on income. The process is administrative and does not involve court orders or the services of social workers.

Children under the age of 14 years who have been orphaned and whose caregivers fit the above criteria are eligible for the CSG. However, the Department of Social Development, as well as non-governmental organisations (NGOs), encourage families caring for orphans to apply instead for the Foster Care Grant.

The Foster Care Grant: The two Acts that govern the FCG are the Child Care Act 74 of 1983 and the Social Assistance Act 59 of 1992.

It is crucial to note that, unlike the CSG (which is not linked to any social services), the FCG is a component of the foster care system. The foster care system was designed as a mechanism for intervening in the lives of children needing protection. In particular, it was aimed at supporting children facing abuse and neglect. It is a cornerstone of the child protection system.

The processes involved in accessing a FCG are therefore more complex than those for the CSG:

- To qualify for a FCG, the child must be placed in formal foster care. This means that the courts, with the support of social workers, must find the child to be 'in need of care' (the legal criteria are outlined in the Child Care Act). They must then place the child in the safe custody of adults who are not the child's biological parents. The foster parents are recognised as the legal custodians of the child for as long as the child is in their foster care.

- The foster parents can apply, in 2005, for a FCG of R560 per month for each fostered child who is under the age of 18 years. The FCG amount is more than three times the amount of the CSG. The foster parents do not have to pass an income-based means test to qualify for the FCG.

- Foster care placements are linked to a 'basket' of services which by law include ongoing monitoring and support of children and their families by social workers.

- Foster care placements are made for a maximum of two years at a time, at which stage a renewal process is required.

According to the Child Care Act 74 of 1983 (section 14 (4)), children who do not have any living biological parents are defined as being 'in need of care'. This makes them eligible for foster care placement and the FCG.

What role is foster care currently playing in practice?

Research shows that increasing numbers of poverty-stricken families who are caring for orphaned children are relying on foster care placements as a way to access the more substantial financial support offered by the FCG. This is understandable, considering the lack of adequate alternative cash grants, the high levels of poverty in the country, and encouragement from the government to do so.

As a result, the purpose of foster care placement is in practice being shifted away from child protection to poverty alleviation. This is likely to increase as the AIDS pandemic progresses unless a more adequate social security policy is put in place.

The new provisions proposed by the South African Law Reform Commission (SALRC)

During the process of drafting a new Children's Act, the SALRC recommended that the following cash grants (amongst others) be made available to support the care of children:

- A universal child grant aimed at providing support to all South African children up to the age of 18 years. This extends the age limits on the current CSG and removes the income-based means test.

- An Informal Kinship Care Grant for children up to 18 years of age, who live in the care of relatives (but not with their biological parents), and who have not specifically been placed there by a legal order of the court.

- A Foster Care Grant for children up to 18 years of age who the courts have found to be 'in need of care' and who have been placed in the care of foster parents to whom they are not related.

- A court-ordered Kinship Care Grant for children up to the age of 18 years whom the courts have found to be 'in need of care' and who have been placed in the care of relatives. It was suggested that relatives applying for this grant should go through an income-based means test. This approach is an attempt to provide financial support to relatives to care for children 'in need of care' but without all the administrative and monitoring procedures required by foster care placements.

The SALRC made provision for informal kinship care and court-ordered kinship care to be recognised as new legal forms of 'alternative' care. In each case, kinship caregivers are given 'parental rights and responsibilities' for children in their care.

Changes made by the Department of Social Development

The Department of Social Development made a number of substantial changes to the SALRC's draft of the Children's Bill:

- They removed the chapter providing for social security.

- They removed the provisions for the recognition of informal kinship care as a new legal form of alternative care.

- They kept the provisions for court-ordered kinship care as well as those for foster care. In other words, they have allowed for a placement which is similar to foster care, but where the court formally places the child with relatives.

All of these changes were accepted by Parliament during its deliberations on the Children's Bill in 2005.

What are the implications of the ongoing implementation of current provisions – how practical, effective, equitable and appropriate are they?

Foster Care Grants undeniably benefit the household members of the few orphaned children whose caregivers' are able to access them. But there are a number of reasons why we argue that they may not be an appropriate response to addressing children's socio-economic vulnerability in the context of the AIDS pandemic in South Africa.

Are orphan children 'in need of care' from the State?

Some children who are orphaned may indeed require the intervention of the child protection system in order to secure adult care. However, local and regional research findings show that only a small number of children find themselves living without an adult, in child-headed households. The majority of orphaned children live with relatives, without intervention or incentives from the State.

"It is quite clear that these children [orphans] are in need of money! They are not 'in need of care'." Magistrate based in KwaZulu-Natal

How will the already over-burdened and under-resourced social services system manage to meet the demand?

The administrative processes for foster care placement and for the proposed court-ordered kinship care placement are complex and impractical for the applicants, as well as for social services and court systems, which are already severely over-burdened and under-resourced.

Consider the following figures: At the end of September 2004 there were a total of 236,000 children in foster care. It was estimated that in 2004 there were about 250,000 newly orphaned children who would have qualified for foster care placement and grants. This means that the total number of

children in foster care in September 2004 was less than the number of newly orphaned children who would have qualified in 2004 alone.

Research findings clearly demonstrate that in many parts of South Africa there are already far too many foster care applications for social workers to process. If we look at the predicted number of orphans in the country, it is clear that social welfare and court capacity and resources are utterly inadequate. If the State continues to provide poverty relief to these children through the child protection system, it will fail to reach vast numbers of eligible children and their families who need support.

Will the use of foster care as a poverty alleviation mechanism detract from the real purpose – that the foster care system is meant to protect particularly vulnerable children?

The huge number of applications for fostering orphans is already creating bottlenecks in the severely over-burdened system. Access to this system by those who most need protection – whether they are orphans or not – is becoming increasingly difficult. This means that the care of children who have been abused, neglected or who require temporary removal from their families is being, and will increasingly continue to be, compromised.

Is it ethical for the State to provide support to poor people caring for children who are not their own, while failing to provide adequate and equal support for poor parents caring for their biological children?

Poverty is widespread in South Africa. So why should children who live with foster parents or with relatives require special grants that are of a substantially higher value, and continue for a longer time, than grants for poor children who live with their biological parents (many of whom are also sick)? Such a system is inequitable. It fails to provide adequate support to vulnerable families and also introduces a perverse incentive for impoverished families to place their children in the care of others.

The important concept to focus on is what is meant by vulnerability in the context of the AIDS pandemic. Internationally and locally, attention has focused on children's orphanhood as a result of the AIDS pandemic as the primary measure of their vulnerability. However, there is a need to focus more broadly on other children who also live in the context of AIDS and who are also vulnerable. For example, there are children who are living with sick caregivers who face increasing struggles as their capacity to earn an income is reduced, and much of their money is spent on health care and treatment. There are also children who live in households where the income is spread thinner and thinner because there is a need to provide for – and share the burden of illness and death with – relatives, families and neighbours. The government needs to address the poverty of all children in South Africa.

What are the comparative costs of different social security scenarios?

A costing study was conducted to estimate what the proposed universal CSG would cost the State in comparison to the current policy of providing the CSG to poor children up to the age of 14, with all double orphans (those who have lost both

biological parents) being eligible for foster care placement and Foster Care Grants. The findings demonstrate that, while the implementation of a universal CSG would be more costly than the current policy, the relative costs would decrease substantially over time. At the time that orphan numbers are anticipated to be at their peak, the additional cost of providing a universal CSG would be a maximum of one-third more than providing for the system that is currently legislated. It would be possible to return part of this additional cost to the fiscus through tax.

It is important to note that, while extending the CSG to all children under 18 years would cost more than implementing current policy, a universal CSG would reach far more children in need faster and would alleviate the pressure on social workers and the courts. By 2017 the current system will reach less than half of all children in need. In contrast, should a universal CSG be rolled out, roughly 125% more children would stand to be assisted within 15 years.

At first glance, the monetary value of the CSG appears to be substantially less than a FCG, and so it is difficult to appreciate that it would have the same impact for individual children as the FCG. However, research shows that the broader spread of a universal CSG would result in a greater net transfer of financial support to neighbourhoods (and in some instances households) than the more targeted scenarios which currently exist. In other words, poor neighbourhoods would in fact be better equipped to provide support to children in need of their care than is the case under the current system.

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What are our conclusions and recommendations?

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In order to address the needs of children adequately in the context of HIV/AIDS, including those children who have been orphaned, those who are poor, and those who are in need of protection, we recommend the following reforms to the social security system:

■ Implement a universal CSG to address children's poverty. Extend the grant to 18 years of age, to every child, and adjust the amount with inflation each year. Recover some of the costs of the universal CSG through tax from those who can afford to maintain their own children.

■ Strengthen the foster care system to accommodate those children who need protection and who need State intervention in their care arrangements. Discontinue the use of the foster care system for poverty alleviation. This is only feasible if the CSG is extended to all children up to 18 years.

■ Keep the provisions in the Children's Bill for foster care as a placement option for children legally 'in need of care'.

■ Remove the provisions in the Children's Bill for court-ordered kinship care as a placement option for children found to be legally 'in need of care'. We recommend this because:

  • These provisions are redundant if foster care provisions are legislated to protect children.

  • These provisions are based on inappropriate assumptions about children's safety in the care of relatives, as opposed to other adults.

  • These provisions will perpetuate the problems that we have already described in relation to the current foster care system.

To sum up: We recommend that more children be brought into the social security 'safety net', not on the basis only of their orphanhood, but rather on the basis of their poverty levels and their 'need'. It is only with the implementation of such social assistance that children in South Africa will be appropriately and equitably supported through the AIDS pandemic.

Sources

This section has drawn extensively on the following paper:

Meintjes H, Budlender D, Giese S & Johnson L (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.

Schools as nodes of care and support for children affected by HIV, AIDS and poverty

Sonja Giese (Absolute Return for Kids), Helen Meintjes and Jo Monson (Children's Institute)*

The HIV and AIDS pandemic is one of the greatest threats to the fulfilment of child rights in South Africa. The pandemic aggravates the ongoing and widespread effects of poverty, which has already significantly undermined child well-being. The impact in areas heavily affected by HIV and AIDS is felt collectively by everyone in the community and is severely straining communities' economic and social safety nets.

In responding to these tremendous challenges we need to maximise the potential of existing services and deepen collaboration at every level. In this section we explore an expanded role for schools as sites where vulnerable children can access a range of services.

This section focuses on the following questions:

- How do HIV, AIDS and poverty threaten the well-being of many children?

- What characterises current responses to the needs of children?

- How can schools operate as nodes of care and support for children?

- What are our conclusions and recommendations?

How do HIV, AIDS and poverty threaten the well-being of many children?

Between 2000 and 2003 the Children's Institute undertook extensive research and consultation on the high impact that the rate of AIDS-related sickness (morbidity) and AIDS-related death (mortality) amongst adults have on children. The research showed that children take up various caregiving roles and responsibilities. For example, following the death of her mother, 13-year-old Sindi[†] took responsibility for cooking and cleaning for her sickly father, her 76-year-old grandmother and three younger siblings.

Another child, 16-year-old Goodness, said after the death of her mother:

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

Source: *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS: Research report and recommendations.*

The Actuarial Society of South Africa (ASSA) estimates that in July 2005 there were a total of 3.4 million children in South Africa who have lost one or both parents. Researchers Johnson, Bradshaw and Dorrington estimated that 250,000 of these children had lost both parents. Contrary to popular belief, the vast majority of these children currently live with, and are cared for by, extended family and neighbourhood networks. A Children's Institute working paper that investigated social security provisions for orphans in the context of the AIDS pandemic indicated that only a very small minority live without resident adult caregivers in so-called 'child-headed households'. Consequently, fewer adults care for more children, with fewer resources (including income and food). The rate of this continues to increase and makes further demands on these kinship and neighbourhood networks of care and support.

The result is that the majority of children in affected communities are feeling the effects of HIV, AIDS and poverty, and not only those who are orphaned. Many children do not have enough food to eat, adequate clothing to wear, or uniforms and equipment to attend school. Many children struggle to access schooling and health care services. Many children (and their caregivers) do not have access to social service grants because of poor access to service sites, long delays and a lack of documentation.

What characterises current responses to the needs of children?

Some government strategies and many international funders have concentrated resources on helping so-called 'AIDS orphans'. However, this narrow focus on orphans has sometimes resulted in children being seen as 'commodities' (as goods that have monetary or resource value) and has, in some instances, also resulted in their increased stigmatisation. Given the collective effect of HIV, AIDS and poverty, it is inappropriate to focus only on orphans, or on any one category of child or need.

According to the Children's Institute-commissioned paper *Conceptualising and Addressing Vulnerability in South Africa in the Context of HIV/AIDS: A Policy Review*, it is critical that, in responding to the needs of children, there should be "caution against paying attention to only one aspect within the risk chain or addressing a single component within a complex set of vulnerabilities that are often not only interrelated but are in themselves multi-dimensional".

Over the past decade, another characteristic of the response to the needs of children affected by HIV and AIDS has been a mushrooming of, and a reliance on, non-governmental organisations and community-based services. This trend has not been adequately co-ordinated or supported by the government. There is also insufficient channelling of funds from the State to these organisations and services, with many of them relying on unpaid volunteers who are themselves poor.

> "Women are not coming (to volunteer) as they used to and there are now very few left. They complain that they, and their children at home, are hungry. They are disappointed with the project as they hoped they would get jobs or be trained as a nurse."

Source: *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS: Research report and recommendations.*

[†] All names of children quoted in this section have been changed to protect their identities.

A number of national government departments have focused on developing policies on HIV and AIDS, including the Departments of Health, Education and Social Development. However, the implementation of these policies is fraught with difficulties and barriers; for example a lack of access, bureaucratic procedures and people's reluctance to disclose their HIV status because of stigma and ignorance. Where services are available, they are seldom co-ordinated and there is little departmental collaboration, despite the above-mentioned departments trying to develop a National Integrated Plan for the Social Cluster.

Programme planners need to recognise the broad impact of the HIV and AIDS pandemic, together with poverty, on children, households, communities and service providers. Interventions must be sensitive to addressing the needs of the range of vulnerable children, including orphaned children, children living with and frequently caring for sick adults and siblings, HIV-positive children, and children living in households where limited resources are stretched further as a result of supporting additional people (whether they are resident or not).

Given the scale of the challenges we face, there is a need to explore the roles that different service providers can fulfil in terms of supporting all vulnerable children. We also need to build collaboration between all service providers, and mainstream care and support activities wherever possible.

How can schools operate as nodes of care and support for children?

Research highlights the important role that schools can play (and many already do) in providing care and support to vulnerable children through school-based services, and through assisting children to access support outside of the school. We use the term 'schools as nodes of care and support' to refer to this vision for an expanded role for schools.

Examples of good practice illustrate how schools can function as nodes of care and support by creatively using their existing resources and levering other resources from within government and the community. Consider the following story about Sbongile Kuzwayo, principal of a small rural school in northern KwaZulu-Natal.

The mother to many

When Sbongile* realised that Thabiso* was homeless and sleeping in the bushes at school because he had nowhere else to go, she spoke to the school governing body. They decided to let the boy sleep in an old classroom. Since then, other children in difficult circumstances have moved in and the school governing body built a three-roomed house on the school property to accommodate them.

Sbongile has leapt into action as she's come to realise more and more of the difficulties that the children attending her school experience. She was alerted to the weekend-long hunger of many of the children in her school when she noticed a child who lay down, barely touching the Monday morning plate of food and clutching her stomach in pain. The child had not eaten since the previous Thursday when the school-feeding scheme last operated. Nor, it emerged, had several other children.

After meetings with her staff and with the children's caregivers (and with the financial assistance of a local trust), Sbongile instituted an extended feeding scheme on Fridays and over the weekends so that those children who receive no other food at home could be fed before leaving on Fridays, and return to the school on Saturdays and Sundays for a meal. "At least," says Sbongile, "if they come to the school, we know the children get the food."

The school always grew a patch of mealies and vegetables to augment feeding scheme supplies, but this provided insufficient food for all the children. So, with an ever-increasing number of mouths to feed, Sbongile approached the Department of Agriculture for help in learning about food production. The result is a school fish pond, and a clutch of hens that lay eggs and provide food for the fish.

Sbongile described initiatives to identify and support vulnerable learners, including a 'postbox' to enable children to share their concerns through written letters to her and their teachers. The school also uses parent-teacher meetings as opportunities

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* Names have been changed.

The education policy environment

Education policy, legislation and leadership, through partnerships with other sectors, make provision for schools to play a larger role than they currently do in identifying, caring for, and supporting vulnerable children. The *Education White Paper 6* provides the framework for establishing an inclusive education and training system that enables education structures, systems and learning methodologies to meet the needs of all learners.

Education White Paper 6 marks an important conceptual shift in understanding barriers to learning. Previously these were understood from a deficit or medical model, which "presupposes vulnerability and disability as inherent in the individual". According to Baxen and Mosito, barriers to learning are now acknowledged as being the consequence of a 'complexity of multiple factors' and as being 'located primarily in the environment'. *Education White Paper 6* also emphasises the critical role of intersectoral collaboration in achieving the aims and objectives of inclusive education. It emphasises, amongst other things, establishing district support teams that consist of a wide spectrum of professionals and mobilising public support.

The commitment of the Department of Education to strengthening the role of schools in the support of vulnerable learners is reflected in the following statement, which was made by the then Minister of Education in his closing address at a national education and HIV and AIDS conference in June 2002:

"Educators are not social workers. Nevertheless they can work with others to provide care and support for those affected by HIV and AIDS …"

Minister Kader Asmal, June 2002

In 2002 the Department of Education also released their implementation plan for *Tirisano* (a Setswana word which means 'working together') – a response to the government's call to improve public service delivery. Part of the *Tirisano* action plan is to, amongst other things, make schools centres of community life, make co-operative government work, and deal urgently and purposefully with the HIV and AIDS emergency in and through the education and training system.

There are many other existing education policies and programmes which can be strengthened and expanded to support the concept of schools as nodes of care and support, for example, the inclusive education policy, the primary school nutrition programme, the safe schools programme and the life orientation/life-skills curriculum.

Why schools?

The education system has several comparative advantages over other services when it comes to the care and support of children. In addition, there are a number of factors that make schools a strategic place for children to access a range of services:

- Schools are relatively accessible and they often provide a physical infrastructure in communities where other crucial infrastructure is absent. The education system has an existing infrastructure of around 28,000 schools. The space and grounds at schools have the potential for expanded use.

- Schools represent an existing network of many components, including school staff, learners, their caregivers, school governing bodies and the broader school community. Each component is a potentially valuable resource for care and support.

- The way schools are currently clustered creates opportunities for further collaboration and provides educators and middle management with more support.

- The school environment is an inclusive environment, which focuses on children and is committed to children's development. The education system reaches approximately 11,500,000 children, including those most affected and most at risk of HIV infection. Children spend a large amount of their time at school over many years. It is also an environment where all kinds of vulnerabilities are

exposed and it therefore has the potential to work against stigma associated with HIV and AIDS. If children feel supported within the school, they will come to school and they will remain within the school.

■ The school can also reach the younger and most vulnerable age group through school-going children and their families, for example, through child-to-child programmes.

■ Educators see children every day for five days of the week and are therefore ideally placed to track their well-being, to recognise change in children's lives, and to identify vulnerable children.

■ In communities with inadequate service provision, schools take on an ever-increasing burden of support. The South African Democratic Teachers Union (SADTU) reports that it is inundated with requests and appeals for help from their members who are faced on a daily basis with learners dropping out of the system due to the impact of HIV and AIDS on their lives. Educators report that they lack the skills and knowledge to deal adequately with the issues as they unfold in their classrooms. This is echoed in calls by educators interviewed by the Children's Institute – for more information, for access to resources, for better support mechanisms, and for the strengthening of collaborative networks to assist them in better supporting vulnerable learners.

"All these learners, one finds that 50% come to school hungry, rape cases, they have live-in partners as young as Grade 8, a lot, a lot no money, nothing, parents passing away, HIV/AIDS, everything … Now you need professionals to deal with those cases! But at the end of the day, you end up going (to your colleague): 'Noxolo, can you help me, this is a girl, can you deal with her in your office?'"

Source: *Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS: Research report and recommendations*

Meeting the challenges

Baxen and Mosito warn that the "expectation that 'education' can bear the greatest burden of addressing social and other vulnerabilities is unrealistic and makes the education sector itself vulnerable".

Many schools and educators working in contexts of HIV, AIDS and poverty are themselves vulnerable and in need of care and support. Many educators are overburdened and also infected or affected by HIV and AIDS.

Schools in the poorest areas have poor infrastructure and

resources. Some operate in a culture of disempowerment, inertia, and cynicism, with poor or undefined leadership. Some schools and school communities are divided by organisational factions, hostile environments, power imbalances, and excessive bureaucracy.

According to Baxen and Mosito there cannot be a 'one size fits all' role for schools. We need to recognise that there are "differences among schools and they have unequal primary starting blocks". What is appropriate or possible will differ from one school to another and what could be put into operation will be very different in different contexts.

There are also challenges related to learners, for example, many of the most vulnerable children struggle to access school and sometimes schools are not the safest places for children. In many instances, the school environment actually contributes to children's vulnerability.

A full discussion on ways to meet these challenges is beyond the scope of this section. However, one critical area that we must highlight is the need to create dynamic ways in which the school, local government activities and civil society initiatives can work together. Local governments by law have to develop their own Integrated Development Plan (IDP), which can be used to co-ordinate and integrate the activities of all government and community role-players in the protection of child rights. Another critical issue is the need to build participatory management in different areas, for example, by building on ward structures as integrating mechanisms for IDPs.

So, while schools are well placed to take on an expanded role, a key consideration must be not to place a bigger burden on educators and to find ways to support schools and school communities to face the growing challenges. Schools should be used as vehicles through which services can reach children and through which children can access support; thus schools must be a site that communities and government use to integrate their service delivery.

What are our conclusions and recommendations?

The HIV and AIDS pandemic combined with poverty affects communities collectively and exposes children to a range of different vulnerabilities. There is an urgent need to increase collaboration and to mainstream services to meet the needs of those most affected. Schools should be used as nodes of care and support from which to identify those most in need and from

which to focus service delivery. However, schools and educators are themselves vulnerable and impoverished and emphasis should be placed on mobilising communities and government towards integrating service delivery at the school site.

Sources

This section has drawn extensively from the following key sources:

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Heroes in the context of vulnerability: The participation of children in the Children's Bill

Namhla Mniki (Children's Institute)

The child's right to participate is entrenched in the United Nations Convention on the Rights of the Child (CRC), which South Africa has ratified. According to the government's National Programme of Action for Children (NPA), this right to participate is seen as an instrument to meet all the other rights of children in South Africa. When children participate in processes and decisions that affect them, they are better able to express what their needs are and what the best solutions to those needs can be. In the context of poverty and HIV/AIDS, the participation of children is crucial, as it enables policy-makers and other practitioners to understand what children's realities are, and how they can be supported and protected in the context of vulnerability.

The Department of Social Development has proposed a Children's Bill to replace the Child Care Act as legislation to protect children against vulnerability. The Bill covers issues such as parental rights and responsibilities, children's rights, protection from neglect and abuse, and court systems. It is divided into two parts, the section 75 Bill deals with national government competencies, while the section 76 Bill deals with issues where the national and provincial governments share competency.

As the Bill was being considered by Parliament, it was important to involve both adults who work in the children's sector and children living in the context of vulnerability in the deliberations on it. Civil society organised themselves into an adult working group made up of organisations working in the children's sector. The Children's Institute set up a parallel process of establishing a children's working group to engage with the Bill. This section presents the story of these children, who called themselves *Dikwankwetla – Children in Action.*

This section focuses on the following questions:

- What were the aims, objectives and activities of *Dikwankwetla*?
- What challenges do children face in the context of poverty and HIV/AIDS?
- What were *Dikwankwetla's* key messages for the Children's Bill?
- What was the impact of *Dikwankwetla's* advocacy action?
- What lessons did we learn?

What were the aims, objectives and activities of *Dikwankwetla*?

The 'Child Participation in the Children's Bill Project' began with the aim of facilitating children's participation in the adoption of the Children's Bill. Twelve children between the ages of 12 and 17 years, who are growing up in the context of HIV/AIDS, were selected to be part of the project. The children were identified through partner organisations from four provinces in South Africa. Since the children were already working with the partner organisations, they were ensured continued support throughout the project. The partner organisations were also instrumental in facilitating buy-in and obtaining consent from the children and their families.

The project was designed to go through three implementation stages, i.e. entry and buy-in (described above), the developmental stage, and the advocacy stage. During the developmental stage, the children attended a series of participatory workshops focusing on two objectives: (a) developing legislative literacy, and (b) supporting the children to become advocates. The intention was to equip the children with the capacity to engage with the provisions in the proposed Children's Bill and to articulate their opinions about it.

Developing legislative literacy

The first workshop had three main objectives:

- to introduce the children to the project and to the facilitators;

- to gain consent and buy-in from the children; and

- to explore the challenges the children faced in their everyday lives.

In this workshop, we came to understand the context in which the children live, the main challenges they face, and the ways in which they deal with these challenges. Most of the issues they raised were relevant for the Children's Bill, and these became focal points of their advocacy strategy.

Four months later a second workshop was held to inform the children about the draft provisions of the Children's Bill. A team of legal experts converted the relevant parts of the Bill into a child-friendly resource pack. This included activities to help children learn about the Bill as well as develop their opinions about the clauses in the Bill. Only those parts of the Bill that addressed the challenges that the children faced were focused on, thus deepening their ownership of the advocacy process. Through a facilitated process the children developed their opinions about the Bill, identifying gaps and formulating key messages.

The third workshop was held two days before the parliamentary hearings. The aim was to prepare the children for their presentation in Parliament and for their meetings with decision-makers. Their views, expressed in letters, drawings and other activities, were used to compile a presentation in the format of their choice.

What challenges do children face in the context of poverty and HIV/AIDS?

In the first workshop, children were facilitated to share their life stories, focusing on the challenges that they face. Below is the broad range of issues they raised.

Neglect by adults

Many of the children had experienced neglect and not being properly taken care of. A 16-year-old girl told us:

"I am taking care of my four siblings with my old grandmother and that doesn't mean that my mother is not alive. She is very alive but the problem is that she doesn't stay at home with us and take care of us; she is always away and when she comes home she comes drunk and abuse us emotionally. These affects me mentally; I cannot cope well with my school and don't have enough time to rest and that goes to my other two sisters who come after me; they don't have time to play like other children and I think that that's abuse."

Another girl, also 16 years, stated:

"My father doesn't take good care for us. My mother struggles alone … I don't know what kind of a human being is my father. He is aggressive. He is always shouting at us. He pushes us aside. He is always drinking."

Abuse

Some of the children also experienced conflict in their homes, as well as physical and emotional abuse in their communities. Some knew children who had experienced sexual abuse.

Below is the story of one boy:

"I am a 16-year-old boy. I have one major problem. I am abused physically by my father since my mother passed away. I am asking that everyone should respect children's rights, even our parents themselves."

And a 15-year-old girl said:

"My younger sister aged eight years was raped by a person. My mother sent her to buy cooking oil late, at about 6.30 pm, and she met the rapist. The rapist asked her for directions to another shop, and then they went together and, instead of going to the shop, he took her to the river bank and raped her … The person who raped my sister was unknown because he gave her a wrong name when he introduced himself to her."

Poverty

Many of the children had experienced a variety of challenges related to poverty, including a lack of shelter and clothing, a lack of access to education, health and social services, and severe forms of hunger and deprivation:

"At home we don't have some shelter. At home we don't have food. At home we don't have money to buy food."
(Boy, 17 years old)

"I come from Limpopo. At home, I'm living with my grandparents. My mother is not working. She is HIV positive and she can't work because she is sicking. So we have nothing. No money, no clothes and even a house of our own. We are forced to live with my grandparents inside a four-roomed. Our life is too hard – no privacy and no freedom. We are slaves inside it …" (Boy, 16 years old)

Children's rights

The children were asked if they think that children have rights. They mostly said no, because:

"Children are not taught what their rights are."

"Children don't run the world. Adults run the world, so it's easy to forget about children."

HIV/AIDS

The challenges related to HIV/AIDS that the children raised were about caring for sick parents and siblings, as well as dealing with loss and grief.

"Home is the most difficult place in my life. At home my mother is HIV positive. My father is HIV positive."
(Girl, 16 years old)

"I have one sister. And one brother. I have father only. I don't have mom. My mom died in 2000 in June 9. My sister died in 2002 May. I live at my primary school. I am in grade six. Next year I in grade 7. My hobbies are playing soccer. At home we don't have something to shelter. At home we don't have food. At home we don't have money to buying food. My brother does not learn because we don't have money …" (Boy, 12 years old)

Peer pressure, pregnancy, drugs, eating disorders, depression

Some children raised other youth-related problems, mainly around drug use and pregnancy. Some of the children were also experiencing other problems such as depression and eating disorders.

"Waking up in the morning and not knowing what life is going to bring my way for that day is hard, but more exciting … The toll of death is no longer an issue for me!"
(Girl, 14 years old)

The Children's Bill is targeted at legislating preventative and protective measures to support vulnerable children. One of the criteria we used to choose children to participate in the project was that they had to be living in the context of vulnerability, particularly affected by HIV/AIDS. It is not surprising, then, that they raised such serious challenges. What is significant, though, is that the most dominant challenges raised were related to poverty. Even the issues related to parental neglect can be linked to the lack of employment, poverty and alcoholism rather than to intentional criminal neglect. This is an important message to heed in the South African context, especially as it relates to policy interventions. What is coming out strongly is that, even in the context of HIV/AIDS, poverty is still the key underlying cause of vulnerability. Other research by the Children's Institute supports this notion that children affected by poverty share many of the same experiences as children affected by HIV/AIDS.

However, these children are resilient despite the challenges they face. This comes through in their choice of a name for their group, *Dikwankwetla*, which means 'heroes'. And they all referred to themselves as 'heroes' because they said that they are brave; they help their parents when they are sick; they take care of their brothers and sisters; they go to school and do well; and they care about others. These children are

not helpless victims of their circumstances. They are active citizens who continuously draw on their creativity and the support structures in their communities to help them live and thrive. One girl, 16 years old, wrote:

"(I am a hero because) I respect others. I think before I act. I am responsible; I care for others; I know myself; I don't let problems take control of me; I help other children who wants to know more about HIV/AIDS. I am proud of myself."

What were *Dikwankwetla*'s key messages for the Children's Bill?

We explored different advocacy strategies in the workshops, including how to engage with decision-makers and the media. The children were also facilitated to produce different advocacy outputs. In between the workshops they designed their own advocacy strategies, deciding on which activities they would engage in, and what they would advocate for. Their activities included speaking to their friends; speaking in school assemblies; presenting in council meetings and at youth rallies; holding meetings with decision-makers; and speaking on radio. However, the climax of the advocacy process was the children's presentation to Parliament. They told members of Parliament about the challenges they were facing, and the provisions to deal with those challenges that they wanted to see included in the Bill. Below are some of the key messages that they advocated for.

- **Children's rights was a key theme.** In one group discussion, the children analysed the right to information about health care. One girl, aged 14 years, asked: "What's the point of having information about health care if you don't have the health care?" They proceeded to amend this right to state that, "Children have a right to access to information and good health care." They also felt that the rights proposed in the Bill were inadequate and they in response developed a pamphlet stating all the rights that they wanted to see included in the Children's Bill.

- *Dikwankwetla* **also focused on abuse and neglect.** They discussed the appropriate punishment for perpetrators of abuse. While the Bill suggested that reported abusers should be jailed after investigation, the children strongly felt that perpetrators must be immediately taken to jail upon reporting. They added:

"The person who is abusive must be the one who is removed from home, not the child. Whatever is done must be done to the interest of the child. Children who don't live with their biological parents; the child should be removed because the caregiver can't be removed from their own homes even if they are the one who are wrong."

Later, two 16-year-old girls co-wrote a letter to the members of Parliament, stating:

"Please raise awareness about child abuse. Those who are already abused should get counselling. The government should see to it that abusers go to jail, 'cause mostly they are not arrested; they get bail and come back and they abuse children again."

- **The issue of corporal punishment was also passionately debated.** The proposed Bill suggested that children could be 'reasonably chastised' by their parents. However, the majority of children believed that corporal punishment in the home is wrong under any circumstance. Two of the children believed that only under very 'strict' circumstances should children be 'smacked', with smacking defined as "a hit on the hand not more than twice!" The rest of the children argued that when parents hit children "they create a scary environment" in the home.

- **The children also discussed parental rights and responsibilities.** They stated that all children should be taken care of by loving caregivers in a safe environment. They also highlighted the support they received from non-governmental and community-based organisations.

What was the impact of *Dikwankwetla*'s advocacy action?

We have not yet conducted an impact assessment study for this project, partly because the advocacy process is not yet finished, and partly because it is difficult to measure the impact of the children's action in isolation from the broader civil society advocacy process that involved other organisations. So, we simply highlight evidence of the children's effectiveness so far.

Dikwankwetla's participation in the Children's Bill process received a considerable amount of media coverage in some newspapers, on radio and in popular journals. Most recently, Dr Maria Mabetoa, the Chief Director responsible for children

in the Department of Social Development, shared the story of *Dikwankwetla* in an interview with a popular magazine, detailing the problems the children raised. The children were frequently mentioned during the deliberations of the Portfolio Committee and their views were incorporated in the discussions of the adult working group. Most notable though, is that progressive changes were made to the section 75 Bill, which was passed by Parliament in July 2005.

This Bill has recognised and is based on children's rights as a fundamental principle. Chapter 2 of the Bill states that, "the objects of this Act are to give effect to the … constitutional rights of children …" and proceeds to name the relevant rights. Secondly, the Bill has progressively shifted from the concept of parental power over children to a concept of parental responsibility for children. The Bill strives to promote the best interests of the child, as well as to recognise child agency. For instance, it recognises that there is a need to make courts accessible to children, and also recognises that there is a need to regulate cultural practices that might be potentially harmful to the child.

The section 76 Bill, to be tabled in Parliament in 2006, focuses more specifically on the issues that *Dikwankwetla* raised and the children are preparing for the next phase of the project.

What lessons did we learn?

This process has given us great insight into the extent of children's daily challenges and potential solutions. We witnessed evidence of children's agency and their abilities to participate in law-making processes. The children's participation was in itself positive because they could stand up for themselves and articulate their needs. But more importantly, it helped inform some of the adult working group's debates on and proposed changes to the Bill, and it influenced the deliberations of the Portfolio Committee on Social Development. Preliminary findings of the evaluation of the Children's Bill working group suggest that members of Parliament appreciated the opportunity to interact with children so that they could make informed decisions on the final version of the Bill.

It is thus evident that children should participate in law-making processes that affect them. This not only yields positive results for the participating children as their right to participate is realised but also assists law and policy-makers in informing their decisions.

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