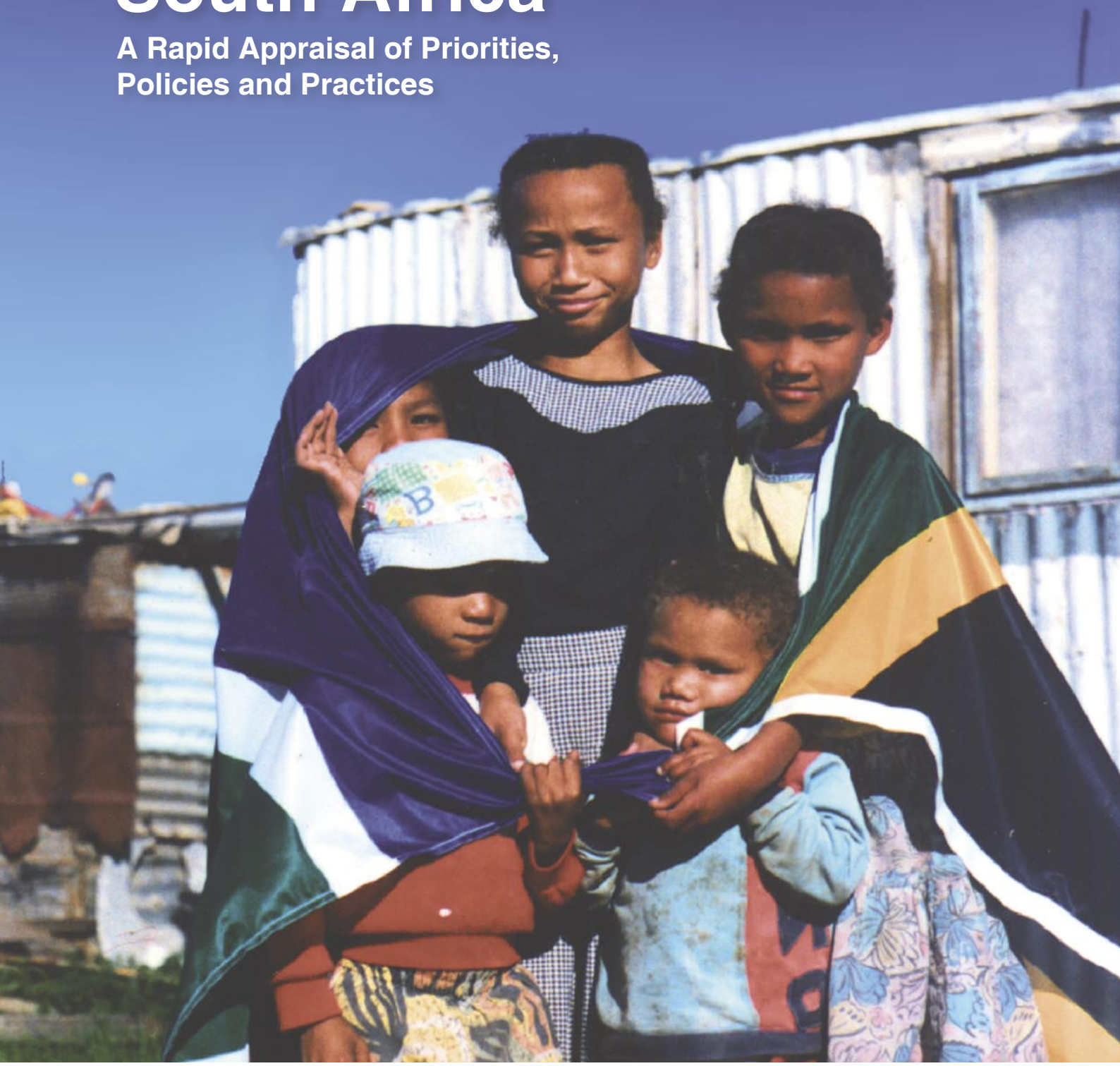
Children Affected by HIV/AIDS in South Africa

A Rapid Appraisal of Priorities, Policies and Practices

Save the Children
South Africa Programme



The Department
of Social Development

CHILDREN Affected by HIV/AIDS in SOUTH AFRICA

A Rapid Appraisal of Priorities, Policies and Practices

JULY 2003

COMMISSIONED BY:
Save the Children (UK)
South Africa Programme

IN COLLABORATION WITH:
The Department of Social Development

RESEARCHED AND WRITTEN BY:
Rose Smart
HIV/AIDS Consultant

Published by:
Save the Children (UK)
PO Box 40623
Arcadia 0007
South Africa
Tel: + 27 012 341 1889
Fax: +27 012 341 1383
e-mail:saveuk@scfuk.org.za

www:savethechildren.org

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A Rapid Appraisal of Priorities, Policies and Practices

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Foreword by the MINISTER OF SOCIAL DEVELOPMENT

2003 sees the scene set for major advances in support for those in our society who are poorest and most vulnerable – in particular the thousands of children whose lives are irrevocably changed because of HIV/AIDS. Every week, in every province and in all sectors, awareness campaigns, institutional adjustments, strengthening partnerships and programmatic scale-ups are taking place as never before.

As this new movement for change gains impetus in the months and years ahead, government will continue to lead the way, working collaboratively to translate the National Integrated Plan into a reality that will benefit all those for whom it was intended. Partnering with government in this are the many civil society structures and organisations – faith-based, non-governmental and community-based – who work tirelessly to translate policy into practice.

We have reached this point as a consequence of a number of consultations, underpinned by many research studies, informed by model projects, and defined by many new legislative processes. This rapid appraisal has sought to capture the most significant of these, to serve as a resource to all policy makers, programme planners and managers, and practitioners involved in the HIV/AIDS and children sector.

My department has once again partnered with Save the Children (UK) in this initiative, as part of our joint commitment to the children of South Africa.

Dr ZST Skweyiya
Minister of Social Development

Foreword by SAVE THE CHILDREN (UK)

HIV/AIDS is fast becoming one of the most critical challenges to the realization of children's rights in South Africa. There are enormous numbers of children who are already orphaned and many more who are living with desperately ill parents. A large body of research and a number of important national and regional conferences have identified the scope and scale of the task that we must tackle. The multifaceted impact of HIV/AIDS on children demands a co-ordinated response from all sectors – government, non-governmental, private, donor, faith based and community. Children's survival requirements for food, shelter, health care, education and clothing must be met. Children also have rights to love, nurture and protection and they have rights to time and opportunity to play and socialize with their peers. It is vital that children be able to participate in the planning, implementation and monitoring of programmes that are to benefit them.

There have been significant developments for children affected by HIV/AIDS in South Africa in the three years since the first appraisal was prepared. A legal and policy framework for the care of children affected by HIV/AIDS has been developed. Guidelines for this care have been formulated by the Department of Social Development. Principles for programming to ensure that the rights of orphans and vulnerable children are realized are being synthesized and good practice models are being developed. This appraisal highlights the critical need for communication between policy makers, researchers and programme implementers so that each of the groups inform and are informed by the others. The appraisal itself is intended to be one form of such information sharing.

However, much more needs to be done. The first appraisal was a call to put orphans and vulnerable children on all national agendas. It is clear that this has happened and is continuing. This appraisal is a call to translate the many policies that have been formulated and resolutions that have been passed into urgent action with and for the thousands of affected children across South Africa. This action must result in meaningful change for the better in all of their lives.

Save the Children UK is honoured to continue to work in partnership with the Department of Social Development and NACCA which bear the primary responsibility for ensuring that such action does take place.

Dianne Stevens
Acting Country Programme Director
Save the Children UK
South African Programme

Save the Children
South Africa Programme

Executive Summary

Following the rapid appraisal of children living with HIV/AIDS in South Africa, which was a NACTT (National AIDS and Children Task Team) project undertaken in 2000, the many new laws, policies, projects and activities prompted Save the Children (UK) to commission an update, in association with the Department of Social Development.

The 2003 rapid appraisal was developed following a desk review of literature and information from a range of key informants. It is intended as a resource for policy makers, programme planners and practitioners working in the fields of HIV/AIDS and/or children, as well as for anyone who needs to develop a "picture" of the OVC situation in South Africa.

There are ten chapters, each dealing with a separate topic, and each of which can be used as a stand-alone resource.

Chapter 1
Introduces the rapid appraisal.

Chapter 2
Provides a snapshot update of the global and South African OVC situation, both the current estimates and future predictions.

Chapter 3
Seeks to record the most significant recent international events and responses. In addition, selected examples of country-level responses are provided and analysed to extract what may be considered to be the key elements of a successful national OVC response.

Chapter 4
Focuses on South Africa, and the many local events that have taken place and the responses that have emerged since 2000. This chapter summarises recent legislative and policy changes, the social support and services that are available for children, as well as the OVC-related resource materials that have been developed.

Chapter 5
Lists the main national role players operating in the OVC field in South Africa.

Chapter 6
Summarises the many resolutions and recommendations that have been made in national consultations with an emphasis on OVC.

Chapter 7
Brie y covers progress in other significant initiatives, such as youth prevention programmes, mother-to-child prevention programmes, selected mass media campaigns and a campaign to improve access to grants. These examples describe the broader HIV/AIDS-related context within which OVC activities take place.

Chapter 8
Critically analyses progress towards addressing the recommendations of the original 2000 rapid appraisal.

Chapter 9
Re ects key findings from recent research, and then proposes a more co-ordinated response to ensure that priority research questions are identified, and that results of commissioned research are appropriately communicated upwards to policy makers and downwards to projects operating at grassroots level.

At points through out the text recommendations are made. These are consolidated in **Chapter 10**, where 19 recommendations are made for future actions that have the potential to improve the level of debate and the situation for orphans and vulnerable children.

The recommendations are:

1. Develop agreed understandings – at policy and community level – of vulnerability.
2. Define “orphan” and agree on national orphan statistics – current and predicted future scenarios.
3. Create two-way communication between international, regional and national conferences and strategy and planning processes in SA.
4. Publicise the OVC commitments made by South Africa and its neighbours at regional meetings and establish a SADC process to track progress on these commitments.
5. Define the elements of a successful national OVC response, and generate a process to put these elements in place.
6. Wherever appropriate, ensure that children in general and OVC in particular are considered in all legislative processes.
7. Continue advocacy efforts until reports are adopted and legislation promulgated, and even beyond to ensure effective implementation.
8. Create a mechanism to inform stakeholders of NIP targets and progress.
9. Ensure that VCT guidelines for children are developed and implemented without delay.
10. Ensure that OVC and HIV/AIDS are prominent in both the UN CRC Country Report and the Complementary Report.
11. Create a database of resources and materials, conduct an assessment of needs and develop a prioritised list of required resources.
12. Establish mechanisms to communicate conference results and resolutions to organisations operating at grassroots level.
13. Establish a high level process, within NACCA, to monitor action owing from national conferences and consultations.
14. Take action, beyond the grants campaign, to remove barriers to accessing grants, such as improving the services provided by the Department of Home Affairs.
15. Address the residual recommendations from the original rapid appraisal.
16. Communicate research results upwards – to policy makers – and downwards – to service providers.
17. Define an OVC research agenda, based on gaps, and informed by completed and planned research
18. Conduct high-level advocacy on important OVC issues.
19. Strengthen specific aspects of programmes.

Chapter One
INTRODUCTION

Background to the 2003 rapid appraisal

In 2000, Save the Children (UK), in association with the National AIDS and Children Task Team (NACTT) commissioned a rapid appraisal of the situation of children living with HIV/AIDS in South Africa[1]. This included assessment of emerging lessons from projects and of gaps – both in terms of research questions as well as in terms of services for children. The rapid appraisal encompassed infected as well as affected children, but with the emphasis on HIV/AIDS affected children. The study identified 16 critical issues for action and made recommendations to address each of these. The document was handed to the Minister of Social Development on 19 May 2000, and has since been widely disseminated and used.

By the end of 2002, much had changed, significant progress had been made in many areas, and a great deal of research had been conducted, creating the need for an update. Save the Children (UK), in association with the Department of Social Development, therefore commissioned a second study, building on the first rapid appraisal, and focusing on current and emerging priorities as well as on developments, locally and internationally, particularly within the areas of policy and practices relating to children affected by HIV/AIDS.

The focus of the 2003 rapid appraisal is on policies and practices for **HIV/AIDS affected** children henceforth referred to as **orphans and vulnerable children (OVC)**, as opposed to those for HIV infected children or on policies and practices that aim to prevent HIV infection among young people. There is however a chapter on other significant initiatives, which covers key prevention strategies (see **Chapter 7** for information on **PMTCT, youth programmes** and **mass media**). This section has been included in recognition of the reality that OVC may also be infected or be at risk of infection.

Methodologies and format

The 2003 rapid appraisal is based primarily on a desk review of documents (see **References**), as well as on information provided by key informants (see **Contacts**).

Where appropriate, an analysis is offered of the material presented. In addition, there is a set of recommendations at the end of the rapid appraisal, each of which is " agged" at the point in the text, (as illustrated) at which the recommendation emerged.

Recommendation #

The rapid appraisal consists of the following sections:

Target readership

The 2003 rapid appraisal is intended to inform debate and discussion around HIV/AIDS and OVC and to act as a resource for policy makers, programme planners and managers, and practitioners working in the fields of HIV/AIDS and/or children, as well as for anyone who needs to develop a "picture" of the OVC situation in South Africa.

Definitions, concepts and terminologies

The 2000 rapid appraisal used the term CINDI (children in distress) to describe children who were orphaned or who were facing orphanhood. The term orphans and vulnerable children, or OVC, is now more widely used. This recognises that there should be no distinction made related to the causes of orphanhood, whilst acknowledging that children who are affected by HIV/AIDS **do** face a set of problems that other OVC may not experience, or may experience differently.

This is supported by a study conducted in Luweero District, Uganda (high AIDS mortality) and Mandore, Rajasthan, India (high TB mortality) that was presented in Barcelona in 2002[2]. The methodology allowed for comparisons to be made between orphans in AIDS and TB mortality affected communities.

The research found that traditional coping mechanisms do not always provide workable solutions to the problems caused by orphanhood when this occurs in an HIV/AIDS epidemic impacted setting. Short-term coping strategies may in fact serve to increase vulnerability in the long run.

The researchers concluded that orphanhood within a sustained epidemic has severe implications for the life chances of HIV/AIDS affected children. In childhood this may lead to malnutrition, reduced access to health care and education, homelessness and abuse. In later years this may serve to increase the individual's risk to HIV/AIDS.

Whilst recognising that the choice of terminology and the definitions used are fraught with difficulties, the term **orphans and vulnerable children** (OVC), is used in the 2003 rapid appraisal, encompassing the following concepts:

- An orphan is a child under the age of 18 who has lost a mother, father or both parents from any cause.
- A child is vulnerable who is at risk of orphanhood, is living in poverty or is abused, neglected, abandoned, displaced or destitute.

Vulnerability is another concept that is understood differently by both experts in the field as well as within different contexts. There need to be efforts, both in South Africa, as well as globally, to build common understandings of the concept.

Recommendation #1
Develop agreed understandings – at policy and community level – of **vulnerability**

Prof M Olivier (Centre for International and Comparative Labour and Social Security Law) identifies the following as groups of children who are particularly vulnerable[3]:

- Children infected and affected by HIV/AIDS;
- Children with disabilities and chronic illnesses;
- Children living on the streets, in informal settlements and in rural areas; and
- Children of farm labourers, refugees and illegal immigrants.

Groups of children requiring special attention were identified at the national consultative workshop on Children's Entitlement to Social Security, held in Cape Town, in March 2001. The groups identified were:

- Children with disabilities;
- Children with chronic illnesses;
- Children affected/infected by HIV/AIDS;
- Children without care givers;
- Children living in poverty-stricken conditions;
- Children who have been abandoned;
- Children who work (child labourers);
- Children working as sex workers;
- Children living on the streets;
- Children who are being neglected;
- Children who are being/have been abused;
- Children who are refugees; and
- Children used as soldiers.

In the DSD document entitled **National guidelines for social services to children infected and affected by HIV/AIDS,** the following definitions are used:

Affected children refers to children who have become vulnerable because their parents or caregivers can no longer care for them because they are either very ill or have died because of HIV/AIDS.

Orphan – in the context of the HIV/AIDS epidemic in South Africa an orphan is defined as a child under the age of 18 years whose primary caregiver has died.

(Footnotes)

[1] Save the Children & NACTT; Children living with HIV/AIDS in South Africa – a rapid appraisal (2000)

[2] Monk, NO; Processes of orphanhood: understanding the lifeworlds of HIV/AIDS impacted children (2002)

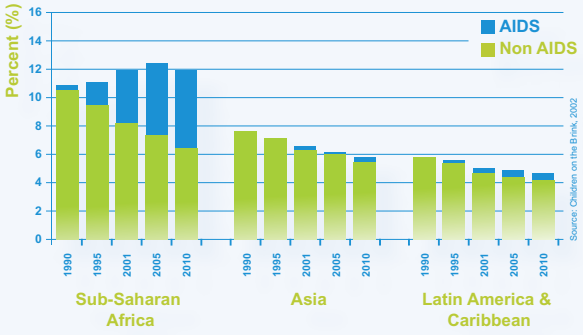
[3] Olivier, M; Social security for children: concerns, issues and challenges; paper presented at workshop on social security for children in South Africa (2001)

Chapter Two
OVC UPDATE – ESTIMATES AND PREDICTIONS

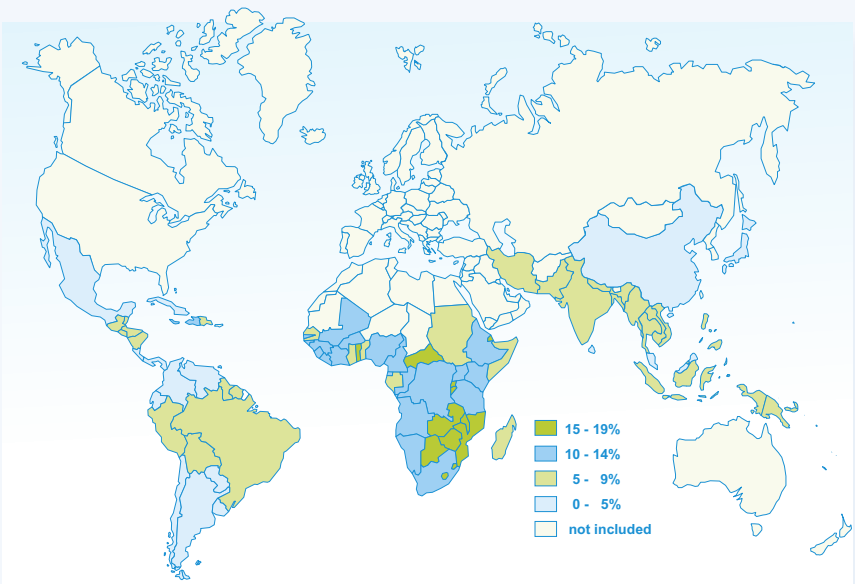
Global update

In all developing countries where the HIV/AIDS epidemic has been well-established for 20 years, the phenomenon of large and increasing numbers of children orphaned by the death of their parents is occurring. UNAIDS defines a child orphaned by HIV/AIDS as a child, under the age of 15 who has lost at least one parent to HIV/AIDS. Based on this definition, there were 13 million orphans at the end of 2000, the vast majority of whom live in sub-Saharan Africa. The future estimations are 24.3 million children orphaned by HIV/AIDS by the year 2010 and 40 million by 2020.

Percent of children under age 15 that are orphans by year, region, and cause 1990-2010



Percent of children under age 15 who have lost one or both parents to AIDS, 2001



Note: This map does not reflect a position by UNICEF on the legal status of any country or territory or the delimitation of any frontiers.

Source: UNAIDS/WHO

South African children

There are almost 18 million children under the age of 18 in South Africa[1] – 40% of the total population. As many as 60% of these children live in poverty – 3.2 million 0 to 5 year-olds, and 10.2 million 0 to 18 year-olds[2]. Using nutritional status as a proxy for poverty, of the 2.3 million South Africans who are nutritionally vulnerable, 35.9% are children aged 6 months to 5 years[3].

Children are our most treasured assets and the future of our country, yet they are silent, innocent casualties of poverty.

EXTRACT FROM SA NATIONAL COUNCIL FOR CHILD AND FAMILY WELFARE REPORT SUBMITTED TO THE COMMITTEE OF INQUIRY INTO A COMPREHENSIVE SOCIAL SECURITY SYSTEM

11 October 2000

Update on the South African HIV/AIDS epidemic

HIV prevalence

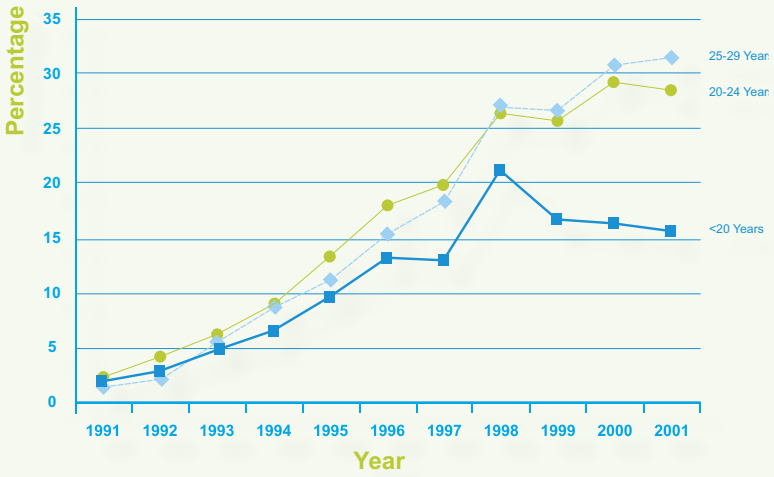
Whilst there are some encouraging signs of reducing prevalence rates amongst teenagers, as shown in the graph below[4], the epidemic in South Africa remains one of the most serious challenges to democracy, transformation and development.

The 2002 HSRC study on HIV/AIDS, which surveyed households across the country, estimated that the prevalence of HIV in the South African population was 11.4%[5].

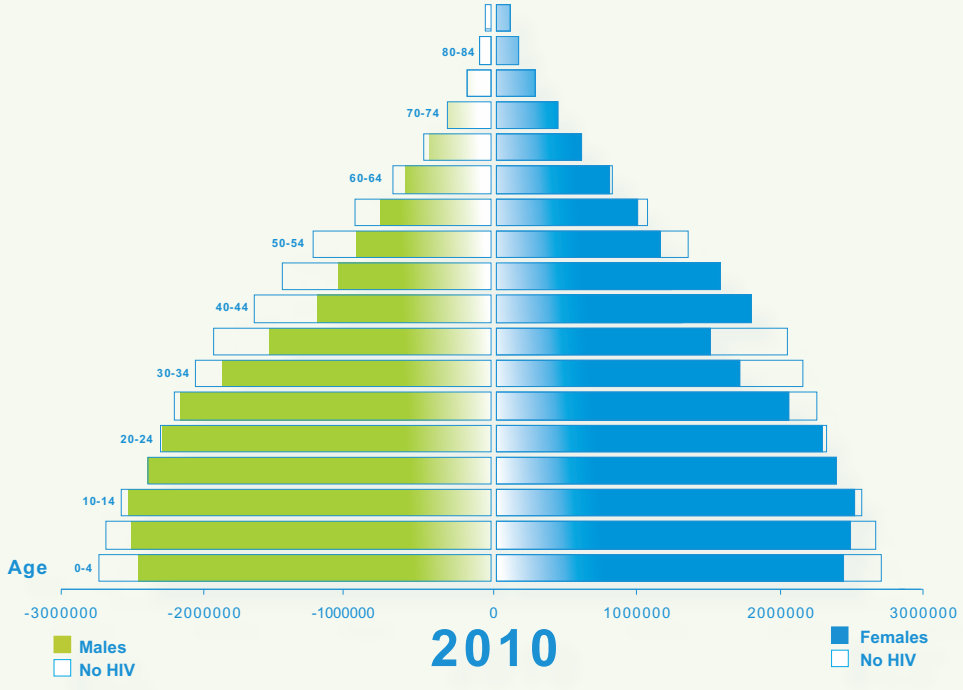
In this study, the HIV prevalence of 5.6% amongst children aged 2-14 years is of particular concern as only a limited proportion of these infections can be accounted for as a result of vertical transmission from infected mother to child. The possible role of sexual abuse and unsafe health care practices needs to be further investigated[6].

It is expected that the number of infected people in the population will peak between 7 and 8 million, and between 5 and 6 million will have died of HIV/AIDS by 2010. The effect of this is well illustrated in the following population pyramid, which shows how the epidemic will impact on the age and dependency structure of the population by the year 2010.

HIV prevalence by age, South African antenatal clinics 1991-2001



Population pyramid in mid-2010 showing the impact of HIV/AIDS on the total population[7]



Orphans and vulnerable children

The HSRC study found that 13% of children aged 2 to 14 years had lost a mother, father or both parents. In addition, 3% of households were found to be child-headed (by a child between the ages of 12 and 18) – 3.1% in urban formal areas, 4.2% in urban informal areas, 2.8% in tribal areas and 1.9% on farms.

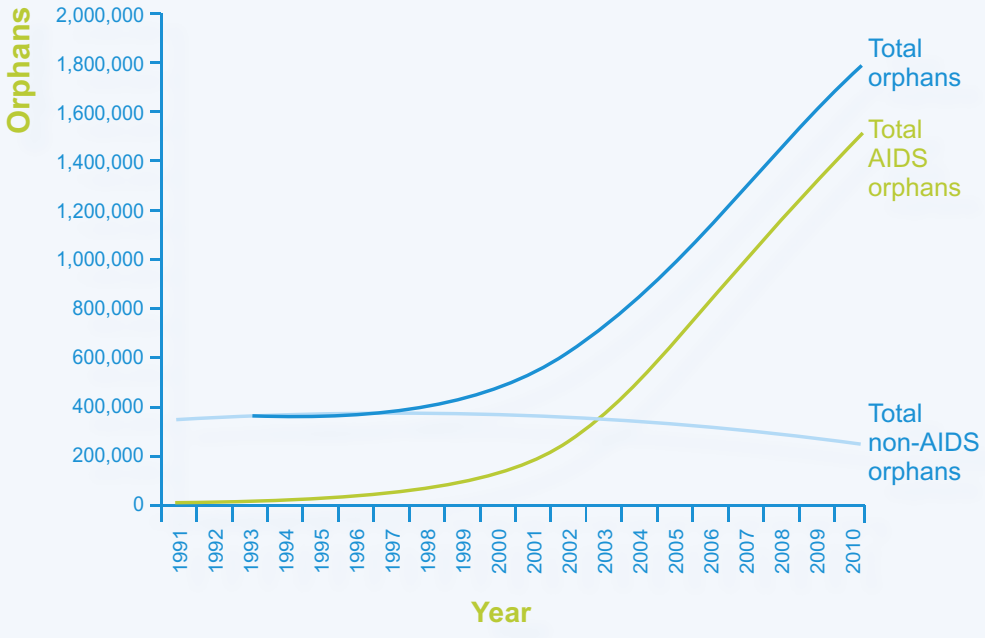
Defining an orphan as a child under the age of 18 whose mother has died, it is estimated that there were over 885 000 orphans in South Africa in July 2002, 38% of whom were orphaned by HIV/AIDS[8]. HIV/AIDS accounted for 73% of all new orphans in 2002, and 81% in KwaZulu-Natal.

Using a different definition of orphanhood, the current estimates provided by UNAIDS are that 660 000 children in South Africa have been orphaned by HIV/AIDS[9], and this figure is predicted to rise to a peak of 1 850 000 around 2015[10]. More than 30% of all children between the ages of 15 and 17 may have lost their mothers by the year 2015. The total number of children who will have lost their parent/s to HIV/AIDS and any other causes (paternal, maternal and double orphans) could reach a staggering 5 700 000 by 2015[11].

On the other hand, effective, large-scale programmes, such as anti-retroviral therapy (ART) to keep infected parents alive, could potentially halve the number of maternal orphans by 2015[12].

South Africa: Maternal orphans under 15 years[13]

Year	Total orphans	Total AIDS orphans	Total non-AIDS orphans
1991	346 751	227	346 524
1992	347 701	581	347 120
1993	350 631	1 398	349 234
1994	355 642	3 162	352 480
1995	363 299	6 736	356 562
1996	373 229	13 469	359 760
1997	388 824	25 520	363 305
1998	412 435	45 799	366 635
1999	447 522	77 887	369 636
2000	493 846	124 989	368 857
2001	555 684	190 993	364 691
2002	636 876	279 102	357 774
2003	739 572	391 052	348 520
2004	865 216	527 054	338 162
2005	1 011 457	684 364	327 093
2006	1 172 985	857 201	315 784
2007	1 336 483	1 034 085	302 398
2008	1 499 424	1 208 646	290 777
2009	1 647 293	1 367 926	279 367
2010	1 770 870	1 502 457	268 413



HIV/AIDS projected peaks and orphans statistics

	New HIV Infections	Total HIV Prevalence	AIDS Deaths
MRC peak years in (brackets)	930 000p.a. (1998)	7- 8 million (2006)	800 000p.a. (2010)

AIDS orphans maternal (under 18)	AIDS orphans paternal (under 18)	AIDS orphans (one or both parents) (under 18)
3 million (2015)	4.7 million (2015)	5.7 million (2015)

Source: Bradshaw. D, Johnson. L, Schneider. H,Bourne. D and Dorrington, R. 2002, Orphans of the HIV/AIDS epidemic: the time to act is now, MRC Policy Brief, No 2.

There is considerable confusion when faced with current and future statistics on orphanhood from varying sources, and this can detract attention from the issue, namely that regardless of which data are quoted, there can be no dispute that the situation is extremely grave and will become worse in the years to come.

RECOMMENDATION #2

Define “orphan” and agree on national orphan statistics – current and predicted future scenarios

(Footnotes)

[1] 1999 October Household Survey; 17 891 164 children under the age of 18

[2] IDASA; Presentation to the Portfolio Committee on Social Development (2001)

[3] Source: SAHRC submission

[4] Source: Summary Report, National HIV and syphilis sero-prevalence survey of women attending public antenatal clinics in South Africa, 2001. Department of Health, South Africa (2002)

[5] HSRC, MRC, CADRE & ANRS; Nelson Mandela/HSRC study of HIV/AIDS: Household survey 2002 (2002)

[6] Plans are in hand to further analyse the data to attempt to confirm the accuracy of the data, to further disaggregate the data by sex and age and to attempt to establish sources/routes of infection

[7] Dorrington, R & Johnson, L; The ingredients and impact of the HIV/AIDS epidemic in South Africa and its Provinces (2001)

[8] Dorrington, R; Bradshaw, D & Budlender, D; HIV/AIDS profile in the provinces of South Africa: Indicators for 2002 (2002)

[9] Source: UNAIDS (2002)

[10] Maternal orphans, as a result of HIV/AIDS, under the age of 15

[11] Dorrington, R & Johnson, L; Epidemiological and demographic; in Impacts and interventions – the HIV/AIDS epidemic and the children of South Africa ed. Gow, G & Desmond, C (2002)

[12] Dorrington, R & Johnson, L; Epidemiological and demographic; in Impacts and interventions – the HIV/AIDS epidemic and the children of South Africa ed. Gow, G & Desmond, C (2002)

[13] Source: Dorrington, R; Bradshaw, D & Budlender, D; HIV/AIDS profile in the provinces of South Africa: Indicators for 2002 (2002)

Chapter Three
RECENT INTERNATIONAL AND REGIONAL EVENTS AND RESPONSES

The first part of this chapter covers some of the international and regional consultations and resolutions that have become milestones in advancing the OVC agenda.

We are not the sources of problems; we are the resources that are needed to solve them. We are not expenses; we are investments. We are not just young people; we are people and citizens of this world. Until others accept their responsibility to us, we will fight for our rights. We have the will, the knowledge, the sensitivity and the dedication. We promise that as adults we will defend children's rights with the same passion that we have now as children. We promise to treat each other with dignity and respect. We promise to be open and sensitive to our differences. We are the children of the world, and despite our different backgrounds, we share a common reality. We are united by our struggle to make the world a better place for all. You call us the future, but we are also the present.

EXTRACT FROM MESSAGE DELIVERED BY CHILDREN TO THE UN GENERAL ASSEMBLY[1]
8 May 2002

International consultations, instruments and resolutions

There are a number of international conventions, goals and other instruments that bind all signatory states, including South Africa, and that define the framework for action for OVC. Significant amongst these are those listed below.

Certain of the Millennium Development Goals are relevant to the rights of all children, including OVC, in particular those related to education:

Universal primary education – By 2015, children, boys and girls, able to complete a full course of primary schooling.

Achieve gender equality – Girls and boys have equal access to all levels of education.

Article 26 of the Universal Declaration of Human Rights, which deals with the same right, states that:

Everyone has the right to education… Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship…

This right includes the right to receive HIV-related education, particularly regarding prevention and care. It is the State's obligation to ensure, in every cultural and religious tradition, that appropriate means are found so that effective HIV/AIDS information is included in educational programmes inside and outside schools.

Many nations have committed to the Education for All (EFA) goals, set in Jomtien, Thailand, at the World Conference on Education for All in 1990 and reviewed at the 2000 Dakar meeting when 164 governments committed to achieving education for all by 2015 or earlier[2].

The Convention on the Rights of the Child (CRC) is the universally accepted framework that guides programmes for all children, including OVC. The four pillars of the CRC are:

- *The right to survival, development and protection from abuse and neglect;*
- *The right to freedom from discrimination;*
- *The right to have a voice and be listened to; and*
- *That the best interests of the child should be of primary consideration.*

In 1998, a UN General Discussion on "Children living in a world with AIDS" was held. The Committee stressed the relevance of the rights contained in the Convention on the Rights of the Child to prevention efforts, recalling that HIV/AIDS was often seen primarily as a medical problem, while the holistic, rights-centred approach required to implement the Convention was more appropriate to the much broader range of issues which must be addressed by prevention and care efforts.

More recently, in June 2001, the UN General Assembly Special Session Declaration of Commitment, set specific targets for all signatory nations, recognising that children orphaned and affected by HIV/AIDS need special assistance.

65. *By 2003, develop and by 2005 implement national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS including by providing appropriate counselling and psycho-social support, ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; and protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance;*
66. *Ensure non-discrimination and full and equal enjoyment of all human rights through the promotion of an active and visible policy of de-stigmatisation of children orphaned and made vulnerable by HIV/AIDS;*
67. *Urge the international community, particularly donor countries, civil society, as well as the private sector to complement effectively national programmes to support programmes for children orphaned or made vulnerable by HIV/AIDS in affected regions, in countries at high risk and to direct special assistance to sub-Saharan Africa.*

In 2002, a UN Special Session on children was convened in New York. Twelve years after the 1990 World Summit for Children, which had adopted a declaration on the survival, protection and development of children and a plan of action that established 7 major and 20 supporting goals that were considered achievable by the year 2000, the meeting reviewed the progress that had been made[3].

Renewed commitment and a pledge to action for the next 10 years was stated in the final document – ***the World Fit for Children declaration*** – which featured protection from abuse, exploitation and violence as a priority area.

At the XIV International AIDS Conference 2002, which was held in Barcelona, Spain (7-12 July 2002), there was only one session that explicitly mentioned OVC in its title[4].

However, one of the satellite sessions[5] provided valuable guidance on the key factors required to foster effective local responses, which is generally agreed to be the optimal way of supporting OVC.

The factors are as follows:

Factor #1: Communities (villages, neighbourhoods, but also youth clubs, groups of PLWHAs, etc) are taking ownership both of the problem and of the solution. They are in the driving seat. Effective responses to HIV/AIDS are community-driven, not commodity driven. Communities that assumed ownership of HIV/AIDS can measure and document their own progress, which is an indicator of their ability to deal with the AIDS threat.

Factor #2: As they are assuming ownership of the problem, communities mobilise for its solution. They rally the support they require for effective responses from the providers of services they find in their local environment: the teacher, the doctor, the agricultural extension worker. Hence effective local responses hinge on local partnerships and sustained interaction between communities and local service providers. For HIV/AIDS related services (VCT, health education, care) to be effective, local communities must own the response against HIV/AIDS.

Factor #3: Effective and sustained local responses often require facilitation. A person or an organisation from within or from outside the community fulfils the facilitation function. Facilitation starts with helping communities to assess how HIV/AIDS is affecting (or might affect) their lives and to take appropriate actions to tackle the issues. It supports the required changes in practices and attitudes of service providers so that they are able to take part in community processes. Facilitation helps establish a favourable environment whereby individuals, families and communities sustain their interactions with those who can support them.

Factor #4: Effective countrywide responses result from three concomitant, interdependent processes:

- Sharing of AIDS-related competence. Such sharing takes place through multiple channels. It is based on invitations from other communities, or through an initiative from within an existing local response. The transfer will lead to additional local responses, emerging in neighbouring communities; but they will always be different from each other as long as communities have their own specific realities.

  Communities determine their own action. This represents a horizontal expansion (scaling-out) where people learn from each other how to respond to HIV/AIDS. It is based on the capacity of individuals to assess the reality of the impact of HIV/AIDS for themselves, and for the community, and on their commitment to take action. Effective local responses grow because they multiply and adapt. Think of them as organic growth. Facilitation can nurture those processes; but forcing them into mechanistic representations and planning instruments kills them.
- Scaling up of the supply, in the local environment and the whole country, of the information, money and commodities that people require to take action.
- The development of a supportive environment for effective responses country-wide; in particular, through political and spiritual leadership, mass communication, supportive taxation and subsidisation, and the adoption and implementation of supportive legislation (including human rights).

The participants at the meeting agreed that:

We need to focus our attention on people more than on the virus itself. Such a change in our attitude will take place by:

- Asking questions rather than providing answers;
- Listening rather than speaking;
- In uence rather than control;
- Building on existing strengths rather than generating needs;
- Generating vision rather than solving problems;
- Responding to invitation rather than selecting beneficiaries; and
- Balancing data gathering with story telling and other qualitative techniques.

In September 2002, an Africa Leadership Consultation entitled **Urgent action for children on the brink** aimed at developing consensus on priorities for a scaled up response to the OVC crisis and proposed actions to mobilise the leadership, partnerships and resources required to deliver on the UNGASS commitments.

And, in November 2000 and 2002, Eastern and Southern Africa workshops on OVC were held in Lusaka, Zambia and Windhoek, Namibia respectively.

- The Lusaka workshop objectives were to investigate ways of building the capacity of communities to respond to the needs of OVC, and of scaling up OVC activities so they reach a far greater proportion of the millions of children needing help. The expressed aim of the workshop was to find consensus on the way forward, rather than simply re ecting on current activities.

  Amongst the key issues recorded were the following:

  - National leadership is central to effective large-scale interventions for children and adolescents affected by HIV/AIDS.
  - Community initiatives continue and develop if they have sufficient resources (internal/external and human/financial); good and trusted local leadership; and community ownership and decision-making.
  - The human rights approach is a participatory methodology for planning and programming. It is based on the Convention on the Rights of the Child, which has been ratified by all governments in the region.
  - The welfare of children depends a great deal on how well the family is able to cope economically.
  - Appropriate education for a nation's children is central to ensuring that nation's future prosperity and stability. Universal education is also the principal weapon against the spread of HIV/AIDS, and the best defence against abuse, neglect and impoverishment.
  - Social safety nets should be implemented only after careful planning, including a situation analysis, a review of welfare assistance in the context of long-term poverty alleviation, and a study of cost-effectiveness.
  - Appropriate roles must be agreed at all levels in delivering social services, and role players' capacity developed to perform these roles effectively.
  - Strategic alliances or partnerships between two or among more organisations will allow for their collective interventions to be more effective and sustainable, and to reach larger numbers of beneficiaries.
  - More data is needed – on the number and relative vulnerability of various groups of orphans – including "social orphans" who are abandoned children, with living parents; as well as on types of support and their impact on OVC.

  Recommendations from Lusaka included:

  - A leadership agenda on OVC;
  - Better care and support to parents/families/caregivers/PLWHAs;

- Expanding the number and quality of organisations that can be involved;
- Getting resources to the base;
- Expanding the role of schools and education systems; and
- Strengthening participation of children, families and communities.

RECOMMENDATION #3

Create two-way communication between international, regional and national conferences and strategy and planning processes in SA

- The Windhoek workshop[6] was convened to:
  - Review progress towards the achievement of the UNGASS goals at country level, and towards the commitments made by countries at the Lusaka OVC workshop in 2000.
  - Explore good practice in implementing large-scale action to achieve the UNGASS goals.
  - Develop a clear vision of the way forward, and make commitments to action, at country and regional level.

  Five thematic groups met and agreed on key messages and most important actions related to:
  - Access to education;
  - Access to health and nutrition;
  - Protection of children's rights and combating stigma;
  - Access to social services and getting resources to community level; and
  - Provision of psychosocial support.

RECOMMENDATION #4

Publicise the commitments made by South Africa and its neighbours and establish a SADC process to track progress on these commitments

The next part of the chapter summarises other significant events related to HIV/AIDS and OVC.

Global fund for AIDS, TB and malaria (GFATM)

The idea of an international funding mechanism to fight AIDS, TB and malaria crystallised at the Okinawa G8 Summit in July 2000. At the urging of UN Secretary General, Kofi Annan, and national leaders, the concept was then unanimously endorsed at the UN General Assembly Special Session on HIV/AIDS in June 2001.

GFATM is an independent public-private partnership to increase the global resources available to combat AIDS, tuberculosis, and malaria, direct the resources to areas of greatest need, and ensure that the funds are used effectively. Programmes aimed at prevention, treatment, and care and support of those infected and directly affected are all eligible for funding.

In the first round of funding, the proposal submitted by the South African National AIDS Council (SANAC), totalling $93 million, was the largest grant immediately approved by the Global Fund. The second award to South Africa was made to KwaZulu-Natal ($72 million). Though agreements were still to be signed, as at 8 May 2003, these were pending and fund disbursement would start shortly thereafter[7].

The second round of grants, to 60 countries, was approved on 31 January 2003, costing $866 million over the first two years. All of the AIDS grants include prevention components; 98% use targeted communication campaigns to change the behaviour of vulnerable groups, including youth and school children, and 70% include prevention of mother to child transmission (PMTCT) and voluntary counselling and testing (VCT). Also, the AIDS grants will provide care and support to 500 000 AIDS orphans and vulnerable children[8].

There is no analysis of the extent to which programmes for OVC were funded in the first or second rounds of GFATM funding[9].

Children's Nobel Prize[10]

On April 15th 2002, Nkosi Johnson, the 12-year old boy who gave children with AIDS a voice that reached around the world, won the Children's Nobel Prize. Nkosi was nominated posthumously, only the second time in the history of the awards that this has happened.

"Nkosi is a worthy recipient of the Children's Nobel Prize because of his magnificent contributions towards raising awareness of the terrible disaster of the HIV/AIDS pandemic," said Jerry Coovadia, Professor of HIV/AIDS Research at the University of Natal and Chair of the Durban conference. "He lived through considerable difficulties as a child yet contributed more during his lifetime than many adults. Let us hope this award will rivet the world's attention and help mobilise the action so long delayed that will prevent the birth of more Nkosis."

Leaders of South Africa's Treatment Action Campaign concurred. "Together with his mother Gail, Nkosi pioneered openness for children with HIV/AIDS at schools. As a direct consequence of the discrimination and subsequent acceptance won by Nkosi at Melville Primary in Johannesburg, the government issued a policy to prevent discrimination against children with HIV/AIDS and their teachers. His stand allowed many children with HIV/AIDS and those affected by HIV/AIDS to attend school and to assert their rights to dignity, equality and education. Nkosi's premature and unnecessary death has made all our lives and worlds poorer and emptier. This award is not only a tribute to his memory but also a clarion call to act."

The final part of this chapter contains examples of regional responses, followed by an analysis which suggests the key elements of successful national responses.

Country responses: Botswana, Malawi, Zambia, Zimbabwe[11] and Swaziland

Efforts to protect children orphaned by AIDS are nearly as old as the epidemic, and many are beginning to show real progress. Several of these encouraging efforts have taken place in Botswana, Malawi, Zambia, Zimbabwe and Swaziland, 5 of the 10 worst affected countries in terms of HIV prevalence.

Botswana

In Botswana, UNAIDS have estimated that 69 000 children had lost their parent/s to HIV/AIDS by the end of 2001. The government in Botswana encourages communities to provide care for orphans and to rely on institutional care only as a last resort. Orphans in Botswana are still usually absorbed by the extended family. Their caretakers are predominantly women.

A National Orphan Programme was established in April 1999 to respond to the immediate needs of orphaned children. The programme is run by various government departments, NGOs, CBOs and the private sector. The Programme's objectives are to review and develop policies, build and strengthen institutional capacity, provide social welfare services, support community-based initiatives and monitor and evaluate activities. A major goal of the programme is to develop a comprehensive National Orphan Policy, based on the Convention on the Rights of the Child.

In the rural subdistrict of Bobirwa, district authorities have contracted out to the Bobirwa Orphan Trust the delivery of essential government services to orphans in the area. The Trust is made up of community volunteers and local extension staff

– government paid employees, including social workers and family welfare educators. The members of the Trust identify and register orphans in the district, and through home visits, schools and churches, screen orphans using established criteria to identify the type of assistance they need. They also initiate community-placed foster placement, and identify local groups who purchase food and clothing and distribute them to orphans. Needy orphans are assisted with food, clothing, blankets, counselling, toys, bus fares to and from school, school uniforms and other educational needs.

But there are still many obstacles and challenges to overcome. Firstly, the country's high-level officials have only recently begun to speak about the problem and to make it a national priority. Because initial government response to the crisis was slow, HIV/AIDS has already done significant damage to previous progress in social development. Secondly, responsibility for AIDS within the Government is not well defined. Thirdly, there is no strong tradition of NGOs working in the area of childcare and rights. Finally, existing child protection laws and policies are fragmented and outdated.

Malawi

Malawi has been struggling with high levels of HIV infection. Also the incidence of tuberculosis has more than tripled since the late 1980's, largely due to HIV infection. The AIDS crisis has had a crippling impact on the country's children and UNAIDS estimated that Malawi had 470 000 children orphaned by HIV/AIDS as of the end of 2001.

It was recognised early on that because communities are in the best position to assess their own needs, they would play an important role in addressing the AIDS orphan crisis. One of the Government's main strategies, therefore, has been to promote and support community based programmes. As early as 1991, the Government of Malawi established the National Orphan Care Task Force. The Task Force was made up of various representatives and organisations, which are responsible for planning, monitoring and revising all programmes on orphan care. One year later, in 1992, National Orphan Care Guidelines were established. The guidelines serve as a broad blueprint to encourage and focus subnational and community efforts. The Task Force also established a subcommittee that is reviewing existing laws and legal procedures to provide greater protection to vulnerable children.

In rural and urban areas across Malawi, communities are developing a variety of ways to cope with the growing crisis of AIDS orphans. Village orphan committees have been established in many villages to monitor the local situation and to take collective action to assist those in need. Anti-AIDS clubs have also been created to educate commu he orphans a kitchen for their home

Lack of administrative capacity at the national level coupled with inadequate resources has made it difficult for the government to keep up with the growing epidemic. At the same time, research and data collection need to be improved in order to assess the severity and scope of the problems presented by large number of orphans and respond effectively. The dedication and solidarity of community members across the country have been a major factor in the progress that has been achieved so far.

Zambia

The HIV/AIDS epidemic has had a devastating impact on communities in Zambia. The estimated number of children orphaned because of HIV/AIDS is 570 000. Many families already worn out by widespread and extreme poverty are stretched beyond their capacity. Many of the rural population is considered to be living below the poverty line and large

numbers of families are forced to ration food, which in turn affects child development. The crisis is eroding the government's ability to provide services, whilst at the same time increasing demand for them. Zambia's primary health care system used to be one of the best administered and most decentralised among all African countries, but now, with increasing household poverty, external debt obligations, and demand placed on health services by HIV/AIDS, the system is breaking down.

Zambia has several policies that pertain to children, but no national orphan policy. Although many ministries have included AIDS issues in their planning the government has been slow to respond to the AIDS orphan crisis. As in many countries, NGOs, CBOs and religious institutions have tried to fill the gaps. In the last few years, the number of groups dealing with HIV/AIDS issues has grown. Most of these organisations recognise that orphaned children should be cared for by the community rather than by institutions. As a result, much of their work focuses on strengthening families and extended families.

Zambia does not provide free primary education to children and with high national poverty rates, parents and guardians are finding it increasingly difficult to pay for the school fees; uniforms and books needed to send their children to school. For the AIDS orphans and their guardians the situation is even worse. A study in urban areas revealed that 32% of orphans were not receiving formal schooling, compared with 25% of non-orphans. In rural areas, the figures for children not enrolled in school were a staggering 68% of orphans compared with 48% of non-orphans.

The Community-based Orphan Support Programme was designed to strengthen the communities' capacity to address the growing number of orphans and to create awareness about the problems these children face. The programme provides education and health services, facilitates local income-generating projects, conducts HIV/AIDS prevention among vulnerable children and links up local communities with agencies working with orphans outside the community.

Communities are remaining at the forefront of care for orphans in Zambia. Although NGOs, CBOs, churches and other volunteer organisations are making significant contributions in strengthening local communities, they have a long way to go before making an impact nationally. A number of factors make it difficult for these institutions to scale up existing interventions. Firstly, their responses are not consistent and there is little co-ordination between them. Secondly, government involvement is severely limited at the present time. Thirdly, the funding is totally inadequate to address the issues on a large scale. Finally, institutions are overwhelmed responding to the immediate needs of these children and families. With little funding and relying heavily on volunteers, many institutions are stretched almost to breaking point. However, the activities of these organisations do mitigate the suffering of the orphans and supporting these efforts is crucial in the monumental task of assisting families and communities in Zambia to care for the country's orphans.

Zimbabwe

Zimbabwe has one of the worst HIV/AIDS epidemics in the world. The epidemic has so far left behind an estimated 780 000 AIDS orphans. The orphan crisis first came to national attention in July 1992, when Zimbabwe's Department of Social Welfare co-ordinated a national conference on orphans. It was recognised that compared to institutionalisation, community-based care was cost-effective and kept children in a familiar social, cultural and

ethnic environment and reduced their distress. In 1995, the Government of Zimbabwe developed a national Policy on the Care and Protection of Orphans, which was finally approved by the Cabinet in May 1999. The policy reaffirmed the position that orphans should be placed in institutions only as a last resort.

Farm workers in Zimbabwe are multiethnic. Many are immigrants or the children of immigrants, and many more are Zimbabweans who have moved from their native villages. Families are often isolated from their extended family networks and so children are often left with no one if their parents die. In 1986, the Farm Orphan Support Trust (FOST) of Zimbabwe was set up as a community response to the situation of orphans in commercial farming areas. FOST aims above all to keep sibling orphans together, within a family of the same culture and in a familiar environment. It operates foster schemes on farms, using farm committees to train caregivers, establish monitoring procedures, and raise community awareness. All the farms register orphans individually and send information to a centralised computer bank. This procedure helps with the tracing of relatives.

FOST promotes five levels of orphan care. It's preferred care is within the extended family. If that is not possible, orphans are placed within substitute families. The third choice is for small groups of orphans to live together on a farm, looked after by a caregiver employed by the farm for this purpose. The next most preferred type of care is an adolescent child-headed household with siblings remaining together, preferably in the family home. Here they are cared for by the eldest child with regular supervision and support provided by the farm's Child Care Committee, the community and the local field officer. Finally, FOST will arrange for temporary care in an orphanage, until a better solution can be found.

Swaziland[12]

Children are a major casualty of the HIV/AIDS epidemic in Swaziland. With 38% of the population infected, 1 in 3 children are orphaned or vulnerable in the poorest communities. In 2000, 40 000 orphans were recorded and 10% of children live in child-headed households.

The Community Action for Child Rights Programme of the Government of Swaziland, UNICEF and partners is working with communities to enable them to maintain the traditional practice of caring for orphans and vulnerable children within the extended family.

Workshops are held to help communities to assess and change their situations. Youth are trained in data collection, community leaders and service providers work on community appraisals, people who cannot read or write are involved in mapping exercises, and local women are engaged in cooking and organising school meals for children. Communities are setting up neighbourhood child protection structures.

The Joint SOS/Salvation Army family carers project, in Sidwashini and Msunduza, in Swaziland offers a new perspective on assisting orphans and vulnerable children[13]. In addition to efforts to keep the children in their parental homes, trained family carers supervise children's hygiene, meals, security, education and study time, domestic problem-solving and con ict resolution, counselling and income generation for older children. To document the psychosocial status of the children, data on schooling, child growth monitoring and the medical history of each under-10 year old is recorded, as well as personal records of the life histories, expectations, goals, struggles and needs of those 10 and above (recorded by the children themselves).

Elements of successful national responses

The country studies highlight a number of key elements that collectively constitute effective national responses.

For example:

- Laws protecting the rights of all children;
- National HIV/AIDS strategies that include an explicit focus on OVC;
- A national OVC policy and guidelines;
- A multisectoral OVC structure;
- A situation analysis and needs assessment;
- Regular national OVC consultations;
- Methods and systems for defining and identifying the most vulnerable children;
- Holistic support for OVC, that includes a focus on psychosocial support;
- Support for communities that are dealing with OVC;
- Linkages with poverty alleviation strategies and programmes;
- Structures at community level responsible for protecting children;
- Community education on children's rights and entitlements;
- Partnerships that focus on OVC;
- State support for OVC; and
- Systems to monitor and evaluate OVC responses.

RECOMMENDATION #5

Define the elements of a successful national OVC response, and generate a process to put these elements in place

(Footnotes)

[1] ChildrenFIRST; Vol.6, No.43 (2002)

[2] Dakar Framework for Action, Education for all: meeting our collective commitments

[3] ChildrenFIRST; Vol.6, No.43 (2002)

[4] AIDS Analysis Africa; Vol.13(2) (2002)

[5] Barriere-Constantin, L; report of satellite meeting entitled Decentralization: going to scale in local, district and state AIDS responses (2002)

[6] The workshop report is due early in 2003

[7] IDASA; Budget Brief No.108: How South Africa fared in the first round of grants from the Global Fund (2002)

[8] Source: GFO Newsletter: Issue 6

[9] Details on each grant are available at www.aidspan.org/round2

[10] Source: Durban AIDS Conference & IAS statement 15.04.02 (2002)

[11] www.avert.org/aidsorphans.htm

[12] Government of Swaziland & UNICEF; Orphans and vulnerable children in Swaziland: Community approaches, good practice, innovative ideas – report prepared for 2002 Eastern & Southern Africa workshop on children affected by HIV and AIDS (2002)

[13] AIDS Analysis Africa; Vol.13(2) (2002)

Chapter Four
SOUTH AFRICAN DEVELOPMENTS AND RESPONSES SINCE 2000

Legislative changes

Many legislative processes, either completed or in progress will affect policies, programmes and services for OVC. Certain of the more significant of these are summarised below.

Regulations to the Social Assistance Act came into operation on 1 April 1998. Amendments to these regulations were gazetted for comment in March 2001, and came into effect on 1 December 2001. The regulations make grants more accessible by, for example[1]:

- Introducing assessment panels for disability and care dependency grants;
- Removing the three-month limitation on the payment of arrears; and
- Simplifying the procedures for the review for eligibility for grants.

In January 2003, a new draft **Social Assistance Bill** was circulated for comment.

In October 2002, the **review of all child-related law by the South African Law Commission**, resulting in the draft Children's Bill, was completed. The **report** was released in December 2002.[2] Chapters include constitutional imperatives, parental rights and responsibilities, prevention and early intervention services for children, child protection (health rights and consumer rights), children in need of special protection (severe poverty, disability, HIV/AIDS infected and refugees), ECD, foster care, adoption, customary law and the monitoring of child care legislation.

Chapter 25 of the report focused on grants and social security for children, and proposed a review of the Foster Care Grant (FCG). Recommendations were made for the establishment of grants aimed at subsidising adoptions. The Child Support Grant (CSG) was considered to be inadequate, and it was recommended that it be brought in line with in ation rates and extended to target all poor children under 18 years[3]. A top-up grant for children with special needs was also proposed. It was recommended that recipients of social security be exempted from school fees.

The report specifically recommended the establishment of an independent body – the 'Office of the Children's Protector' – to act as a watchdog and to oversee the activities of those responsible for the implementation of child care legislation.

The **Children's Bill**, when passed, will replace the 1983 Child Care Act, and will regulate the child care system, ensuring that South Africa's obligations towards children (international and constitutional) are taken into account; that all child care legislation is harmonised; and that the child care system is "Africanised"[4]. The Bill was handed to government by the South African Law Commission on 21 January 2003.

An important part of the Bill is the introduction of a comprehensive social security scheme for children that includes the following grants, benefits and services:

- Universal grant (for all children under 18 years);
- Foster care grant;
- Court-ordered kinship care grant;
- Adoption grant;
- Emergency court grant;
- Supplementary special needs grant (for children with disabilities and chronic illness including HIV/AIDS);
- Subsidy for assistive devices for children with disabilities; and
- Free basic services for children in court-ordered alternative care[5].

Possible barriers that may delay the passing of the Bill are that[6]:

- It has not yet been costed; and
- There is a need for consultation with other government departments affected by the Bill as well as a need to consult with the NGOs that provide the bulk of services to children.

RECOMMENDATION #6

Wherever appropriate ensure that children in general and OVC in particular are considered in all legislative processes

The draft **National Social Security Agency Bill** seeks to create a separate public entity, outside of the public service, that will be primarily responsible for the delivery of social grants. In October 2002, Cabinet gave approval in principle to set up such an agency.

The new **National Health Bill**, which provides the framework for the provision of health care services did not recognise children as a vulnerable group in need for specialised structures and services[7] in the version that was published for comment[8]. It does however, in Chapter 2, protect patient rights to, for example, confidentiality and testing without consent, and so, when implemented, it will also protect children's rights. It also, importantly, requires every institution to have a complaints procedure, so that patients or guardians can report poor quality services or abuses of rights.

A Bill dealing with the **testing of alleged sexual offenders** at the request of a victim of a sexual offence was published late in 2002. If the magistrate is satisfied that prima facie evidence exists that a sexual offence has been committed by the alleged offender against the victim, and no more than 50 days have elapsed since the time of the offence, he or she must order the HIV test to take place[9].

The closing date for submissions on the Bill was 27 January 2003, and public hearings took place on 6 February in Parliament[10].

On 8 August 2002, the **Child Justice Bill**[11] was introduced into Parliament. Dealing with children in trouble with the law, it clearly sets out assessment procedures, the central role of the preliminary inquiry and alternative sentencing, to name a few relevant elements[12].

Committee of Inquiry into a comprehensive social security system (The Taylor Committee)
As re ected in its title, the committee was established to investigate the social security system. As part of the consultation process, many organisations made submissions to the Committee. The final draft report was presented to the Ministerial Committee in March 2002, following which it was submitted to Cabinet and released for public comment. Cabinet's decision is expected in 2003. The changes propose a package of programmes to protect against poverty, including a basic set of services – health care, education, water and sanitation, electricity, public transport, housing and jobs and skills training[13].

RECOMMENDATION #7

Advocacy efforts should continue until reports are adopted and legislation promulgated, and even beyond to ensure effective implementation

Court cases

In the case of **the National Coalition for Gay and Lesbian Equality vs the Minister of Home Affairs** (2000), the Constitutional Court has, in recognising the right to family life, established that gay and lesbian couples with foreign partners should be treated equally with married couples where one partner is not South African[14]. It has been argued that although the case dealt with an equality issue, the recognition of "family life" as a right is significant as it is not expressly provided for in the Constitution. On the basis of this case, there are implications for children's rights to family life as well.

The judgement in the **Grootboom** case interpreted the economic and social rights in the Bill of Rights in terms of the state's responsibility to provide homeless children with shelter[15]. Section 28(1)(c) of the constitution provides that every child has the right to basic nutrition, shelter, basic health care services and social services. The applicants (390 adults and 510 children) were 'squatters' who were relocated and their homes demolished. It was argued that the best interests of the child lay in living with their parents and that the right to shelter for children should accordingly be extended to their parents to retain the family unit intact. The court held that the appropriate organ or department of state was obliged to provide the applicant children and their parents with shelter until such time as the parents were able to shelter their own children.

Minister of Health & others v Treatment Action Campaign & others (2002). The Treatment Action Campaign (TAC) successfully challenged the government's policy in terms of which an antiretroviral drug, Nevirapine, was made available only in certain research sites within the public health sector, for the purposes of testing the efficacy of the programme to prevent mother to child transmission of HIV. The court found that the government policy failed to meet constitutional standards, because it excluded those who could reasonably expect to be included, where such treatment was medically indicated. The court ordered government to implement the intervention without delay in all situations where the necessary infrastructure was in place.

Policies

A number of policies have important implications for OVC.

The HIV/AIDS and STD strategic plan for South Africa 2000-2005[16]

This document provides a framework consisting of 4 priority areas for the country's response to the epidemic. Within the priority area **treatment, care and support**, goal 9 is to *develop and expand the provision of care to children and orphans*. Selected strategies include:

- Promote advocacy of all relevant issues that affect children;
- Mobilise financial and material resources for orphans and child-headed households;
- Investigate the legal protection of child-headed households;
- Provide social welfare, legal and human rights support to protect educational and constitutional rights;
- Investigate the use of welfare benefit to assist children and families living with HIV/AIDS; and
- Subsidise adoption of AIDS orphans.

The National Integrated Plan for children infected and affected by HIV/AIDS (NIP)

The National Integrated Plan was developed early in 2000. Giving effect to a unique collaboration between three government departments, namely Education, Health and Social Development (and recently including Agriculture as well), its stated aim is to *ensure access to an appropriate and effective integrated system of prevention, care and support services for children infected and affected by HIV/AIDS*.

The key features of the NIP are[17]:

- Life skills education – to educate learners about sexuality and how to make healthy choices.
- Home/community-based care and support – which aims to promote and support a person's maximum level of comfort and health. The programme identifies community strengths, and builds on community potential to care for its vulnerable members.

  The programme of home/ community-based care and support includes a component of support for children affected by HIV/AIDS. This is based on research into models of care and support.

  A comprehensive 12 module, 59-day training programme has been conducted in all provinces, to give caregivers the necessary skills. The training covers STIs, TB, nutrition, palliative care, spiritual and cultural aspects of care and support, infection control, communication skills and social support[18].
- Voluntary counselling and testing – which aims to increase access to counselling and testing for HIV and to make people more conscious of the risk of HIV infection, their own control over this risk and to serve as a key entry point to other services.
- Poverty relief – to enhance the ability of communities to participate and specifically to ensure food security, improve social support structures, provide income generating opportunities for rural women and start community-based child care initiatives amongst others.

RECOMMENDATION #8
Create a mechanism to inform stakeholders of NIP targets and progress

The main funding mechanism for the NIP is via conditional grants to provinces. The budget is R1.946 billion over the medium term – R520 million in 2003/4, R680 million in 2004/5 and R746 million in 2005/6[19].

VCT (voluntary counselling and testing) policies

- A South African VCT policy is currently being developed. It recognises that testing is appropriate in the following contexts which include children:
  - Women or couples considering pregnancy or concerned about transmission of HIV to their unborn child.
  - Young people, who are increasingly vulnerable to HIV infection. Youth who are 14 years of age and older may consent to HIV testing without the assistance of their parent or guardian. Where young people are able to consent on their own they must be given their test results and this information may not be given to their parents without consent.
  - Children and youth under 14 years of age should receive VCT services only with parental/guardian consent and only if there is a clear benefit to the child.
  - Personnel providing VCT to children and youth should be specially trained to provide services to these special populations.

- A VCT policy and guidelines specifically for children has been identified as urgently needed, and a national consultation on the issue was held late in 2002. A declaration adopted at the meeting identifies the common concerns, namely that:
  - Advice, support, assistance and legal services are needed for juvenile offenders, pregnant children, undocumented child migrants, children with disabilities, children who are homeless, children who live on the streets, children who have survived sexual assault and rape, children in foster homes and places of safety, children in hospitals and clinics, children who care for their parents, siblings and other family members, children who are orphaned by HIV/AIDS, children who are placed in institutions for the mentally challenged and children who are attending

nursery, primary and secondary school.

- Children should have all the relevant information – in a language that they understand – about their health status, including their HIV status.
- It is in the best interests of children if they are empowered to learn about their health and to make decisions regarding their own health, including their reproductive and sexual health.
- It is in the best interests of children that – where possible – they are able to participate in any decision to disclose their own HIV status or any decision to disclose the HIV status of a parent or care giver.
- It is in the best interests of children to have access to both pre- and post-test counselling when undergoing an HIV test. Pre- and post-test counselling must take place in a supportive environment and in a language that a child understands.
- The government guidelines should be amended to include a specific section for children who need access to PEP (in the case of sexual assault), PMTCT (in the case of pregnancy) and treatment and prevention of OIs and STIs (where medically necessary)[20]. In respect of VCT, the recommendation is for a separate set of guidelines for children.
- The Draft Children's Bill that will replace the current Child Care Act does not significantly deal with issues concerning children living with and affected by HIV/AIDS.
- It is difficult to decide the age at which a child is able to make informed decisions about their health. The factors that in uence a child's ability to make a mature decision include the place where they live, their socio-economic status, the school they attend, their gender, their race, their religion, levels of support within their family and community, their friends and peers, and finally their teachers. It is advisable to avoid prescriptive recommendations. Instead, all of these factors should be considered when deciding at what age a child can legally consent to HIV testing and medical treatment.

The proposed way forward is either to develop draft guidelines, or to refer the matter to the South African Law Commission for further research.

RECOMMENDATION #9
Ensure that VCT guidelines for children are developed and implemented without delay

Guidelines

National guidelines for social services to children infected and affected by HIV/AIDS were developed by the Department of Social Development for use by NGOs, community-based organisations, government officials, volunteers and community care givers, family members and donors.

The guidelines list the following essential services for children[21]:

- Early identification of children and families in need;
- Addressing the needs of child-headed households;
- Ensuring that the basic needs of families, children and sick parents/guardians are met, eg food, shelter, education and alternative care;
- Linking families and care givers with poverty alleviation programmes and services in the community;
- Providing families with information to increase their access to grants and other financial support services;
- Providing counselling to address the psychological needs of children and their families;
- Addressing discrimination, stigmatisation and disclosures;
- Addressing capacity building needs of families and children;
- Ensuring co-ordination of the entire programme; and
- Addressing burial costs especially for poor families of the deceased.

Social support and services for children

The idea of "coping" originates from the unwillingness of the rich or those in power to do anything more than apply a bandage to the wounds of national or global inequality when what has been required for a very long time is extensive and expensive surgery.

MBULAWA MUGABE, MARK STIRLING AND ALAN WHITESIDE AFRICA LEADERSHIP CONSULTATION – ACTING FOR CHILDREN ON THE BRINK
Johannesburg, 10th September 2002

Child Support Grant

The number of children receiving the Child Support Grant (CSG) has increased from 348 532 in April 2000 to 1 574 927 in April 2002[22]. There has been an increase of 4 400% during the period 1999 to 2002, however this still falls short of the target of 3 million children[23].

Problems that are commonly expressed regarding the CSG have been:

- The age restriction of seven – until very recently, only children under this age qualified for the CSG[24];
- Birth certificates – the care giver must supply the child's birth certificate when applying for the CSG; and
- The barriers to accessing the grant represented by the services provided by the Department of Home Affairs.

In the 2003/4 budget the CSG was increased from R140 to R160 per month.

Foster Care Grants (FCG)

This grant is given to the care giver of a child who is not the care giver's own child by birth. The number of FCG beneficiaries has increased from just less than 44 000 in 1998 to 90 680 in 2002.[25]

Integrated nutrition programme (INP)[26]

At the ANC National Policy Conference (September 2002) there were calls for a comprehensive social security system. This included a proposal to extend the school nutrition programme[27]. With the greatly increased funding available, the INP will expand to improve frequency of feeding, expanding the number of schools involved, including Grade R learners in the programme, and standardising menus across schools[28].

Food security programme

Led by the Department of Agriculture, government will provide relief measures to vulnerable groups who cannot afford adequate and nutritious food due to poverty and escalating food prices. It was announced in the 2003/4 budget that R400 million (R170 million to assist neighbouring states that are devastated by famine and hunger) would be allocated to improve food security. Families who do not have an income and spend a maximum of R200 per month on food and basic household essentials will receive food parcels – 240 000 poor households will benefit in the 2003/4 financial year[29].

National Social Security Agency

Cabinet has decided to establish the National Social Security Agency. The agency will be a specialist and focused institution for the management, administration and payment of social grants[30].

Poverty continues to be enemy number one of all South Africans, the sub-region and continent. Our attack on poverty is underpinned by our desire to empower our people to extricate themselves out of poverty.

BUDGET VOTE SPEECH BY DR ZOLA SKWEYIYA
MINISTER OF SOCIAL DEVELOPMENT
TO THE NATIONAL ASSEMBLY
27th March 2003

Programme of action against child labour[31]

The Department of Labour, in co-operation with the International Labour Organisation's International Programme on the Elimination of Child Labour (IPEC), led a process, early in 2003, to advance discussion on child labour. The consultations considered the dangers and disadvantages of child labour, action that can be taken and capacity to respond. The planned output is the formulation of a Child Labour Action Programme.

Services for child rape survivors

The phenomenon of child sexual abuse has been receiving increasing attention, not least because of the risk of HIV transmission in such situations. The Department of Social Development released guidelines in 2001 that define the following roles of service providers in the notification of child sexual abuse and in supporting the survivor[32].

Social worker

- be alert to and recognise abuse
- screen cases and determine whether it's a first referral
- assist victim with disclosure
- evaluate safety of child and arrange place of safety (if necessary)
- counselling for victim and family
- report to central child abuse register
- co-ordinate services and refer to other role players
- investigate social circumstances
- arrange case conference
- follow up on referrals to CPS team members
- prepare victim for court
- prepare final Children's Court Inquiry (CCI) report
- convey and explain outcome of court proceedings to child
- arrange after-care services
- on-going monitoring and evaluation of services for the victim

South African Police

- take initial statement
- refer to the FCS
- refer to forensic social worker where appropriate
- inform and request a social worker to join investigation
- take victim's statement
- ensure victim's safety
- decide with social worker whether to proceed with a criminal case
- refer and escort victim to doctor for examination and J88 completion
- visit scene of crime for evidence and exhibits
- obtain forensic evidence and send off specimens to labs
- obtain relevant statements
- trace and arrest perpetrator
- take perpetrator to court within 48 hours
- attend case conference and prepare documents
- oppose bail
- take case to court
- adjust perpetrator's record if found guilty
- report to perpetrator database
- terminate case

Public Prosecutor

- avoid delays where possible
- go through docket
- examine medical report to ascertain injuries
- apply timeously for an intermediary
- interview each witness
- confer with CPS and determine charges to be laid
- organise opposition to bail; inform victim/family of bail conditions if it is granted
- see victim is not exposed to accused or his family/friends whilst awaiting trial
- work with social worker throughout process
- see that justice is done

Justice

- the Clerk of the Court must notify the Director General of convictions and the outcome of the Children's Court Inquiry if the reasons for the removal was child abuse or neglect

Health workers

- recognise sexual abuse
- be kind and believe child
- notify social worker and CPU/FCS
- ensure confidentiality and privacy

Doctor

- explain process to child and care-giver
- obtain consent
- take full history
- undertake a full medical and forensic examination and complete J88
- treat STDs, give pregnancy prophylaxis, HIV counselling and testing and offer antiretrovirals
- arrange referral to mental health services or paediatrician
- attend court

Nurse

- receive and support child
- be present during medical examination

Psychologist

- psychological assessment
- conduct disclosure interviews
- provide psychotherapy
- supervise counsellors
- attend court

CBOs, youth, community workers and community structures

- support and encourage child and family involved
- help reintegrate child into society after the case
- child abuse prevention

Teachers

- identify suspected sexual abuse
- discuss with child/parents
- refer cases to social worker where child lives or police
- share any relevant information with team members
- support child
- protect child when in school
- inform all children at school who they can talk to about child abuse

The Child Protection Register is now implemented in all provinces[33].

Report to the Committee on the Rights of the Child

All governments must submit a "Country Report" to the Committee on the Rights of the Child every 5 years, and South Africa submits its 2002 report early in 2003. The Committee is tasked with monitoring the implementation of the UN Convention on the Rights of the Child in countries that have ratified the CRC.

Civil society (NGOs, FBOs, CBOs etc) may collectively submit an Alternative (or shadow) Report within a year of the submission of the Country Report[34].

RECOMMENDATION #10

Ensure that OVC and HIV/AIDS are prominent in both the CRC Country Report and the Complementary Report

Resource materials

Until recently there was an acknowledged dearth of information, materials and resources that could be used to support OVC. That is changing, with the changing emphasis, away from almost all initiatives being prevention-focused to a more balanced position, which also prioritises care and support. The following are examples of these resources, without attempting to constitute a comprehensive list.

As part of the **Khomanani** communication campaign, a range of materials have been developed amongst which are the following that can be used in supporting affected children:

- *Circles of support for our children,* which explains children's rights and needs, identifies categories of children in need and then describes different ways to help children in need and provides referral details (**see Chapter 7 for more information on the three circles of support**).
- *Helping children deal with grief and death,* which is a booklet about helping a child deal with the death of a loved one. It can be used by parents, families, care givers and others to help children in these situations.
- *Government grants for children,* which details the grants that are available and how to access them.
- *Keeping children safe and healthy at home*, which has a special section on caring for children who are HIV positive.
- *Keeping children in school,* which covers a child's right to schooling, what children need so that they can attend school, and problems like discrimination, with an emphasis on discrimination as a result of HIV/AIDS.

The Department of Health, has taken the lead in developing most HIV/AIDS related materials. Amongst the materials relevant for OVC are the following:

- *A guide for educators, entitled HIV/AIDS: Care and support of affected and infected learners*[35], to assist educators in their understanding of and in their dealings with infected and affected learners. The guide includes a template for a monthly report on learners with problems.
- *Curriculum for the training of community based home caregivers and Learner handbook for the training of home/community based caregivers*[36] – the H/CBC curriculum and learner handbook were developed to standardise the training of caregivers. On Day 44 there is a session on bereavement/ mourning/loss/grieving related to orphans (Module 6 – section B). Module 10 deals with social support for patients, families and children at risk. It also includes an "orphan co-ordination questionnaire" which provides for a comprehensive assessment of orphans or potential orphans.

The Department of Education has produced a range of materials that have a valuable role in supporting affected children, within the education sector, such as:

- *The HIV/AIDS Emergency – Guidelines for Educators*, which includes 8 key messages about prevention, and strategies for building an enabling environment and a culture of non-discrimination.

The bulk of their other materials deal with life skills and prevention.

The Department of Social Development has developed various resource materials to support the implementation of home/community-based care and support programmes, including:

- A manual on how to establish a home/community-based care and support programme. Trainers will be trained using the manual during 2003 in order to assist service providers.
- A manual on Child Care Forums, which aims to assist stakeholders in establishing Child Care Forums in their communities. As part of this process, 41 Child Care Forums have been established in communities where there are vulnerable and orphaned children.

The Department of Justice and Constitutional Development has also developed and distributed an excellent resource entitled:

- *These are your rights*, which describes, for children, the rights of South African children in the context of the UN Convention on the Rights of the Child[37]

NGO resources

- Soul City has a range of materials, which include basic information on HIV/AIDS, information on living positively with HIV and life skills materials, for children, parents and teachers. In mid-2003, the next series of Soul City will be broadcast, with a strong focus on OVC.
- Save the Children commissioned a number of studies in 2000/1 to advance the debate regarding OVC. Many of the products of these studies are useful, such as *Child HIV/AIDS Services*, which is a directory of organisations providing services for infected and affected children; and a trainer's handbook entitled *The rights of children and youth infected and affected by HIV/AIDS*, which can be used to train service providers on children's rights.
- Noreen Ramsden developed a handbook for people looking after orphaned children. Entitled *Community help for children living in an HIV+ world*, it provides information on applying for grants and includes a list of contacts and community-based resources[38].
- Lawyers for Human Rights are presently finalising a resource that sets out the policy and legal framework within which assistance can be provided to children in child-headed households. It is intended for use by those working closely with OVC, and affected families and communities[39].

Planned resources

There are likely to be a number of planned resources, but there is no ready source for this information.

- Ethical Guidelines for Children's Participation will be developed during 2003 to help protect children from harmful practices and encourage sound practices.

RECOMMENDATION #11

Create a database of resources and materials, conduct an assessment of needs and develop a prioritised list of required resources

Analysis of emerging trends in responses for OVC

There are indications that certain emphases are changing in relation to policies and programmes for OVC. These are welcome changes because:

- The past prevention focus is now supplemented by a recognition of the importance of treatment, care and support;
- There is less emphasis on services for so-called "AIDS orphans" with the understanding that there is little or no benefit in targeting services based on the cause of orphanhood or vulnerability;
- Similarly, there is a better balance between programmes for HIV infected children and those for OVC; and
- Donors are responding to these changes and agreeing to support projects that will benefit OVC.

(Footnotes)

[1] Department of Social Development; Annual report: April 2001 – March 2002 (2002)

[2] South African Law Commission; Review of the Child Care Act. Discussion Paper 103 (2002)

[3] See on under heading (National workshop on social security for children in South Africa in pg.39 Chapter 6) for details of the amendments to the CSG that were announced in the 2003/4 budget

[4] Copies of the report and of the draft Bill are available on www.law.wits.ac.za/salc/salc.html

[5] ChildrenFIRST; Vol.7, No.46 (2003)

[6] ChildrenFIRST; Vol.7, No.47 (2003)

[7] ChildrenFIRST; Vol.6, No.42 (2002)

[8] The National Health Bill is available on www.doh.gov.za

[9] Source: Gerntholtz, L; AIDS Law Project

[10] The definitions relating to rape have changed, with some implications for children, such as the inclusion of boys (as victims/survivors which was not previously the case)

[11] The Bill is available on www.pmg.org.za/bills/020808childjusticebill.htm

[12] ChildrenFIRST; Vol.6, No.45 (2002)

[13] ChildrenFIRST; Vol.6, No.44 (2002)

[14] Source: De Waal, J, Currie, I & Erasmus, G; The Bill of Rights Handbook (4th ed) (2001)

[15] Grootboom v Oostenberg & others 2000 (3) BCLR 277 (C)

[16] Department of Health; HIV/AIDS and STD strategic plan for South Africa 2000-2005 (2000)

[17] Khomanani; The National Integrated Plan (2002)

[18] Khomanani; Home- and community-based care and support (2002)

[19] IDASA Budget Brief No.127: What does Budget 2003/4 allocate for HIV/AIDS? (March 2003)

[20] PEP = Post exposure prophylaxis; PMTCT = Prevention of mother to child transmission; OIs = Opportunistic infections; STIs = Sexually transmitted infections

[21] Department of Social Development; National guidelines for social services to children infected and affected by HIV/AIDS (2002)

[22] Department of Social Development; Annual report: April 2001 – March 2002 (2002)

[23] The Minister of Social Development announced in his budget speech to parliament in March 2003, that more than 2.6 million children under 7 years had been registered for the CSG

[24] The President announced in his State of the Nation address that the CSG will ultimately be available to children up to the age of 14. In 2003, the age limit has been raised to 9, in 2004, it will be 10, and in 2005, it will be 14. Sources: Mail & Guardian (February 28 – March 6 2003) and budget vote speech of the Minister of Social Development (March 2003). This could result in an additional 3.2 million children receiving the CSG over the next 3 years

[25] Department of Social Development; Annual report: April 2001 – March 2002 (2002)

[26] The budget allocation for this programme has been increased from R592 million in 2002/3 to R809 million in 2003/4. Source: Mail & Guardian (February 28 – March 6 2003)

[27] ChildrenFIRST; Vol.7, No.47 (2003)

[28] Source: IDASA Budget Brief No.127: What does Budget 2003/4 allocate for HIV/AIDS? (March 2003)

[29] Sources: Mail & Guardian (February 28 – March 6, 2003) and budget speech of the Minister of Social Development (March 2003)

[30] Source: Budget speech of the Minister of Social Development (March 2003)

[31] The discussion document entitled *Towards a national child labour action programme for South Africa* is available on www.labour.gov.za

[32] Source: Department of Social Development (2001)

[33] See under heading (Child sexual abuse, pg.65 Chapter 9) for recommendations re improving services for children who have been sexually abused

[34] Information on progress on the Alternate Report is available from the Children's Rights Centre: info@childrensrightscentre.co.za

[35] Department of Health; HIV/AIDS: Care and support of affected and infected learners (2001)

[36] Department of Health; Curriculum for the training of community based home caregivers (2001) and Department of Health; Learner handbook for the training of home/community based caregivers (2001)

[37] Department of Justice and Constitutional Development; These are your rights (undated)

[38] ChildrenFIRST; Vol.6, No.43 (2002) Available from the Children's Rights Centre; Tel: 031 307 6075, e-mail: childrts@mweb.org.za

[39] Lawyers for Human Rights; Legal and policy framework: children growing up in child-headed households (draft) (2003)

Chapter Five
ROLE PLAYERS IN SOUTH AFRICA

In 2001, Save the Children and UNICEF supported a NACTT project to develop and disseminate a directory of organisations that provide services to children infected and/or affected by HIV/AIDS
(see www.childaidsservices.org)
This remains the most comprehensive resource of South African role players, however the following are selected key national organisations working in the field of children and HIV/AIDS, and are listed to serve as a ready reference.

The **National Programme of Action** or **NPA** is situated in the Office on the Status of the Child within the Office of the Presidency. This is intended to facilitate the involvement of all government departments and all sectors in civil society, in the vision to ***put children first***.

Contact: Tel: 012 337 5216 or 012 300 5200; e-mail: jabu@po.gov.za

The **National Action Committee for Children affected by HIV/AIDS**, or **NACCA**, is the reconstituted NACTT, a national forum established to ensure co-ordination between all stakeholders. Other objectives are to share information, promote active collaboration to improve services and programmes, ensure that research is conducted into pertinent issues, and conduct advocacy.

Save the Children supported NACTT until the end of 2002, when a permanent secretariat was established within the Department of Social Development.

Following the national conference for co-ordinated action for children affected by HIV/AIDS, NACCA was tasked to lead the process of developing action plans in each of seven strategic areas:

- Housing
- Education and recreation
- Food security
- Training and capacity building
- Database and communication
- Care and support
- Social security and placements

An eighth task team is responsible for cascading co-ordination from national to provincial level. Task team plans are due to be presented to NACCA early in 2003.

Contact: Abram Phahlamohlaka, Tel: 012 312-7876; e-mail: abramP@socdev.gov.za

ACESS or the **Alliance for Children's Entitlement to Social Security** is a civil society movement that was established in March 2001.
Contact: Tel: 021 761-0117; e-mail: patricia@acess.org.za

THE MOVEMENT'S VISION IS AS FOLLOWS:
We believe in a society that takes care of its vulnerable members, in a world where children do not suffer from hunger, abuse, cold, illness, or hardship.

We believe that all children should be able to benefit from a comprehensive social security system. The system must ensure children's survival and a standard of living adequate for their development. Furthermore it must create an environment that enables all children to enjoy their constitutional rights, especially the rights to equality, dignity, health, education, participation and protection from abuse and neglect.

There are three **national help lines** that provide 24-hour toll-free services:

- Child Line – 0800 055 555
- AIDS Helpline – 0800 012 322
- Circles of Support Hotline – 0860 222 777

The vision of the **Nelson Mandela Children's Fund**, **NMCF**, is to create a society that will nurture, motivate and care for children and youth. Established in 1994, the Fund had, by the end of 2001, supported almost 1 000 projects. The Goelema pilot programme seeks to improve the wellbeing of OVC through innovative community support and economic strengthening strategies in 10 sites in KwaZulu-Natal, Mpumalanga, Limpopo and Gauteng[1].

Contact: Malebo Mahape, Tel: 011 786-9140; e-mail: malebogo@nmcf.co.za

SABCOHA or the **South African Business Coalition on HIV/AIDS** provides HIV/AIDS related services, particularly information services, to private sector companies. SABCOHA has endorsed the Save the Children advocacy campaign to mobilise corporate support for affected children.

Contact: Tracey King,
Tel: 011 880-4821;
e-mail: tracey@sabcoha.co.za

The **South African National Council for Child Welfare** has been in existence for decades, established to protect and promote the development, safety and wellbeing of children, in partnership with its affiliates, associates and government.

Contact: Lynette Schreuder, Director: National Programmes,
Tel: 011 339-5741; e-mail:
schreuderl@childwelfaresa.org.za

SANAC – the **South African National AIDS Council** – is a high level body that advises government on all matters relating to HIV/AIDS. SANAC is chaired by the Deputy President and consists of representatives from 16 government departments and 16 civil society representatives. SANAC is assisted by technical task teams comprised of experts in various fields.

The South African National HIV/AIDS and TB Programme in the Department of Health was, until recently, the administrative arm of SANAC, however, this will change with SANAC's new status as a legal entity[2].

Contact: Tel: 012 312-0121

International organisations in the children's sector include:

- Save the Children (UK) – Tel: 012 341-1889
- Save the Children (Sweden) – Tel: 012 341-1166
- UNICEF – Tel: 012 338-5000
- Association François-Xavier Bagnoud – Tel: 011 728-0486
- Bristol-Myers Squibb: Secure the Future – Tel: 011 456-6400
- World Education – Tel: 011 339-7505

(Footnotes)

[1] NMCF; Sakha ikusasa; edition 2 (2002)

[2] Star; 3.02.03

Chapter Six
CONSULTATIONS, RESOLUTIONS AND RECOMMENDATIONS

A number of national and sectoral consultations have taken place between 2000 and 2002. The most important are listed below, with the key resolutions and recommendations that emerged.

National workshop on social security for children in South Africa (7-8 March 2001)

The aim of the workshop was to make recommendations for preferred options for a comprehensive social security system for children in South Africa. At the workshop, a civil society movement, the Alliance for Children's Entitlement to Social Security or ACESS was established.

Recommendations that emerged related to the CSG were to:

- Increase the age limit from 7 to 18 years and the value of the grant;
- Abolish means testing for the CSG and provide universal access;
- Improve access to CSG for children without primary care givers;
- Develop and strengthen NGOs, CBOs and community structures to access and administer the grants;
- Develop measures for children orphaned by HIV/AIDS and child-headed households to access grants immediately;
- Ring-fence amounts allocated to provinces for CSGs; and
- Improve administrative and service delivery systems to improve accessibility.

Longer-term transformational recommendations were to:

- Introduce a basic income grant for everyone – to improve the situation for the poor;
- Provide an additional amount and services for children with special needs; and
- Provide additional support and services through fee waivers and subsidisation schemes (health services, education, transport, housing and sanitation).

Protecting the right to innocence: conference on sexuality education (19-21 August 2001)[1]

The conference was convened in recognition of the importance of developing a nationwide programme to educate and guide the nation's youth around issues of sexuality. The Plan of Action includes 3 HIV/AIDS related objectives and a number of activities such as:

- Train teachers as first-level counsellors;
- Appoint school social workers to support learners and educators;
- Enforce the SA Schools Act relating to orphans, including exemption from school fees; and
- Establish a database of orphans and vulnerable children to inform responses.

National Children's Forum on HIV/AIDS (22-24 August 2001)[2]

Aged between 7 and 18 years of age, 90 children affected by HIV/AIDS met to discuss their experiences, and then to present the key issues to decision makers from national government and parliament.

The common issues were that:

- Many children are denied access to education because they are unable to pay their school fees;
- Many health care facilities are not child and youth friendly;
- Existing social security measures are not meeting the needs of poor children and their families;
- High levels of child sexual abuse have resulted in many children becoming infected with HIV;
- Stigma and discrimination associated with HIV/AIDS are key problems;
- Children caring for sick and dying parents struggle to cope;
- Many children are living without adult caregivers and are themselves taking on this role;
- Many children who have lost their biological parents are exploited and abused by their caregivers; and
- Children had both positive and negative experiences from churches, whilst many received support from NGOs and CBOs.

Workshop for Commissioners of Child Welfare (6-8 March 2002)[3]

The workshop was convened by the Department of Justice and Constitutional Development to assist magistrates to provide a better, more uniform service to protect children and give meaning to their rights.

The workshop goals were:

- To introduce the social context approach to judicial decision-making to judicial officers who work in the children's court;
- To raise awareness and sensitivity to the plight of children affected and infected by HIV/AIDS; and
- To identify problems existing in the children's courts with a particular focus on foster care placements, adoptions, other placements and the issue of child care grants.

Recommendations were that:

- A report should be compiled which clearly identifies the problems detailed by participants and proposes solutions for the short, medium and long-term.
- A discussion needs to be held on the implications of the Child Justice Bill for the Children's Courts.
- A training needs analysis should be undertaken which includes other family court staff.
- A specialised training programme should be developed for Children's Court Commissioners on the law and procedure which includes skills development eg how to conduct a children's court inquiry.
- Provincial training workshops should target all magistrates who work either solely as children's court commissioners or as relief commissioners.
- There is a need for networking and sharing of information. A newsletter, for example, could address this need.
- The formation of a working relationship at national, provincial and local level, which includes all the relevant role players such as Justice, Welfare and Health, could help identify coherent methods to address the problems identified at the workshop.

Save the Children dissemination workshop (13-14 March 2002)[4]

Save the Children convened a national workshop:

- To share and validate the results from various studies;
- To discuss the implications of the results for policies and programmes; and
- To identify any further steps that need to be taken.

The studies presented were:

- Children, HIV/AIDS and the law;
- Stigma and discrimination and how these increase the vulnerability of children;
- Awareness vs behaviour change;
- Child sexual abuse; and
- Mechanisms for identifying CINDI (children in distress).

Key findings and recommendations are included in the chapter on Research.

Conference on HIV/AIDS and the education sector (31 May-1 June 2002)[5]

The conference was organised in recognition of the fact that the education sector is under siege from HIV and AIDS, and the impact on learning institutions and sub-sectors can no longer be ignored.

The conference adopted a Declaration of Intent that contained the following resolutions:

- Accept wholeheartedly the mandate of making South Africa AIDS-free in and through the education sector;
- Maximise our efforts to prevent the further spread of the disease;
- Demonstrate care and support for those infected and affected by the disease, with special concern to provide support systems for orphans and other vulnerable children; and
- Mainstream HIV/AIDS in every aspect of our professional lives.

It was agreed that the means to achieve these resolutions would be through a multi-sectoral, non-sectarian education coalition against HIV/AIDS tasked to:

- Develop a Plan of Action for the education sector;
- Formulate guidelines to promote the functioning of the coalition at all levels throughout the country; and
- Monitor the implementation of priorities for action by sector partners.

Within the Plan of Action, Theme Two: Social support for affected learners and educators has the following strategic objectives:

S1 Provide support for learners and educators, including psychosocial support.

S2 Improve nutritional, health and medical services for orphans and other vulnerable children, young people and educators infected and affected by HIV/AIDS.

S3 Improve liaison among professionals in the social sector to help both educators and learners.

S4 Establish human rights codes in all learning institutions to create an ethos that re ects human rights, inclusion and acceptance.

S5 Under the umbrella of the human rights codes, practice zero tolerance of violence, harassment and sexual abuse in all learning institutions.

S6 Establish research priorities and commission investigations on issues related to behaviour change.

S7 Disseminate information.

S8 Monitor the implementation of interventions, application of codes and regulations, best practice, and collaboration procedures.

On a practical level, keeping children in school was recognised as a key goal. Strategies to achieve this will include:

- Enforcing the South African Schools Act that provides for exemptions from school fees for those whose parents cannot pay and for children who are orphaned;
- Investigating alternatives to school uniforms or finding funding for school uniforms for those who cannot afford them; and
- Working towards broadening access to the school nutrition programme.

A call to co-ordinated action for children affected by HIV/AIDS (2-5 June 2002)[6]

The Department of Social Development, in collaboration with the Nelson Mandela Children's Fund, convened a national consultation to create a common understanding of legislation and policy applying to the identification of children in need of services, accessing social grants and other services, alternative forms of care of the children and mechanisms for co-ordination at different levels and between different sectors.

The conference made seven recommendations:

Recommendation 1:

Establish a co-ordination structure (based on the model below)

Co-ordination Structure

Recommendation 2:
Engage in a national process for identifying orphans, vulnerable children and duty bearers, and create a database.

Recommendation 3:
Fast track the process for accessing social security grants.

Recommendation 4:
Establish how civil society (NGOs/CBOs/FBOs) can assist the Department of Social Development with social grants/assistance.

Recommendation 5:
Engage in a national process for creating awareness about services available to orphans and vulnerable children.

Recommendation 6:
Develop suggestions of how government can fast track the process for establishing home/community based care in communities that have insufficient or no existing models for care.

Recommendation 7:
Engage in a process for identifying and capacitating NGOs, CBOs, FBOs and CSOs that are involved in offering services to orphans and vulnerable children.

Shortly after the conference, Minister Skweyiya announced that R2 billion had been set aside for children eligible for grants such as CSGs.

Ford Foundation roundtable discussion: Understanding and preventing the sexual abuse of young children; next steps on the South African operational research agenda (22-23 August 2002)[7]

The Ford Foundation and the Child, Youth and Family Development Research Programme at the HRSC, convened a small meeting of key researchers, advocates and service providers to discuss and broaden understandings of the problem of child sexual abuse and to make recommendations on strategies to combat it.

Key issues identified were:

- The need for operational research to support programme activities, especially at community level.
- The importance of poverty and family dysfunction in the aetiology of child sexual abuse.
- The chronicity of the majority of cases of child sexual abuse, in which children are abused over several years before the abuse is detected.
- The existence of children who are markedly vulnerable, including dislocated children and disabled children.
- The emerging problem of the commercial sexual exploitation of children and child trafficking, including the commercialisation of child sexual abuse cases through corruption and bribes.
- The lack of national data, a lack of capacity for national data collection, and the need for standardisation in definitions of child sexual abuse for data collection.
- The importance of available databases for immediate analysis and integration.
- A need to document the failures and micro-successes in prosecution and protection in child abuse cases managed through the welfare and criminal justice systems.

South African home/community based care (H/CBC) conference (18-21 September 2002)[8]

The Department of Health convened a national HBC conference with the objectives to:

- Develop a coherent response;
- Agree on steps to scale up responses;
- Improve the involvement of PLWHAs; and
- Consolidate networking.

The preliminary resolutions recognised that the scope of H/CBC has broadened to encompass:

- VCT as the entry point to H/CBC; and
- Comprehensive care including palliative care, caring for carers, bereavement counselling and care for orphans and vulnerable children.

Other recommendations were:

- To mainstream HIV/AIDS within H/CBC.
- The private sector to provide support to community initiatives for workers beyond the workplace.
- To build a mentoring programme, which provides a support base to build the capacity of non-profit organisations to deliver quality services.
- To build an effective and efficient referral system by:
  - Creating a data base/directory of services of all local initiatives
  - Creating a better understanding of the reciprocal roles of health workers and traditional healers so that their benefits can be effectively utilised.
- To implement compulsory monitoring and evaluation systems, including management accountability systems and financial management for project funds.
- To involve PLWHAs in policy, planning and delivery of H/CBC services.
- To recognise that stigma and discrimination has an impact on the delivery of H/CBC and to adopt a rights-based approach in the provision of education and support to families who are infected and affected.
- To ensure that orphans and vulnerable children are an integral part of care initiatives within the H/CBC interventions.
- To make palliative care an essential component of training for all care givers, health workers and traditional healers.
- To identify 'Best Practice' in nutritional care and support and nutritional supplementation.
- To develop and integrate a programme of care and support for care givers.
- To develop a management policy and guidelines for volunteers, including selection criteria, recruitment, training guidelines, supervision and remuneration across all programmes and sectors.
- To encourage the involvement of men in the provision of H/CBC services.

RECOMMENDATION #12

Establish mechanisms to communicate conference results and resolutions to organisations operating at grassroots level

Analysis of conference resolutions and recommendations

Many of the resolutions and recommendations complement each other, and re ect the reality for the majority of orphans and vulnerable children.

The commonalities include, but are not restricted to:

- The importance of identifying OVC;
- Improving access to schooling;
- Addressing stigma and discrimination;
- Improving access to grants;
- Building capacity amongst care givers and other service providers to improve care and support for OVC;
- The need for guidelines on a range of topics;
- Strengthened partnerships and improved networking;
- The vulnerability of OVC to special risks, like child sexual abuse; and
- Establishing M&E systems.

RECOMMENDATION #13

Establish a high level process NACCA to monitor action owing from national conferences and consultations.

(Footnotes)

[1] Department of Education; Report of the Protecting the right to innocence: Conference on sexuality education (2001)

[2] University of Cape Town & the Children's Institute; National Children's Forum on HIV/AIDS: Workshop report (2001)

[3] Source: Workshop report

[4] Save the Children; Children affected by HIV/AIDS – Dissemination workshop report (2002)

[5] Department of Education; Conference on HIV/AIDS and the education sector; report and sector plan of action (2002)

[6] Source: Draft workshop report

[7] Ford Foundation; Report of the meeting on the sexual abuse of children younger than 12 years of age (2002)

[8] Source: procare e-mail forum

Chapter Seven
OTHER SIGNIFICANT INITIATIVES

A number of initiatives that are underway or planned have either direct or indirect implications for care and support for OVC. To illustrate this, examples of projects and programmes are given below, but it should be noted that their inclusion does not necessarily infer that they have any particular significance in comparison with other projects and programmes.

This chapter also covers selected **prevention** initiatives that have been introduced since 2000.

Circles of Support

The Circles of Support orphans and vulnerable children (OVC) campaign is a key component of the Moving the Nation to Act Campaign. This campaign aims to reduce discrimination and stigma towards orphans and vulnerable children and increase community support for OVC.

The campaign is built around the concept of a number of circles. The **first** circle implies help from family, neighbours and friends who can:

- Give food and clothes, if they are able;
- Care for the sick;
- Offer to cook a meal;
- Go shopping;
- Help with food gardens or in the fields;
- Look after children;
- Tell stories to children;
- Take a child to the clinic for immunisations or if they are sick;
- Accept and care for people living with HIV and AIDS;
- Make sure that others do not hurt or exploit vulnerable children;
- Listen to someone's problems; and
- Give help to people who are willing to offer foster care to children in need.

The **second** circle includes help from the community, particularly through the formation of a Circle of Support Group. "This could start with a few neighbours or it could grow into a big group. The aim is to develop a network of people who care for and work with children in some way. Together you can do so much more to meet the needs of children. Together you will be stronger and better able to fight stigma and discrimination against people with HIV and AIDS"[1].

The **third** circle involves resource people in the wider society, such as:

- Youth and church groups – who can help with caring for the sick, fighting stigma, and looking after children.
- Local AIDS support groups, like NAPWA – who can give emotional help, care for the sick and fight stigma.
- NGOs like Hospice, NICRO or Street Children's Forum – who can help children cope with sickness and death in the family. They could also help with abuse.
- Local businesses – that can sponsor food, clothes and things for school.
- Local leaders – who can help the community to fight discrimination.

- Women's groups – that can help with caring for children or sick people, and in family abuse situations.
- Teachers from local crèches – who can look out for children who are being cared for by their older brothers or sisters.
- Traditional Leaders – who can play an important role in decreasing stigma and discrimination.
- Home based care organisations – that can help to identify children in need. Sometimes they are able to provide gloves and other basics to help with caring for AIDS-sick people. They could also help with training of carers at home.
- Local Authorities – that may be able to help with funds.
- Local clinics and hospitals – that can identify children who have sick or dying parents and need help. They can also help with cleaning materials.
- Local Child Welfare Society – that can help children who are having a difficult time at home because they are abused or poor.
- Local social workers – who can counsel children who are unhappy or behaving badly.
- Caring teachers – who can keep an eye on children in need, refer them to social welfare or NGOs for help and organise a school feeding scheme.
- Representatives of the SA Police – who can help fight abuse or help children who are not supported by surviving parents.
- Department of Social Development – that has government grants for families most in need.

Almost all the above could help with getting grants: eg NGOs, local clinics and hospitals, local child welfare societies, para-legal organisations, community resource centres, local social workers, caring teachers and traditional leaders.

A Circles of Support hotline was established in September 2002, but to date has not been extensively used.

Grants empowerment campaign[2]

As part of President Mbeki's drive to ensure that all poor children are registered for poverty relief grants, Soul City and ACESS have joined forces with government on a grants empowerment campaign. Called ***Lend a Hand,*** the campaign runs from October 2002 until June 2003. The overall aim of the campaign is to increase the numbers of children that access grants by empowering communities, dealing effectively with obstacles and creating an enabling environment for optimal service delivery.

The following essential objectives have been identified:

- The creation of awareness for children, their care-givers and the public in general about accessing grants and social assistance, using popular media;
- The monitoring and evaluation of the uptake of grants and levels of social security delivery to inform advocacy strategy;
- Advocacy, education and training and support for agencies in the children's sector and those who deal with social security issues and grants;
- The strengthening of all ACESS partners by equipping them with information and skills to deal with grant and social security issues.

Workshops, with civil society were held in all provinces, and children were involved through the Soul Buddyz Clubs. Materials that have been developed as part of Soul City 6 and Soul Buddyz 2 also include a strong focus on grants.

The third phase of the grants campaign was designed to link up with the Soul City 6 radio launch and planned to take form of big "jamborees" (commencing in January 2003) in order to attract large numbers of people. The government identified nodal points (of extreme poverty) to be targeted as geographical areas of focus. The radio stations agreed to take the launches to these areas and broadcast the events live on all 9 language stations; further extending the reach of the Grants Empowerment Campaign messages.

RECOMMENDATION #14

Take action, beyond the campaign, to remove barriers to accessing grants, such as improving the services provided by the Department of Home Affairs

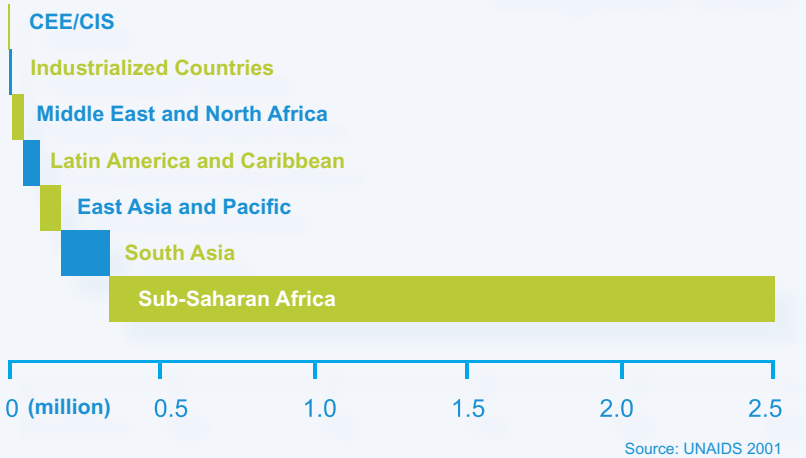
Prevention of mother to child transmission (PMTCT)[3]

Mother to child transmission (MTCT) of HIV through pregnancy, labour, delivery, or breastfeeding is responsible for over 90 per cent of HIV infections in infants and children under the age of 15. Already HIV/AIDS has begun to undermine the years of steady progress in child survival. The under 5 mortality rate is expected to increase by over 100% in the worst-affected areas by 2010. However, effective and feasible interventions to reduce mother to child transmission are now available and could save the lives of 400,000 children each year.

Pregnant women with HIV need voluntary and confidential counselling and testing, access to antiretroviral therapy, safe delivery practices, and guidance in selecting a suitable infant-feeding option in order to prevent mother to child transmission of HIV.

Over 2.5 million children were at risk for HIV infection through mother to child transmission in 2001. Without preventative interventions approximately 35% of infants born to HIV positive mothers contract the virus. Some 15-20% of infections occur in pregnancy, 50% occur during labour and delivery, while breastfeeding accounts for 33% of infant infections. Many HIV-infected women live in conditions which lack access to clean water and sanitation. This limits their ability to employ safe breast milk substitutes. The UN Interagency Task Team on mother to child transmission of HIV recommends that when replacement feeding is acceptable, feasible, affordable, sustainable and safe, HIV-infected mothers should avoid all breastfeeding. Otherwise exclusive breastfeeding is recommended during the new-born's first months of life.

Over 2.5 million children at risk of HIV infection through MTCT in 2001



Source: UNAIDS 2001

South African PMTCT pilots[4]

At the end of 2000, a decision was taken by the government to implement a pilot programme for the prevention of mother to child transmission (PMTCT) of HIV. This resulted in 2 pilot sites being selected per province for the implementation of a PMTCT protocol developed by the Department of Health. These 18 pilot or learning PMTCT sites, involving 193 health facilities, were established to improve the effectiveness and efficiency of PMTCT services, and to inform planned expansion of the programme.

The protocol stipulates that pregnant women who are 28 weeks or more in their gestation be given a tablet of nevirapine (NVP) for self-administration in the event of going into labour. In addition, obstetric practices that minimise the risk of vertical transmission of HIV must be practiced – such as avoiding the artificial rupture of membranes and instrumental or assisted vaginal deliveries, and minimising the duration of active labour. The babies of HIV positive mothers receive a dose of NVP suspension between 24 and 72 hours after delivery.

Findings from the first evaluation were that:

- 51% of pregnant women agree to be tested for HIV, with the testing uptake varying considerably from province to province.
- Of those women who agreed to be tested, about 30% were HIV positive.
- The correct administration of Nevirapine to both mother and child was only given to just under one third of pregnant HIV positive women.

Transmission rates in a pilot such as the South African one can be described as follows:

- In a sample of 100 HIV positive pregnant women who receive no PMTCT treatment:
  - 23 babies will be born HIV positive;
  - During 12 months of breast feeding, a further 8 will become infected;
  - There will be a total of 31 infected babies.
- In the same sample, where Nevirapine is administered, but mothers continue to breastfeed their babies:
  - 13 babies will be born HIV positive;
  - During 12 months of breast feeding, a further 9 will become infected;
  - There will be a total of 22 infected babies.
- In the same sample, where Nevirapine is administered and babies are given exclusive formula feeding:
  - 13 babies will be born HIV positive;
  - There will be no further infections;
  - There will be a total of 13 infected babies.

Whilst preventing HIV transmission to children is clearly an important intervention, other interventions that can have an impact are:

- Addressing child malnutrition and poverty;
- Improving immunisation coverage rates and the quality of primary level child health clinical care;
- Improving the care of children at home; and
- Improving maternal health outcomes and female literacy rates.

Keeping infected mothers alive

Maternal survival is a strong predictor of child survival. In studies presented at the International AIDS Conference in Barcelona in 2002, the risk of child mortality up to the age of 5 was shown to be five times higher for children whose mothers had died, than for those whose mothers were still alive[5]

At the Barcelona Conference[6], a $50 million programme was launched in 8 countries, including 3 sites in South Africa. Called PMTCT-Plus, the programme provides life-long treatment and care, including antiretroviral drugs, to infected mothers, their partners and infected children. The aim is to ensure the survival of parents after the births of their babies and the care and nurture of their children within their families.

Youth programmes

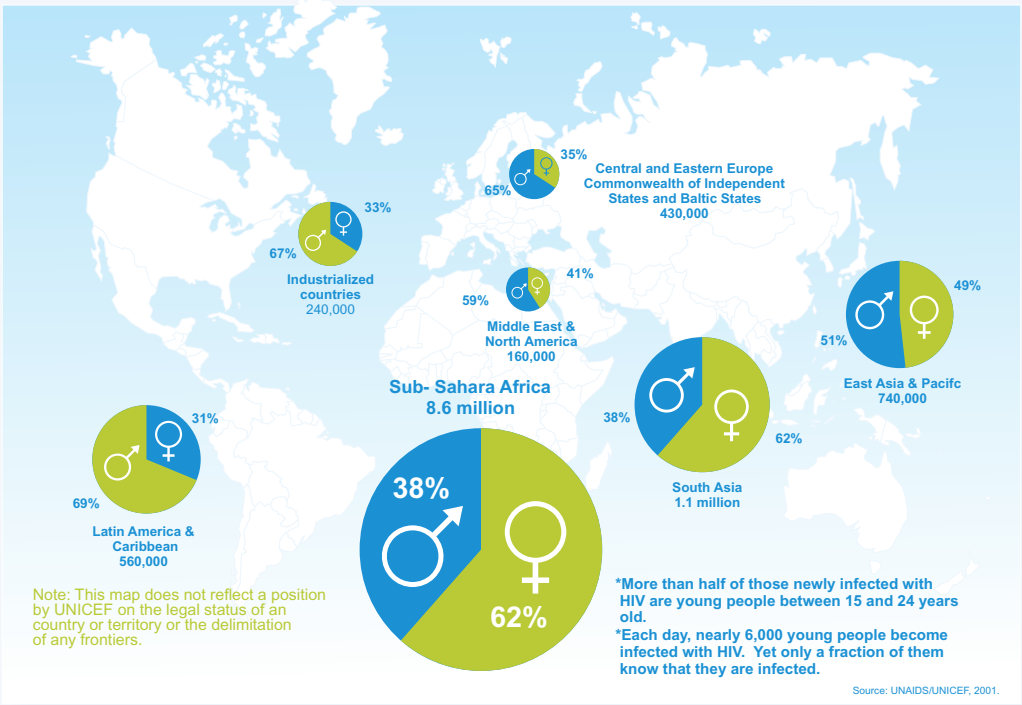
Young people and HIV/AIDS – globally

Young people are vulnerable to infection with HIV for a number of reasons including risky sexual behaviour, substance abuse, and lack of access to HIV/AIDS information and prevention services.

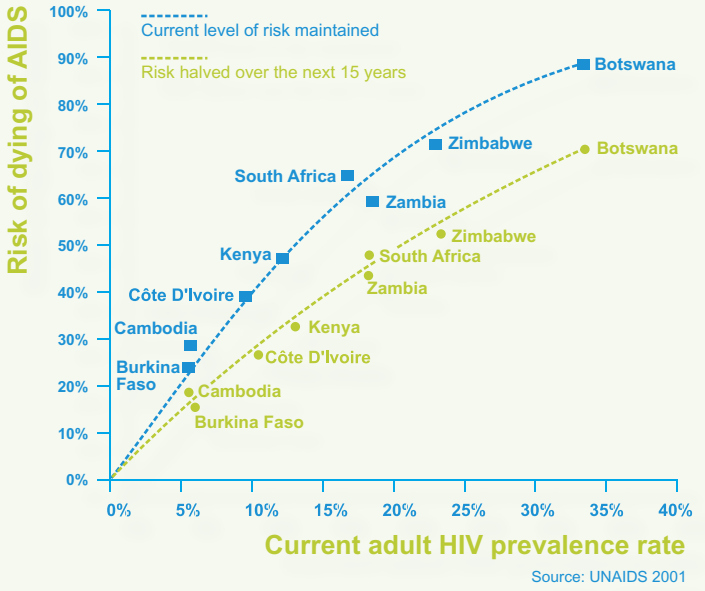
In developing countries, young women are particularly vulnerable, due to a multiplicity of social and economic factors.

Some adolescents become sexually active early, without the benefit of the necessary information, education, skills, and services to protect themselves from HIV. Programmes targeting young people often fail to acknowledge such early sexual activity. Sexual relations are often unplanned and sometimes coerced. Forced sex can result in the tearing of delicate genital tissue, thereby increasing the odds of acquiring HIV and other sexually transmitted infections. Young people exposed to sexual abuse and exploitation (including incest, rape, and forced prostitution) are especially vulnerable to HIV infection.

11.8 million young people (age 15-24) living with HIV/AIDS 7.3 million young women and 4.5 million young men



Lifetime risk of AIDS death for 15-year-old boys



Source: UNAIDS 2001

Even if prevention campaigns are very successful and the risk of HIV is drastically reduced, the proportion of young people who will die of AIDS is appallingly high in many countries: in virtually any country where 15% or more of all adults are currently infected with HIV, at least 35% of boys now aged 15 will die of AIDS.

Young people and HIV/AIDS in South Africa

A number of studies have investigated the knowledge, attitudes and practices of young people in South Africa.

The most recent is the HSRC study, which found that[7]:

- Only a few children aged 12-14 reported having had sex.
- In the age groups 15-24 similar proportions of males and females had had sex.
- Sexual experience amongst 15-24 years olds was significantly higher in informal urban areas.
- Partner turnover was not high, with 84% of youth reporting that they had had only one partner in the past year.
- Secondary abstinence – having had sex previously, but not having had sex in the previous 12 months was 23.1% in the 15-24 year age group.
- The perception that condoms were readily accessible was high at 90%. Condom use at last sexual intercourse was 57.1% (males) and 46.1% (females), amongst young people aged 15-24 years.
- Knowledge of key facts about HIV/AIDS is high, though some misconceptions remain regarding the virgin cure myth, and also whether HIV causes AIDS. Correct knowledge was also strongly associated with self-reported behaviour change.

Youth programmes – youth in-school

The youth in-school programme supports young people and helps them to develop the knowledge and skills to make responsible, positive choices, and to grow up healthy.

This is achieved through:

- Implementing life skills as part of the school curriculum for all learners in primary and secondary schools.
- Training teachers to use participatory techniques and a learner-centred approach.
- Working with parents, principals and community leaders to create a supportive environment for youth to act on what they have learned.

Implementation of life skills in secondary schools began in 1995, supported by a range of age-appropriate and youth-friendly educational materials.

Tirisano and the National Curriculum Statement mandate that information about HIV/AIDS and sexuality education must be integrated into the curriculum at all levels. The curriculum will impact basic HIV/AIDS information, but understanding that sexual responsibility ows out of self-esteem and self-knowledge and not just the acquisition of information, it will seek to provide students with the skills needed to gain such qualities.

EXTRACT FROM MANIFESTO ON VALUES, EDUCATION AND DEMOCRACY DEPARTMENT OF EDUCATION
August 2001

The focus of the life skills programme is on HIV prevention through the integration of life skills, HIV/AIDS and sexuality education across the curriculum. This is done mainly through:

- The training of teachers to enable them to teach the life skills programme;
- The training of peer educators (learner to learner);
- The provision of support materials to schools;
- Community-based life skills activities; and
- The establishment of nutrition, support and referral programmes for OVC.

Key achievements are[8]:

- 1 000 master trainers have been trained;
- 35 000 educators from Grades 1-12 have been trained;
- Learner support materials for Grades 1-12 have been developed;
- Peer education guidelines have been developed;
- Parent resource guides on communicating sexuality issues to their children have been developed and printed in all official languages;
- On-going advocacy and information workshops for School Governing Boards (SGBs) are being held;
- Partnerships have been established with loveLife, Soul City, Takalani-Sesame Street, youth structures and structures representing PLWHAs;
- Life skills co-ordinators have been appointed in all provinces; and
- A database of OVC is being established.

Youth programmes – youth out-of-school[9]

Young people out-of-school are reached through the South African AIDS Youth Programme (SAAYP). The SAAYP mobilises youth formations around HIV/AIDS, and has, as its vision, the development of a Youth Movement which actively participates in the fight against the epidemic.

In addition, specialised youth and adolescent health services are being strengthened within the primary health care system (including the management of STIs and VCT).

Mass media

The effective use of the mass media is a critical component of HIV/AIDS prevention. In South Africa there are three major programmes that utilise the national mass media platform for HIV/AIDS prevention. These are the Beyond Awareness II campaign, the multimedia edutainment programme, Soul City, and the youth programme loveLife.

Beyond Awareness II finished in October 2000 and subsequently the Department of Health commissioned a new consortium, the AIDS Action Team (ACT), to deliver the next phase of government HIV/AIDS communication.[10]

loveLife was launched in 1999. loveLife describes itself as a "deliberate departure from traditional approaches to HIV prevention, relying on a combination of commercial marketing and public health techniques to promote a new healthy lifestyle among 12-17 year old target group."

loveLife is a five year strategy designed to reduce the rate of HIV infection among 15-20 years olds by 50% in five years. loveLife combines high-powered media awareness and education with development of adolescent-friendly reproductive health services and other outreach and support programmes for hard to reach youth in poor communities.

The annual budget for loveLife is R150 million; R60 million is spent on their media component including television, radio, advertising and print media. Sixty percent of the total loveLife budget is spent on work that does not involve the mass media. Notably, loveLife promotes the establishment

of youth Y- centres (which operate as multi-functional lifestyle and health centres), support to the National Adolescent Friendly Clinic Initiative, and a school sports programme.

The planning behind loveLife's brand awareness has been extensive. Their aim has been to position the loveLife brand as part of youth culture. The key to loveLife's approach is to get young South Africans to talk about sex, sexuality and gender relations or "talk about it". The loveLife media campaign has concentrated on brand awareness and promotion through an initial teaser campaign designed to create intrigue to a clearer focus on sex and HIV.

The three objectives for the campaign in the first year were to:

- Initiate a national conversation about the loveLife brand and excite the popular imagination about loveLife;
- Guide this dialogue towards sex and specifically adolescent sexuality with an emphasis on inter-generational communication about sexuality; and
- Make explicit the link between sexual behaviour and HIV.

The start to the whole the campaign was a series of billboard teasers titled "Foreplay".

In Phase 2 of the campaign, the payoff line "Talk about it" was introduced and the youth sex talk show loveLife "JikaJika" launched, as well as the toll-free telephone help line.

In Phase 3, the second television series "S'camto" was ighted and billboard messages designed to shock complemented the series. The publication "The Impending Catastrophe" was widely distributed in the print media aiming to inform the broader South African public of the ramifications of the epidemic.

In the final phase of the first year's campaign, the link between behaviour and HIV was made more explicit by using the theme "The future ain't what it used to be". The print media was more targeted in this phase, challenging parents to talk to their children about sex. During this final phase the LoveTrain made stops in Cape Town, Durban and other smaller towns.

There are, however, many who continue to criticize the campaign for being obtuse and disjointed.

Programmes benefiting OVC

The scope of the rapid appraisal does not permit any attempt at comprehensive coverage of the many programmes that are supporting OVC, and affected families and communities. Readers seeking information on such programmes are referred to the programmes described in the original rapid appraisal[11].

Since 2000 other OVC programmes have emerged, such as **Goelama**, which is supported by the Nelson Mandela Children's Fund and **Heartbeat**, which is funded by a number of national and international funders.

Goelama is a project operating in 10 sites and based on a model that has been developed for orphaned children, as well as for children whose life situations predispose them to social vulnerability.

Contact: Ally Cassiem,
Tel: 011 786-9140;
website: www.mandela-children.org

Heartbeat operates in sites in Gauteng, the Free State, and North West Province. Providing support in the form of improved access to services, food security and psychosocial support, the project benefits about 5 000 children.

Contact:
Sanette Pienaar,
Tel: 012 807-4528;
e-mail: heartbeat@mweb.co.za

(Footnotes)

[1] Source: Draft campaign pamphlet

[2] Soul City; Grants awareness and empowerment campaign: briefing document (2002)

[3] http://www.avert.org

[4] HST; Interim findings on the national PMTCT pilot sites – lessons and recommendations (2002)

[5] AIDS Analysis Africa; Vol.13(2) (2002)

[6] MRC; AIDS Bulletin; Vol.11, No.3 (2002)

[7] HSRC, MRC, CADRE & ANRS; Nelson Mandela/HSRC study of HIV/AIDS: South African National HIV prevalence, behavioural risks and mass media – Household survey 2002 (2002)

[8] The NIP conditional grant for the life skills programme for the 2002/3 financial year was R142 000 000, of a total of R345 707 000 for Health, Education and Social Development.

[9] Khomanani; Youth programmes (2002)

[10] Coulson, N; Developments in the use of the mass media at the national level for HIV/AIDS prevention in South Africa (2002)

[11] Save the Children & NACTT; Children living with HIV/AIDS in South Africa – a rapid appraisal (2000)

Chapter Eight
PROGRESS TOWARDS ADDRESSING THE RECOMMENDATIONS OF THE 2000 RAPID APPRAISAL

The 2000 rapid appraisal of children living with HIV/AIDS in South Africa[1] made a number of recommendations, clustered under four headings, namely:

- First steps – immediate, short-term actions;
- Recommendations to improve the policy environment for action for affected children;
- Recommendations for planning and programming; and
- Capacity building recommendations.

One of the incentives for the development of the 2003 rapid appraisal was the need to "take stock" of progress or non-progress towards these recommendations. The following analysis seeks to do this, in many instances without attributing progress or non-progress to any agency, sector or initiative.

First steps

Identifying CINDI

Finding: The identification of orphans and other vulnerable children, when it is done, tends to be ad hoc.

Recommendation: There should be a standardised form and process for registering CINDI, and this process should, in turn, facilitate grant applications and allocations. Schools, clinics, churches and home-based care projects represent opportunities for the identification of OVC.

Progress: Research has been done in Eastern Cape (Bambisanani), Free State (St Nicholas) and Western Cape and Limpopo (Children's Institute). A framework for the identification, support and monitoring of children experiencing orphanhood has been developed.

One of the recommendations from the DSD national conference (June 2002) is to **engage in a national process for identifying orphans, vulnerable children and duty bearers, and create a database.**

A database of organisations working with and for children

Finding: Service providers in the children's sector identified the lack of knowledge of what is happening outside of their immediate area as a significant constraint to more effective action.

Recommendation: The compilation of a comprehensive database of who is doing what and where would greatly facilitate communication and collaboration.

Progress: The directory, **Child HIV/AIDS Services**[2] has been developed in electronic and printed format and widely distributed.

In 2001, the Department of Social Development commissioned a rapid appraisal of 466 home/community based care projects, 136 of which are receiving government funding.

Networks and co-ordination mechanisms

Finding: Networks and co-ordination mechanisms have advantages for the individual member organisations as well as enhancing overall, collective ability to deal with the problem.

Recommendation: A generic model of how a network can operate should be developed and training conducted with potential partners on how to initiate, construct, manage and sustain a network.

Progress: NACTT, now NACCA, is a national network that meets regularly.

One of the recommendations from the DSD national conference (June 2002) is **to establish co-ordination structures (replicating the NACCA structure) at provincial and local level**[3].

Non-progress: Training of partners throughout the country on how to initiate, construct, manage and sustain networks has not been done.

The policy environment

A policy framework

Finding: The lack of a policy framework on children and HIV/AIDS was identified as a barrier to effective co-ordinated action.

Recommendation: The national framework (the NSF) should be finalised, disseminated and actively promoted as the framework within which all sectors should develop and implement their initiatives.

Progress: Supplanting the NSF, the National Integrated Plan (NIP) was developed in a consultative manner and adopted by government as the framework for action and for funding[4]. It has a somewhat broader focus than children.

Poverty and AIDS

Finding: HIV/AIDS precipitates families into poverty and even into destitution.

Recommendation: Wherever possible, poverty alleviation programmes should work hand-in-hand with projects for children.

Non-progress: Some provinces are integrating HIV/AIDS into their Poverty Reduction Strategy Papers (PRSPs). However, there is no evidence that children's issues are adequately addressed in these processes, nor that poverty alleviation programmes are methodically incorporating children's issues into their planning and programmes.

Promoting a rights-based approach

Finding: Projects do not operate from a rights perspective and none have strategies to ensure child participation.

Recommendation: The best interests of the child should be a guiding principle in all projects. Training care givers and children in understanding children's rights should be included in all training programmes. Strategies for ensuring child participation should be an integral part of all programmes.

Progress: Resource documents and training modules have been developed, (commissioned by Save the Children) and trainers trained to be able to offer training on children, HIV/AIDS and the law. Reports have been received that the trainers who participated are indeed integrating rights training into their curricula.

Non-progress: Whether or not these initiatives translate into improvements in the lives of affected children is not known at this time.

Community mobilisation

Finding: There is universal agreement that effective responses to HIV/AIDS must be situated in and owned by affected communities. Yet the reality is that HIV/AIDS is impoverishing communities and unravelling families, the very structures that constitute communities.

Recommendation: Let communities identify their own concerns and what responses are possible with existing internal resources, knowledge, skills and talents. Then decide on priority needs and what outside capacity or resources are needed.

Progress: The Department of Social Development has developed a comprehensive Assessment Tool to monitor and evaluate projects and an analysis of this could provide some indication as to the effectiveness of community mobilisation.

Non-progress: Strategies to support families and communities are part of the NIP, but success stories are very localised and the situation for most affected families and communities is worsening rather than improving.

Discrimination and stigma

Finding: Stigma and discrimination associated with HIV/AIDS still constitute significant barriers to effective service delivery.

Recommendation: It requires debate and conscious decisions within projects, as well as deliberate actions to address instances of stigma and discrimination.

Progress: The understanding of stigma and discrimination has been advanced with the Save the Children studies and awareness of this has been enhanced with the focus on the issue at the dissemination workshop and other similar events.

Mr Mandela has made the issue of HIV/AIDS related stigma and discrimination his focus in 2002 and 2003. Similarly, it is central to the Circles of Support campaign.

Non-progress: Despite an improved understanding of the issue and a focus on challenging stigma and discrimination, improvements on the ground are not evident.

Plans and programmes

Home based care (HBC) as an access point

Finding: Few HBC projects are identifying or supporting affected children or orphans.

Recommendation: Every HBC project, at whatever stage, should also cater for affected and orphaned children, as an integral part of the programme.

Progress: The concept is implicit in the NIP – home/community based care and support extends to care and support for OVC. There is much informal evidence that HBC programmes are indeed expanding to cater for affected children.

Holistic care and support within a comprehensive continuum

Finding: Holistic care and support are concepts that apply to clients/patients, but not necessarily to affected children.

Recommendation: Care and support for affected children should encompass physical, emotional, spiritual and social needs. Each element should be defined within a continuum of prevention, care and support. This requires health-focused initiatives to consider a new expanded model and welfare-focused initiatives to do likewise.

Progress: There is evidence that those working in the field have accepted that HIV/AIDS responses cannot be neatly categorised as prevention or care, but that responsive projects must encompass elements across the prevention/care spectrum and that the spectrum includes support for affected children.

Planning for the future of children who will be orphaned

Finding: The stigma associated with disclosing an HIV diagnosis remains prevalent and results in many ill and dying parents choosing not to disclose their status to their care givers, families or children. This often results in a 'silence' about their impending death, which becomes a barrier to making plans for their children's future.

Recommendation: Using Memory Books or family conferences benefits both parents and children by creating a safe environment in which to talk about the future. On a very practical level, documents such as birth certificates can be located during such processes.

Progress: The Memory Book and family conferences to plan for the future of affected children are elements of some programmes.

Non-progress: The reality in most other contexts is that planning does not take place and this results in the common situations of grandmothers, who are left to care for children, battling to access social support.

Grants

Finding: Awareness of the availability of grants is limited, the process of applying for grants is fraught with difficulties and the processing of applications is protracted.

Recommendation: Understanding the processes and supporting families to access grants will greatly alleviate hardship and poverty. Projects should ensure that training incorporates modules on the relevant welfare legislation, and the criteria and processes which apply.

Progress: ACESS was established as an alliance with the aim to improve access for children to social security entitlements.

In 2002, the Minister of Social Development travelled to all Provinces to assess access to social services (focusing on children) and subsequently the **Lend a Hand** grants campaign was launched and is making progress in getting children registered for grants.

There are more and more success stories, and the number of children accessing CSGs is increasing dramatically, but access to grants remains an enormous challenge, particularly when it involves the Department of Home Affairs.

Planning guidelines and assistance for projects

Finding: Many projects arise as an emotional response to an observed need and are not based on adequate planning.

Recommendation: Proper planning, which anticipates the demands on the project, and the necessary expertise that will be required, would prevent many difficult situations from arising.

Progress: There is increasing evidence that projects benefit from training and technical assistance. Planning represents a specific challenge, as it is not an activity that has been well done in the past. Some assistance has been provided by organisations like the POLICY Project, and the National Departments of Social Development and Health do assist provinces to develop business plans for conditional grants. At NACTT meetings, however, representatives of the Department of Social Development often report that poor business plans are a consistent obstacle to transferring funds to the provinces.

Support for affected children

Finding: Affected children are generally neglected and services and resources for them (support groups, counselling, homework supervision, meals, income generating activities etc) are lacking.

Recommendation: Community-based projects should undertake a process to identify the specific needs of affected children, and then consider the feasibility of establishing centres from which to provide these.

Progress: Drop-in centres that offer a range of services for affected children seem to be accepted as a necessary part of a comprehensive community response to HIV/AIDS. However, the process of agreeing on the locations of such drop-in centres and the services that they should provide is a complex one involving intensive community consultation.

Capacity building

Supporting children as care givers

Finding: All projects report that children are caring for dying parents, yet, perhaps because it is so unacceptable a concept, little has been done to prepare them for this role or to support them in carrying it out.

Recommendation: Where there is no viable alternative, children must be prepared to care for their infected parents. They must be trained and resourced to do so, and provided with information on where to go for help.

Progress: Some of the CINDI Network partners in Pietermaritzburg have developed a home-based care course in isiZulu and a community child care training programme for project managers. The Nakekelisizwe Network in northern KwaZulu-Natal identified the need to develop training for foster parents. The Bambisanani Project in the Eastern Cape has trained social service providers (health, education, welfare, home affairs and local government) in issues related to OVC. In addition, they have identified the training of community child care committees as a critical need, for which funding is being sought.

However, training for children who are care givers and the sharing of training resources and experiences is not happening optimally.

Analysis of overall progress

Whilst progress is impressive in many areas, there are some key recommendations or aspects of recommendations that have been neglected, such as:

- The need for more efficient dissemination/sharing of information and resources;
- The absence or inadequacy of child-centred initiatives eg to build the capacity of children caring for parents;
- The challenge of capacity building of role players (eg to write business plans to access funds), in order to minimise barriers to effective service delivery;
- The need to invest in establishing and maintaining networks that can function to protect OVC;
- The importance of establishing a much stronger link between poverty and the vulnerability of children; and
- The missed opportunities to plan for the future of children, and the need to strengthen families and communities to do this more effectively.

RECOMMENDATION #15

Address the residual recommendations from the original rapid appraisal

(Footnotes)

[1] Save the Children & NACTT; Children living with HIV/AIDS in South Africa – a rapid appraisal (2000)

[2] www.childaidsservices.org

[3] See the approved structure in Chapter 6, pg.42 under heading - A call to co-ordinated action for children affected by HIV/AIDS (2-5 June 2002)6

[4] See information on the NIP in Chapter 4, pg.27 under heading - The National Integrated Plan for children infected and affected by HIV/AIDS (NIP)

Chapter Nine
RESEARCH

Research commissioned by Save the Children and funded by the Ford Foundation (2000-2002)

Save the Children received a grant to commission a range of studies to inform the debate around HIV/AIDS affected children and to address selected issues identified in the 2000 rapid appraisal. Some of the key findings and recommendations are presented below.

Stigma and discrimination and how this increases the vulnerability of children infected and affected by HIV/AIDS

- Children infected with and affected by HIV/AIDS are even more vulnerable than adults as they face the possibility of stigma relating to their own status as well as stigma owing from their parent's or caregiver's status.
- This stigma often continues even after the death of their caregiver, when they are rejected or treated with scorn by the extended family and the community. It forms part of wider denial of the HIV/AIDS epidemic. Children infected with and affected by HIV/AIDS too often form a constant reminder of the death of a parent or sibling: something that the community does not want to face and confront.
- Children and youth are protected against unfair discrimination both by the Constitution and the Equality Act, therefore neither the State nor any person may unfairly discriminate against children and youth.
- Despite this protection, affected children report being marginalised and isolated from other children, being teased and gossiped about, being presumed to also be HIV positive, and not receiving care.
- Discrimination is widespread in education, in access to appropriate alternative care, in health care and in access to social services. The law is therefore insufficient to protect affected children from stigma and discrimination.
- Responses to stigma and discrimination should include:
  - A legal and human rights response, based on law review and reform, increasing awareness of legal rights, as well as increasing and improving access to legal remedies; and
  - A broader programmatic response dealing with various other aspects relating to stigma and discrimination, such as community perceptions and awareness, knowledge of HIV transmission and knowledge of rights, access to health care services, and programmes to address vulnerability.
- Specific recommendations include:
  - Law reform;
  - Improving access to legal remedies and improving legal literacy; and
  - Community interventions that improve services for children.

Understanding the gap between awareness and behaviour change

- There is no national behavioural surveillance system in South Africa and there have been no comprehensive attempts at drawing conclusions from the many KABP studies that have been conducted.
- There are multiple factors that in uence behaviour change – awareness, social in uences and conventions. This means that prevention needs to target not only individuals and their immediate social environments, but also contextual factors that could provide support for behaviour change.
- Most of what has been achieved to date has been developed though mass media channels and, to a lesser extent, through organised sectors of society, such as health and education, both public and NGO. These responses have however been less than adequate.
- It is important not to offer solutions which society is unable to deliver, without simultaneously advocating and creating a context for such delivery.

HIV/AIDS affected children and the corporate sector

- Good corporate citizenship means engaging with children affected by HIV/AIDS because:
  - Children are producers of today as well as tomorrow;
  - Today's poor children are often tomorrow's poor parents;
  - Investing in children is investing in the future;
  - Richer children are the richest generation of young consumers;
  - Childhood is a once-off window of opportunity and development; and
  - Child poverty creates a drag on business growth.
- There is a solid business case for business to engage with affected children and youth.
- There are multiple entry points for corporate organisations at any point along a continuum of involvement with affected children and youth.

Child sexual abuse

Important research findings will shortly be released that will advance the understanding of the problem of child sexual abuse and some recommendations to improve services for children who have been abused.

A recent evaluation of medico-legal services for rape survivors in Gauteng was reported in the AIDS Bulletin (March 2002)[1]. The study, which focused on the availability, accessibility, quality, effectiveness and acceptability of services, identified concerns related to:

- Problems of access;
- Charges of insensitive treatment of rape survivors;
- Incompetent documentation of medico-legal evidence;
- Lack of human and financial resources;
- Inadequate training;
- Disparities across clinics; and
- Weak inter-sectoral collaboration.

Both structural and process recommendations were made, which were translated into a set of priority action steps at a workshop in September 2001. Although developed for Gauteng, and focusing primarily on adult survivors of sexual abuse, these findings, recommendations and action steps have much wider application.

The Gauteng findings are supported by the work of a task team set up in March 2000 by the National Directorate of Public Prosecutions, in collaboration with other government departments. From a review of rape statistics from 1996 to 2000 the task team's report presented findings that[2]:

- Only 7.7% of reported rapes in 2000 resulted in convictions;
- 40% of all reported rapes in South Africa are child rapes; and
- It can take up to 18 months for a rape case to be finalised.

Identification, support and monitoring of OVC

A framework has been developed to facilitate the identification, support and monitoring of orphans and other vulnerable children. The framework is intended to generate thought and discussion around the roles and responsibilities of different stakeholders in the identification, support and monitoring of vulnerable children, and to identify gaps in a service response within a given context. It may be applied at different levels, from, for example, exploring the roles and responsibilities of different stakeholders within a single school, to exploring roles and responsibilities within the whole of a school district.

This study is closely liked to the DoH commissioned study, which is reported below.

Essential elements for a quality service and cost effectiveness[3]

UNICEF commissioned a study by the Institute of Urban Primary Health Care (IUPHC) and the Health Economics and HIV/AIDS Research Division (HEARD) to describe and cost different models of care for orphans and vulnerable children. The essential elements (below) are a very useful way of discussing minimum standards.

ESSENTIAL ELEMENT

Food

- Nutritious and balanced diet with 3 meals a day as an absolute minimum.
- Involving children in the preparation and choice of food (which creates opportunities for participation and for teaching the child important life skills).

Clothing

- At least one change of clothing which offer protection against the elements.
- Nappies for infants.

Home environment

- Shelter against the elements and protection against environmental and other hazards.
- A personal and safe sleeping space which provides privacy for older children and protection for all children.
- Basic household amenities and cleanliness.
- Spare bedding.

Education/schooling

- Schooling from age 7 to 15 years even where there are no funds for school fees or a school uniform.
- Time to go to school and time and space to do homework.
- An adult caregiver or older child available to do homework with the child.
- Entrepreneurship skills training for older children to increase their capacity for self-sufficiency.

Hygiene/infection control

- Facilities for personal hygiene practices.
- Universal precaution materials and guidance where there is a risk of infection.
- Access to water and sanitation.

Treatment and health care

- Immunisation and recording in the Road to Health Card.
- Access to basic treatment and health care.
- Reliable caregiver to administer medicines, dietary supplements and home remedies as directed.
- Reliable caregiver who is aware of and can respond to indications of illness and needs for basic first aid.

Protection

- Against discrimination, stigmatisation, abuse and neglect.
- Arrangements for the care of the child before the parent dies, including drawing up a will, nominating a legal guardian for the child and stipulating the child's inheritance.
- A caring, constant and reliable adult presence to whom the child can disclose abuse, and who can access help for the child.
- Healthy discipline practices including setting rules and limits.

Affection

- A caring, constant and reliable adult presence who offers security and continuity and with whom the child can communicate openly.
- An adult caregiver with a positive communication style which includes "being there" for the child, taking time to listen and communicate at the child's level.

Identity

- Birth registration.
- Retaining and respecting the child's name, kinship and identity.
- Capturing memories for the child such as photos, artefacts, details of significant others and cultural connections.
- Acknowledging the individuality of the child, for example celebration of birthdays.

Participation

- Adult caregivers who discuss care plans with the child and get their contribution to these plans.
- Opportunities for children to participate in all decisions affecting their lives.
- Decision-making that involves the child around their care plan and that provides a sense of security and protection as well as a sense of future.

Understanding, information and communication

- Training for children in basic survival skills and life skills.
- Caregivers who are able to communicate, at least on a basic level, with children in the language of their community of origin (to foster a sense of belonging, cultural connection and identity for the child).
- Information and open communication with children about their own health status if HIV positive.
- Information and open communication with children on health issues, including sexuality and relationships.

Counselling/supportive services

- Support and guidance for children who are experiencing social and emotional difficulties. Where caregivers are unable to do this, access to appropriate assistance.
- Open communication with children about death, of a parent, family member, friend or their own death and emotional and spiritual support.
- After-death services including transport of body to mortuary and a dignified burial.

Recreation/leisure

- Balance between household chores, recreation and leisure time.
- Time to play and be able to be children.

Freedom of expression

- The time and opportunities to question and discuss values, ethics and morals and to be able to freely seek information and express their ideas.

Guidelines for health and social services for addressing the needs of children experiencing orphanhood as a result of HIV/AIDS

The Department of Health commissioned the Children's Institute to develop guidelines containing recommendations for health, social development and education services to address the needs of children who have been orphaned and who are at risk of being orphaned in the near future.

The guidelines will be available during the course of 2003. The following key recommendations were refined during a consultative process with government and are due to be approved (or amended shortly)[4]:

Putting children first

Policy, programme and financing decisions should all bear witness to the South African government's commitment to Putting Children First, re ected in South Africa's ratification of the United Nation's Convention on the Rights of the Child and the vision of the South African National Programme of Action for Children, housed in the Office of the President.

Orphanhood within the context of other childhood vulnerabilities

A response to the needs of children who have been orphaned and who are living with terminally ill adults should be integrated into a service response to the needs of all vulnerable children in South Africa, and in particular into a response to address widespread poverty.

Defining orphanhood

A critical shift in the conceptual thinking around the category of children called 'orphans' is required.

Services need to respond to a broader and more nuanced category of children, i.e. children *whose care is compromised* as a result of the terminal illness and/or death of an adult who contributes to the care and/or financial support of the child. At the current stage of the pandemic in South Africa, more attention should be paid in particular to supporting children in the care of and caring for sick adults, i.e. children who are at immediate risk of being orphaned.

Preventing orphanhood

The most effective way of reducing the burden of increasing numbers of orphans on services is by providing treatment and support to HIV-positive caregivers, to enable them to care for their children for as long as possible and to prevent further orphanhood and vulnerability in South Africa.

Addressing orphanhood within the context of poverty in South Africa

Within the context of poverty, the recommendations is against directing support to children on the basis of their orphan status, to the exclusion of other children in need.

Central to effectively addressing the needs of orphans and children at risk of being orphaned is the strengthening of national poverty reduction strategies. The immediate extension of the age of eligibility for the child support grant to 18 years as the first step towards the progressive realisation of broader poverty alleviation measures such as a basic income grant is recommended.

In addition to direct cash transfers in the form of a grant, indirect benefits should included as part of a 'basic package of services and support' for all children, including orphans and children at risk of being orphaned.

The package should be weighted towards the provision of services and support that are of *direct benefit to the child* - such as exemption from payment of school fees, feeding schemes for children and free primary, secondary and tertiary health care.

Until such time as this 'package' of direct and indirect benefits is available to *all* children in South Africa, it is recommended that the package be provided - with immediate effect - to the most vulnerable children, determined on the basis of a needs assessment.

Indicators of vulnerability linked to orphanhood would be included in such a needs assessment, but not to the exclusion of other indicators of vulnerability such as those related to poverty.

In most instances the motivation for foster care applications by caregivers of orphans and other vulnerable children in the context of HIV/AIDS, is poverty-related. The motivation is fuelled in part by the lack of alternative poverty alleviation mechanisms and the large discrepancy between the amounts of the foster care grant and the child support grant.

The researchers recommend against the use of foster care grants to address the poverty-related needs of OVC, and argue that money be allocated instead to addressing poverty through more accessible poverty alleviation mechanisms such as those mentioned above.

The use of the foster care grant as a poverty alleviation mechanism will create more bottlenecks in an already overburdened system and detract from the very real purpose the foster care system serves in the protection of particularly vulnerable children, including some children experiencing orphanhood.

In response to the urgent need to address hunger, a national food security programme is recommended. The programme should include strategies for strengthening existing programmes as well as developing new ones – to ensure comprehensive, accessible and sustainable food security for all children, including orphans and other vulnerable children in the context of HIV/AIDS.

Orphanhood as a result of AIDS

Children orphaned by AIDS should not be seen or treated as a separate group of children to those experiencing orphanhood due to other causes.

The silence that surrounds HIV/AIDS as a result of stigma and discrimination prevents effective service access and delivery and needs to be urgently addressed.

The special needs of HIV-positive orphans should be recognised and addressed through, for example, the extension of the care dependency grant to include children with special needs as a result of HIV, through the provision of more accessible health care and basic nutrition, through the provision of palliative care facilities for terminally ill children, and through fast tracking the inclusion of recommendations for the treatment and care of HIV-positive children in the IMCI guidelines and training.

Supporting care arrangements for orphans and other vulnerable children in the context of HIV/AIDS

Responsibility for the care of orphans and other vulnerable children cannot be borne by poor households and communities in the absence of adequate support. Community development and the implementation of tangible household support mechanisms are crucial for the support of children experiencing orphanhood and other vulnerable children.

Models of care for OVC should be viewed as a nest of options rather than a hierarchy, and mechanisms for supporting the full range of care options need to be put in place.

The existence of households in which children live alone or with young adult siblings and households with sick adults, in which children are assuming care and support responsibilities, are inevitable. These care arrangements need to be recognised and supported appropriately and allowances need to be made within services and through social grants, to accommodate these children.

Support for the elderly is a crucial component of a service response to the needs of orphans and other vulnerable children in the context of HIV/AIDS.

It is recognised that in certain contexts there is a role for residential care facilities for children, particularly in the form of small group homes (*ie* caregiver/s caring for small groups of children within households*)* situated within communities. However, institutionalisation of children should be avoided as far as is possible within the best interests of the child.

Strengthening service access and delivery

The researchers strongly support broad initiatives to increase resource allocation to the social sector, as well as other existing efforts to address problems within primary level health care services, education and social service delivery. Improvements to basic services will directly benefit children who are experiencing orphanhood.

The Departments of Health, Education and Social Development should strive to ensure that the environments within services do not in themselves contribute to children's vulnerability, particularly those children without adult caregivers in a position to negotiate on their behalf.

A national response to the needs of orphans and other vulnerable children should be integrated into, supplement, and contribute to the improvement of mainstream health, education and social development services. The costs involved in integrating activities could be minimised by focusing on the roles that service providers are best placed to fulfil.

The research suggests that, with adequate support and good collaboration, schools are ideally placed to act as vehicles through which many of the health and social needs of children can be addressed.

Home- and community-based care models should be developed further and scaled up as a response to the needs of sick adults as well as children experiencing orphanhood, and as a bridge between households and other services.

The capacity of social workers on the ground needs to be greatly strengthened and supplemented to accommodate the increasing demand for social development services from caregivers, and the counselling and support needs of orphans and other vulnerable children.

More substantial, sustainable and accessible financial and professional support should be provided to non-governmental, community-based and faith-based organisations currently shouldering much of the burden of care and support for OVC in South Africa.

Training, support and supervision of health workers, social workers, educators, staff of non-governmental organisations and community lay workers should be prioritised in order to give maximum effect to existing policies and programmes and to recognise and begin to address the impact of HIV/AIDS on the professional and personal lives of service providers.

Child participation

In any decisions affecting a child, the opinion of that child should be heard and considered. In particular, children should be provided with the opportunity to contribute meaningfully to discussions regarding where and with whom they will live and what they believe to be in their own best interests.

It is crucial for effective, appropriate policy-making and programme planning and implementation that opportunities be created for the participation of children at every stage in the process.

Children have a role to play in addressing the needs of orphans and other vulnerable children in the context of HIV/AIDS. Opportunities should be sought within services and schools to accommodate children as peer educators, supporters, and counsellors.

Commitment and collaboration towards implementation

The co-operation and committed involvement of all government departments is core to a successful policy and programming intervention to address the needs of children experiencing orphanhood in South Africa. There is a need to move beyond the emphasis on social sector responsibility, to include broader partnerships, including Home Affairs, Labour, Agriculture, Housing, Water Affairs, Justice and the business sector.

In particular, role clarification and improved collaboration and co-ordination is needed between the Departments of Health, Education and Social Development. Several policies and programmes within the three departments relate directly or indirectly to OVC. The full potential of many of these policies and programmes remain unrealised, partly as a result of insufficient collaboration.

The Department of Provincial and Local Government needs to be involved in planning and instituting the implementation of strategies to address the needs of orphans and other vulnerable children. Children's issues in general (including OVC) should be integrated into the current review of the Integrated Development Plans (IDP) as an aspect of all programmes and budgets.

Survey of affected and infected children

The Department of Social Development, in partnership with UNICEF, initiated a research project at the end of 2002, regarding children affected and infected by HIV/AIDS, which includes a comprehensive survey on the situation of children in three provinces, namely KwaZulu-Natal, Eastern Cape and Limpopo[5].

Testing an HIV vaccine on children

There is interest in considering the issues involved in testing HIV vaccines on minors – as they are at high of HIV infection, but there are many ethical, legal and scientific considerations. Preliminary work to spell out these issues will begin in 2003, co-ordinated by the South African AIDS Vaccine Initiative (SAAVI). The MRC ethical guidelines on the issue will be produced in the first quarter of 2003.

Mapping the OVC situation

The first province in South Africa has embarked on a process to develop a database of OVC. A study in KwaZulu-Natal, due to be completed in mid-2004 will provide a dramatically improved means of identifying, locating, mapping and tracking children in need of support and care. It will also provide the basis on which organisations and departments can design interventions and strategies to reach these children, provide and care for them and devise some means to maintain contact with them. It is hoped that it may lead to a system to track orphans and vulnerable children and add value to the role and function of the Department of Social Development, whose role it is in the first instance to provide for these young people[6].

Research related to the living conditions of groups that qualify for social grants

The Directorate Monitoring, Evaluation and Audit, within the Department of Social Development, commissioned the School of Development Studies at the University of Natal in Durban to develop an annotated bibliography of recent research relating to the living conditions of the main target groups of social security grants in South Africa[7]. The Directorate is responsible for the monitoring and evaluation of government's social security programme, and has identified that of the critical elements to monitor is the socio-economic impact of social security policies and strategies on the lives of beneficiaries. The Directorate aims to assess whether the implementation of social security policies and strategies is having the desired developmental impact in the longer term, and specifically the extent to which social security reaches the most vulnerable groups and how it impacts on them, how accessible and cost effective social security is for beneficiaries and for the Department, and how it is aligned with constitutional and international obligations, as well as the effectiveness and efficiency of social security delivery systems at a macro level.

A study into the situation and special needs of children in child-headed households

A study, commissioned by the Nelson Mandela Children's Fund (NMCF)[8], looks at the status and needs of orphans living in child-headed households, particularly those orphaned by HIV/AIDS, and assesses the support systems available to them. The research was conducted in Gauteng, Northern Province, Mpumulanga, and KwaZulu-Natal. The priority needs of child-headed households were found to be food, clothing and education, followed by emotional support and guidance. Stigmatisation by the community towards households headed by "AIDS orphans" was found to lead to isolation and neglect. Although the extended family structure is still widespread and absorbs many orphans, it is also apparent from the study that the burden of support is becoming increasingly difficult and that families cannot cope with additional costs. As a result, older children often drop out of school in order to support siblings. Many of the children interviewed, particularly those in rural areas, were not aware of the grant system, and social welfare services were considered difficult to access due to red tape.

Survey of households impacted by HIV/AIDS in South Africa[9]

The aim of the study was to document the impact that HIV/AIDS is having on households, and the ability and resources available to households to respond to this illness, in South Africa. The objectives of the study were to describe a stratified sample of households affected by members with HIV/AIDS, and those that have died of AIDS, in terms of their perceived needs for care and support; household access to income and resources and the way finances are allocated within the household; food security and nutrition; coping mechanisms to deal with increasing financial demand caused by HIV/AIDS and other challenges; any changes in school enrolment of children in the household; support from informal community social networks; and support from health and welfare services and NGOs/CBOs.

Clear policy and planning implications that arose from the study include:

- The need to expand and extend the grants to support poor adults and children;
- Many of these households need nutritional support, and ways need to be found to expedite this;
- There needs to be strong multi-sectoral approach to the issue of care and support for orphans;
- Health services need to plan for an increased number of AIDS cases, and health workers need more training and support; and
- There continues to be a need to fight stigma and discrimination, through high profile commitment on this issue, and the creative use of media to communicate messages that destigmatise this disease.

Rapid appraisal of HBC projects[10]

In 2001, the Departments of Health and Social Development identified the need to audit all home/community-based care (H/CBC) projects by means of a questionnaire tool.

Key findings include:

- The bulk of child-headed households were reported in KwaZulu-Natal – 4 570 of the total number of 7 456 reported. This information should however be treated with circumspection, as many respondents did not complete this question. It is also not comparable with the last census estimates of child-headed households.

The database will be updated annually.

RECOMMENDATION #16

Communicate research results upwards – to policy makers – and downwards – to service providers

Remaining research questions

The 2000 rapid appraisal noted that although significant amounts of research are being undertaken, there is no clearly defined research agenda guiding this. This has not changed in the last two years, and remains an area that requires attention.

RECOMMENDATION #17

Define an OVC research agenda, based on gaps, and informed by completed and planned research

Note:

A meeting on 30 May 2003, hosted by the University of the Western Cape, will begin this process.

(Footnotes)

[1] AIDS Bulletin; Vol.11, No.1 (2002)

[2] Source: Mail & Guardian (15-21 November 2002)

[3] Loening-Voysey, H & Wilson, T; Approaches to Caring for HIV/AIDS Orphans and Vulnerable Children: Essential Elements for a Quality Service (Draft) (2000)

[4] Giese, Meintjes, Croke and Chamberlain, (2003) Contact the Children's Institute for a copy of the final recommendations, Tel: (021) 685-4103

[5] The results will be available in due course

[6] Source: To develop a spatial framework for the management of support to orphans and vulnerable children in KwaZulu/Natal: Extract from the TOR (2002)

[7] Hunter, N & Rushby, J; Annotated bibliography of recent research on the living conditions of the main target groups of social security grants: Research report No.53 (2002)

[8] NMCF; A study into the situation and special needs of children in child-headed households (2001)

[9] Abt Associates; Survey of households impacted by HIV/AIDS in South Africa – what are the priorities? (2002)

[10] Available on http://population.pwv.gov.za

Chapter Ten
RECOMMENDATIONS

Let us all work for the strengthening of our families and communities to enable our children to grow up in a healthy, caring and safe environment. A happy child brings about a happy family, a happy community and a happy society.

MINISTER OF SOCIAL DEVELOPMENT
BUDGET VOTE SPEECH TO THE NATIONAL ASSEMBLY
March 2003

The following recommendations, defined during the development of the rapid appraisal are proposed to scale up and strengthen OVC responses in South Africa.

RECOMMENDATION #1:
Develop agreed understandings – at policy and community level – of **vulnerability.**

Orphanhood is not necessarily synonymous with vulnerability. We need to develop a common understanding of the concept of vulnerability, as well as agreeing on processes to define criteria of vulnerability in different local contexts.

RECOMMENDATION #2:
Define **"orphan"** and agree on national orphan statistics – current and predicted future scenarios.

Using different definitions of "an orphan" leads to different estimations of the problem, and creates confusion, particularly at a strategic level, where estimates and predictions are important planning inputs. We need a single set of figures that describes the situation now and predicts it in the future. We also need agreement on the important variables to be disaggregated in the data, such as age and gender.

RECOMMENDATION #3:
Create two-way communication between international, regional and national conferences and strategy and planning processes in SA.

The principles, frameworks and global guidelines exist, yet there is a gap between those and what happens at country level. We need to formalise a process to review these principles, frameworks and guidelines, and then to adopt or amend them for the South African context. We also need a mechanism to track their implementation.

RECOMMENDATION #4:
Publicise the OVC commitments made by South Africa and its neighbours at regional meetings and establish a SADC process to track progress on these commitments.

Targets, such as the UNGASS targets, are indeed being reported on in various forums by countries that adopted them. However, there is little critical review and documentation of progress towards these targets. We need a regional peer review process to address this.

RECOMMENDATION #5:
Define the elements of a successful national OVC response, and generate a process to put these elements in place.

Certain critical elements of a successful national OVC response have not been addressed, which

compromises the rest of the South African response. We need to define a comprehensive response, based on our experiences, as well as the collective experiences of other countries, and then institute a process to implement **all** the critical elements.

RECOMMENDATION #6:
Wherever appropriate ensure that children in general and OVC in particular are considered in all legislative processes.

It is an opportunity lost if the special needs of OVC and the present and potential future impact of the HIV/AIDS epidemic are not considered in legislative processes. We need on-going advocacy to ensure that this happens.

RECOMMENDATION #7:
Advocacy efforts should continue until reports are adopted and legislation promulgated, and even beyond to ensure effective implementation.

The gap between policy development and practical implementation is recognised as a reality in many countries. We need to develop our advocacy strategies in light of this reality and extend our advocacy activities into the implementation phase.

RECOMMENDATION #8:
Create a mechanism to inform stakeholders of NIP targets and progress.

The NIP has the potential to create a co-ordinated, synergistic response which is unique and deserves support. However, to do this effectively, we need easily accessible sources of regularly updated information on NIP targets and progress.

RECOMMENDATION #9:
Ensure that VCT guidelines for children are developed and implemented without delay.

VCT is an important intervention in the HIV/AIDS continuum of prevention and care. We recognise, however that there are special situations that apply to children and VCT, situations which need to be clearly articulated in national guidelines.

RECOMMENDATION #10:
Ensure that OVC and HIV/AIDS are prominent in both the UN CRC Country Report and the Complementary Report.

OVC and HIV/AIDS often "slip off' the agenda of national processes like UN reports. We should ensure that advocacy maintains OVC and HIV/AIDS as priority issues, amongst all the other issues, and that these are accurately re ected in as many reports and publications as possible.

RECOMMENDATION #11:
Create a database of resources and materials, conduct an assessment of needs and develop a prioritised list of required resources.

There is a fair amount of information and a good selection of materials and resources available that can be used in support of OVC projects. There is however no central database of this, which means that most practitioners remain unaware of helpful resources that they could use. We need a well disseminated, user-friendly database of existing materials, and then a regular process of defining gaps, and taking action to fill these gaps.

RECOMMENDATION #12:
Establish mechanisms to communicate conference results and resolutions to organisations operating at grassroots level.

Most grassroots organisations are not represented at national conferences, yet implementation of the resolutions taken at national conferences relies on these same organisations. We need to establish effective communication mechanisms with NGOs, CBOs, FBOs

and service providers to ensure that conference results and resolutions are be translated into practical reality on the ground.

RECOMMENDATION #13:
Establish a high level process, within NACCA, to monitor action owing from national conferences and consultations.

2001 and 2002 saw a number of pivotal conferences taking place, each of which generated many very important resolutions and/or actions. Apart from the formation of task teams, responsible for taking some elements of the work forward, we need a national structure and an approved process that will link the outcomes of the various conferences and ensure that progress takes place as synergistically as possible.

RECOMMENDATION #14:
Take action, beyond the grants campaign, to remove barriers to accessing grants, such as improving the services provided by the Department of Home Affairs.

There is much to celebrate in terms of improvements in accessing grants. However, we should not underestimate the remaining barriers to access, particularly by poor families and particularly in relation to procedural barriers, such as obtaining the necessary documentation to apply for grants.

RECOMMENDATION #15:
Address the residual recommendations from the original rapid appraisal, particularly that:

- Wherever possible poverty alleviation programmes should work hand in hand with projects for children.
- The best interests of the child should be a guiding principle in all projects.
- Training care givers and children in understanding children's rights should be included in all training programmes.
- Strategies for ensuring child participation should be an integral part of all programmes.
- Planning for the future of children who are likely to be orphaned. Using memory books or family conferences benefits both parents and children by creating a safe environment in which to talk about the future. On a very practical level, documents such as birth certificates can be located during such processes.

RECOMMENDATION #16:
Communicate research results upwards – to policy makers – and downwards – to service providers

Too often research results remain within the purview of researchers. We need, to a much greater extent, to be guided by research, and to develop practical applications of research to inform policies and programmes.

RECOMMENDATION #17:
Define an OVC research agenda, based on gaps, and informed by completed and planned research.

Vast amounts of research have been conducted, which has value in terms of advancing the debate around OVC and informing projects and programmes. However, decisions to research a specific issue are often not made linked to an accepted research framework. We need an inclusive process that will generate a common research agenda, based on real information needs and gaps.

The final two recommendations are not specifically drawn from the 2003 rapid appraisal. Rather they are additional issues that are considered to be important.

RECOMMENDATION #18:
Conduct high-level advocacy on important OVC issues.

In most instances the voices of orphans and vulnerable children are not heard, and it is up to others to advocate on their behalf. The following are recommended areas where advocacy is required, to ensure an appropriate focus on OVC:

- Integrate issues related to OVC into poverty reduction planning and programming;
- Scale up and roll out appropriate responses/models of care and support;
- Promote corporate engagement with OVC; and
- Maintain a public focus on the crime of child sexual abuse.

RECOMMENDATION #19:
Strengthen specific aspects of programmes.

These are still many lessons to be learned. At a programmatic level, there are opportunities to:

- Develop models of partnership to benefit OVC;
- Generate common understandings about holistic care and support;
- Emphasize the importance of psychosocial support for affected children;
- Provide appropriate and sustained support for the care givers and service providers; and
- Develop and test indicators to be used to monitor and evaluate programmes.

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Contacts

Alison Hickey, IDASA
Ann Strode, HIV/AIDS and human rights consultant
Heidi van Rooyen, School of Psychology, University of Natal (Pietermaritzburg)
Pilani Dzanibe, Laywers for Human Rights
Catherine Slack, University of Natal (Pietermaritzburg)
Jacques van Zuydam, Chief Director, Population & Development, Department of Social Development
Gill Schierhout and Saul Johnson, Health Development Africa
Chris Desmond; Child, Youth and Family Development Programme, HRSC
Anita Marshall; National Co-ordinator, NIP, Department of Health
Abram Phahlamohlaka, NACCA Co-ordinator, Department of Social Development
Kenau Swart, Life Skills Co-ordinator, Department of Health
Lucinda Franklin, Research Fellow, HEARD, University of Natal (Durban)
Thoraya Phandi, Media communications for Soul City
Ros Halkett, Child welfare consultant
Savera Kalideen, Soul City
Sanette Pienaar, Heartbeat
Sonya Giese, Children's Institute
Maria Mabetoa and Johanna de Beer, HIV/AIDS Directorate, Department of Social Development
Kevin Byrne, Sian Long and Lynette Mudekunye, Save the Children
Nina Hunter, School of Development Studies, University of Natal (Durban)