## Annex I

# HIV/AIDS and family well-being in southern Africa: towards an analysis of policies and responsiveness

### The HIV/AIDS crisis in southern Africa

Given endemic poverty, scarcity and multiple social ills in Africa, the HIV/AIDS epidemics may be the "last straw" for the peoples of southern African countries.[1] As elsewhere in Africa, the subregion's countries are beset by a wide range of economic, social and political problems besides the epidemics: extreme disempowering and debilitating chronic poverty; economic recessions, foreign debt, the effects of economic structural adjustment programmes and massive unemployment; underdevelopment and poor infrastructure; weak leadership, poor governance and corruption; political instability, conflict and violence; pervasive patriarchy, with women discriminated against and disadvantaged; the effects of droughts, floods and pestilence on agriculture, livelihoods and food security; and rampant disease, including malaria, tuberculosis, waterborne disease and malnutrition – and now HIV/AIDS. The HIV/AIDS epidemics constitute not only the worst scourge and onslaught with which Africa's people must contend; they also occur in a context in which the effects of the epidemics and key issues which they engender are juxtaposed with the multiplicity of societal problems.

Historically, southern African countries were the last in the region to be hit by the pandemic, as it blazed its way relentlessly down the continent from East Africa. Uganda is the only African country to have succeeded in turning the tide on *its* epidemic, through early concerted awareness and prevention strategies. Botswana, Zimbabwe and South Africa have become the hardest hit by the disease among all African countries.[2]

The demographic consequences of the HIV/AIDS epidemics are described in numerous global agency sources and in the research and policy literature, and may be consulted independently. For purposes of the Policy Workshop, suffice it to be noted that southern Africa is the subregion worst affected by the pandemic globally. Indicators of how the epidemics and their consequences have ravaged the countries include mortality rates for worst affected age groups. In 1999, infant mortality rates for the subregion were nearly 70 percent higher than they might have been without AIDS; in Zimbabwe, 72 percent higher. Child mortality rates have proved to be even greater: by 2010 the child mortality rate in South Africa is projected to be more than twice as high as it would be without AIDS, and in Zimbabwe, three and a half times as high (USCB, 1999).

**Uganda: a rare policy success**

*A decade ago Uganda had one of the worst HIV/AIDS epidemics in Africa. HIV surveillance data have since shown that the epidemics have proved to be far worse in some southern African countries – notably, Botswana, South Africa, Zambia and Zimbabwe.*

*HIV prevalence among Ugandan antenatal women in Kampala and the Rakai district was earlier as high as 30 percent. Since 1993 the prevalence rates have fallen to reach 15 percent in 1999.*

*Uganda was the first country in Africa to admit to an AIDS epidemic. With strong political backing the country's AIDS programmes made an impact. President Museveni steadfastly stressed the importance of political leadership in the fight against AIDS and the results of such leadership are evident in Uganda.*

**Source: US Census Bureau, 1999:18.**

**'AIDS is killing our children'**

*Figures released by the SA Medical Research Council in late December 2003 show that almost half of all childhood deaths in South Africa are due to HIV/AIDS. The disease is the leading cause of death among young children; in 2000 it accounted for 40 percent of childhood deaths.*

*Although the percentage of AIDS associated deaths is higher in the 1-4 year age group, the largest number of deaths occurs in the <1 year age group. Until very recently, the South African government had stalled on the provision of anti-retroviral drugs which will reduce mother-to-child transmission of HIV. The MRC has shown that even at its current efficacy, the prevention of mother-to-child transmission is the single most effective intervention to reduce mortality among children under five.*

*Deaths due to poverty – or from poverty related infectious diseases such as diarrhoea, respiratory infections and malnutrition – were also found to be a leading cause of death among 1-4 year olds.*

*AIDS related mortality among young adults, young women in particular, has also increased dramatically. The MRC points out that such mortality and the illness preceding it have a devastating effect on children leading to increased morbidity, mortality and orphanhood. One of the most important results of the roll-out of anti-retroviral therapy, the MRC suggests, will be the extension of the lives of AIDS sick parents leading to a decline in the number of orphans.*

**Source: SA Medical Research Council, Burden of Disease Research Unit Policy Brief, December 2003.**

Although earlier discussion on HIV/AIDS focused on prevention and persons infected with HIV, attention is more recently being directed to the impact of the epidemics on non-infected family members, or those affected emotionally, economically, socially and physically by the illness and the death/s of a person/s with AIDS. Most attention though has probably been given to the children of persons with AIDS – as have these children and so-called AIDS orphans been the focus of the mass media and international agencies such as UNAIDS and UNICEF. However, many HIV infected adults not only have children but also parents – who are likewise affected by their adult children's illness. The consequences of the epidemic for older persons and as parents of adults with AIDS have been comparatively overlooked. Greater attention has been given to their role as grandparents caring for AIDS orphans, than to their interrelationship with AIDS sick adult children. Before they assumed the role of caring for AIDS orphans, however, older persons were burdened with financial demands relating to the health care costs and the provision of material support to both their AIDS sick adult children and the children's dependents.

In South Africa women who are 60 years and over and who receive the social old age pension expend the greater part of their grant income on meeting the needs of AIDS sick adult children and affected grandchildren – indeed some of the children whom themselves may be infected with the virus or have AIDS (Ferreira, Keikelame & Mosaval, 2001). Physical and health effects of the strain of caregiving, additional domestic responsibilities, insufficient income and food deprivation, community stigmatisation, and the emotional effects of caring for a terminally ill person and coping with the loss of a child or children to AIDS all exact an enormous toll on older persons, women in particular. The impact of AIDS on older parents can moreover be particularly harsh, given the often lengthy periods of illness and disability, and their fears for the future.

**Creating a safety net**

*Of the countries most affected by HIV/AIDS, only three – all in southern Africa – have comprehensive social protection measures: Botswana, Namibia and South Africa.*

*In South Africa, non-contributory pensions reach 1.9 million older persons. Pension benefits, an amount of R700 (approximately US$100) a month, are an important source of income to poverty stricken family units. Pension sharing is common in multigenerational households, and is used to support all co-resident family members, and to pay school fees and for clothes and medicines for grandchildren.*

*Social pension programmes have been shown to have a significant impact on reducing poverty and vulnerability in poor households in which a pension beneficiary resides (Møller & Ferreira, 2003), particularly households affected by AIDS (Ferreira et al., 2001).*

*In South Africa, foster care and child support grants are available for age eligible children. In AIDS affected homes the income alleviates some of the financial burden on older persons who care for orphans and vulnerable children. However, complicated administrative procedures make it difficult for older caregivers to access a grant. The government has recently undertaken to streamline the procedures in view of widespread and worsening poverty and the effects of the HIV/AIDS epidemics.*

*Other social protection measures which can alleviate the financial stress of HIV/AIDS affected households include burial societies and revolving credit societies, which provide social assistance to members in the community. Micro loan schemes also provide a lifeline for families experiencing a financial crisis.*

**Sources: International HIV/AIDS Alliance/HelpAge International, 2003; Møller & Ferreira, 2003; Ferreira, Keikelame & Mosaval, 2001.**

In African countries, very little if any public assistance is available to persons with AIDS, but even less or nothing is available to caregivers. Persons with AIDS therefore rely on intergenerational support arrangements, which means that sick adult children and their dependent children often reside with elderly parents. If adult children live elsewhere, for migrant labour or other reasons, and if they develop AIDS, most will return to their parental home to be cared for by a parent until they die (cf. Ntozi & Nakaijwa, 1999).

HIV/AIDS has been described as one of the worst assaults on human dignity in southern Africa today (cf. Secure the Future, 2001). The Secure the Future Programme, being conducted in Botswana, Lesotho, Namibia, South Africa and Swaziland (and recently in several West African countries) is one of several multinational and bilateral programmes carried out in the subregion to address the social and economic effects of the epidemics. The STF programme aims specifically to improve the situation of women and children affected by AIDS, whom it claims are hardest hit in terms of caregiving demands and situations of deprivation. The programme maintains that challenges of the epidemics call for a multisectoral response from governments, the business community, civil society, community based organisations and non-governmental bodies. It points out that historically, most efforts, guided by government strategies, have focused on prevention (awareness, information and education); only later was there a focus on care for persons already infected with or affected by HIV/AIDS. The programme co-ordinators contend that the burden of caring for the terminally ill has been overwhelming and that most health institutions have been unable to cope. As a result, this responsibility has devolved to family members (mainly women and girl children) and community organisations, all of whom and which need to be supported.

Each of the southern African countries represented in the Policy Workshop has already responded to the challenges of caring for increasing numbers of AIDS sick persons by establishing home based care (HBC) programmes – albeit facing enormous challenges in doing so, including a lack of financial and material resources, and a lack of capacity. A range of other creative responses and indigenous solutions to the growing care and support needs of affected persons has also eventualised in the countries. However, disquieting are disjunctures which perceivably exist between national HIV/AIDS policies and the implementation of the policies in practice. The governments appear largely to rely on community organisations to develop and operationalise response programmes; few connections, or synergy apparently exist between policies, the government and the implementation of programmes. The levels of governments' involvement in response programmes in the countries will be a key subject for discussion in the workshop.

**Key issues impacting family well-being**

A myriad of issues arise from the effects of the HIV/AIDS epidemics which impact the sustainability of family units and family networks in the subregion. However, particular family related issues tend to be eclipsed in the literature, which has historically focused on specific generational, or age group effects of the epidemics: first on HIV/AIDS prevention among young adults; then on vulnerable children, and teenagers and their sexual behaviour; then on older persons as caregivers; and then on the home based care needs of terminally ill young adults. In general, the issues probably need to be integrated and recast, to focus on the effects of the disease and associated illness and deaths on families, family structures, intergenerational relations and family capital as a whole. An opportunity exists to create a scaffold for a holistic or intergenerational approach to examine the effects of the epidemics on the "integrity and functioning" (UNDESA, 2002:172) of affected families, to generate understanding and information for policy development.

Key issues of HIV/AIDS and its effects are reviewed only cursorily below. The dominant issue must be unequivocally the context of widespread extreme poverty. HIV/AIDS then exacerbates the poverty situations of affected families in a downward spiral. Family members of persons with AIDS, older women in particular, will sell off their assets and belongings and expend all of what little money they have in desperate but futile efforts to find a cure for their dying child or children. Young adults with AIDS are unable to earn income and become dependent on their elderly parents and what meagre income *they* have to support them and their offspring. Investigations in the subregion have shown that food deprivation is a major issue for affected families, as are expressed material and financial needs for clothes and bedding, schooling expenses for grandchildren and funeral expenses. A major problem is the education of vulnerable children: either through a lack of money to pay for schooling, or because children fall out of the education system because of a lack of money, and end up ill equipped to earn a living one day.

Emotional consequences of HIV/AIDS, which have different generational effects, also constitute key issues: for grandparents, the strain of caregiving, financial difficulties, the pain of coping

**Reduced access to education**

*AIDS orphans and vulnerable children experience great difficulty accessing education services. A lack of free primary education in many HIV/AIDS affected countries in Africa means that school fees – as well as school uniforms, books, transport, etc. – are often unaffordable for vulnerable households. In Zambia, out of 22 orphans and vulnerable children in households affected by HIV/AIDS and headed by an older person, only eight were attending school.*

**Source: Mwape, in International HIV/AIDS Alliance/HelpAge International, 2003, p. 13.**

with the deaths of children, personal health problems, uncertainty and fears about the future; for adult children, anger, distress, shame, sadness, illness, pain and fear; and for grandchildren, anguish and hurt, a lack of understanding, confusion, deprivation, fear, neglect and perhaps abandonment. HIV/AIDS also remains a taboo subject in many African countries, and persons with AIDS and their families may conceal the status of infected family members and thus forego opportunities for community support. Stigmatisation of infected persons and affected families further exacerbates the isolation and loneliness of these persons and families.

**Murdered for having HIV**

*On December 13, 2003, in Khayelitsha, a sprawling township outside Cape Town, South Africa, 21 year old HIV positive AIDS educator, Lorna Mlofana was beaten to death after telling a group of men in a shebeen [tavern] who had just raped her of her status. The Treatment Action Campaign (TAC) thereafter took to the streets in the township to demand that the community and the police make it a priority to apprehend her murderers.*

*'We HIV positive people are stigmatised, we are insulted, we are beaten' said a protestor. 'Our people hate us.'*

*Mlofana's doctor said she had been taking anti-retroviral drugs for the past two years and was a healthy young woman. Mlofana had one child.*

*Police have subsequently arrested four men in connection with the murder and gang rape. In a memorandum of demands to the Khayelitsha police station commissioner, the TAC called for greater efforts to ensure the safety of people living openly with HIV/AIDS, especially women and children.*

**Source*: Cape Argus,* December 23, 2003, p. 6.**

Such are some key social and economic issues which impact the functioning and well-being of AIDS affected families – at a meso level and a micro level. The brief overview of some key issues cannot represent the multiplicity, enormity, complexity and interrelatedness of the issues. A task for the Policy Workshop will therefore be to identify additional issues and to distil key issues, for incorporation or addressing in a policy framework. An overarching issue and need at a macro level then must be the formulation of HIV/AIDS policies by governments, with stakeholder consultation and participation, that appropriately and directly address the vulnerabilities and support needs of affected families and their members. Such policy responses however need to be directed both generationally and holistically, and to take gender into account. In addition, a concomitant overarching issue must be the implementation of the policies, which calls for discourse and concurrence on how the policies should be implemented, by whom, how governments should be involved – and what action must ensue.

**An intergenerational approach**

Despite demographic and social change in the wake of modernisation and globalisation under way in the continent, the majority of Africans continue to live in multigenerational family units. However, traditional extended family system structures have been changing as a result of these forces, particularly in urban areas. It is not necessarily that traditional foundations of the extended family system and intergenerational relationships and transfers are being eroded – as pundits would have it believed; rather, new types of family groupings are evolving which meet the living arrangement needs of contemporary African families. The family remains a central

institution in African societies, and there is no indication that family values and bonds are not as strong as they were previously (cf. Cattell, 1997; Weisner, Bradley & Kilbride, 1997). However, the HIV/AIDS epidemics are putting virtually unbearable new strains and demands on families, with which given rapid societal transition, new social contexts, and diminishing family capital and capacity, they no longer have the resources to cope.

Although multigenerational family units therefore remain common, co-resident family configurations are changing, and a major force propelling such change are the HIV/AIDS epidemics. For example, skip generation households in which middle generation family members are absent are increasingly common – even though this type of family structure is not atypical in Africa, as young adults frequently migrate from a rural area to a town or city for job opportunities and leave young children behind to be cared for by grandparents. Now, middle generation adults are increasingly infected with HIV and later succumb to AIDS related deaths, whereafter grandparents, typically a grandmother, become caregivers to orphaned grandchildren, so forming a skip generation family unit.

A growing preponderance of female headed households, particularly older female heads, is also occurring – in tandem with a growth of matrifocalism in the absence of males and fathers in households. Studies have shown that when a family member becomes infected with the virus, adult male members typically abscond from the household; when themselves infected and ill, they typically return to their maternal family home to be cared for until they die (cf. Ferreira, Keikelame & Mosaval, 2001). In addition, the number of child headed households, where no parent is present because they have succumbed to the disease and no grandparent is available to co-reside with and care for the children, is growing rapidly.

Very little attention has been given in the research and policy literature to the impact of HIV/AIDS and associated deaths on family structures and the generational effects, nor to the impact of associated morbidity and mortality on intergenerational family relations. While it is purported, or recognised that generational effects of the disease disproportionately impact the young (<15/18 years), youth (15/18–24 years) and the elderly (>50/60 years), in particular – by virtue of their vulnerability based on age group membership, relatively scant attention is given to the impact on young or middle generation adults, who indeed typically are the first to become infected with the disease and then to die from opportunistic diseases associated with full blown AIDS. It is fair to say though that community based home care programmes do target these persons when they become terminally ill, to offer what succour, dignity and practical help they can, and thus a focus on these persons is afforded through the programmes. Given traditional strong African family ties and values though, it would seem to behove governments of the countries in the subregion to formulate and implement HIV/AIDS policies which specifically support affected family units, generationally and holistically – by addressing the needs of different generations of family members variously but integrally, and thereby sustaining intergenerational relationships and the integrity and functioning of the family.

Appropriate policies and programmes to support family units and family networks in the wrath of the HIV/AIDS epidemics are thus of immediate and critical importance. However, in the development of such policies and the design of such programmes there is no doubt a need to go beyond a focus on generational interaction patterns and informal helping resources and behaviours, and to define the generational effects of the disease, as well as intra and inter familial relationships between the generations more precisely, so that the effects on the relationships are better understood in traditional and cultural contexts in societies in rapid transition. The changing roles of grandparents, or surrogate parenthood, as a result of the

epidemics, for example, may result in changed relationships between the oldest and youngest generations. Children who become heads of households and must care for other children also experience role changes.

An historical analysis of national and local responses to the epidemics in countries of the subregion will probably show a youth bias and reflect primarily youth centred intervention. A focus has undoubtedly been on affected children and orphans, and how to provide for future orphans. While some concern has been shown for the situations of older persons who must assume roles as caregivers to both AIDS sick adult children, and sick or orphaned grandchildren, very little provision, if any, has been made in policies for the support of older persons – either to support them in their roles as caregivers or in their loss of support structures as their adult children succumb to the disease. Equally, very little consideration has seemingly been given in policies – albeit perhaps noted – to the significant contribution that older persons make in AIDS afflicted and affected households towards sustaining the family unit and maintaining a family environment in which grandchildren bereft of their own parents may be nurtured and grow.

To carry out their roles optimally as caregivers, older persons need to be supported – and policies should aim to ensure that such support is provided. In addition, by supporting the needs of other vulnerable family groupings holistically and integrally, the burden of care on older persons is reduced and the family's functioning and well-being are bolstered. Issues of gender, vulnerability, capacity, need, generational equity and intergenerational support must therefore be prominent in the formulation of policies and responses.

**Policies**

What specific national policies are there which promote the well-being of HIV/AIDS afflicted and affected families in the eight countries? A review of the relevant policies of the different countries and their responsiveness is a task for the Policy Workshop. Given the short lead-in time to the workshop, only a secondary review of some policies of the countries could be undertaken. Ideally, all existing policies which provide for social and economic assistance programmes to HIV/AIDS infected and affected persons should be reviewed and analysed, as should all types of support projects be reviewed, to provide understanding and knowledge on the existence and effectiveness of such projects and their relationship with policies. Ultimately policies and programmes need to be evidence based, and comparative reviews of programmes and projects should be carried out to provide information for decision making on resource allocation. Similarly, a goal of analyses of HIV/AIDS response projects could be an identification of gaps in their implementation, and in the sustainability and co-ordination of programmes. As ambitious a task, for it to be acquitted optimally, may not be feasible for the Policy Workshop, but the principles of such a review process may be followed in the development of a draft policy framework in the workshop.

First, workshop participants may consider what policies there are (or should be) to benefit and support families. All policies should, whichever way, be informed by international declarations of commitment to address HIV/AIDS and its consequences. Declarations which set targets and goals for worldwide actions against HIV/AIDS to which member states have commited include:

The declaration signed at the United Nations General Assembly Special Session (UNGASS) (2001), to which member states committed to "national policies and strategies… [that] provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS" by

2005 and governments to "review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers" (UN, 2001).

The Millennium Development Goals (MDGs), which commit UN member states to halve, by 2015, the number of people living in extreme poverty and halting and reversing the spread of HIV/AIDS. (The epidemics are seriously affecting progress towards reaching the MDGs, including the goals of income poverty reduction, universal primary education, gender equality, hunger reduction and improved child health.)

The Madrid International Plan of Action on Ageing (2002), which commits UN member states to "introduce policies to provide … support, health care and loans to older caregivers to assist them in meeting the needs of children and grandchildren in accordance with the Millennium Declaration" (UN, 2002).

The African Union Policy Framework and Plan of Action on Ageing (2002), which commits member states to regionalised policy action to benefit older persons, which includes addressing the impact of HIV/AIDS.

**Governments to act on HIV/AIDS**

*Governments across the world have committed themselves to tackling the HIV/AIDS crisis. The Declaration of Commitment on HIV/AIDS was made by 189 government representatives attending the United Nations General Assembly Special Session on HIV/AIDS in New York in June 2001.*

*The meeting was convened in response to the global emergency caused by HIV/AIDS. The declaration of commitment covers areas including leadership, prevention, care, support and treatment, and human rights.*

*The declaration specifically mentions older people, in the context of the social and economic impact of HIV/AIDS. Governments have agreed to review this impact 'at all levels of society, especially on women and the elderly, particularly in their role as caregivers, and in families affected by HIV/AIDS, and address their special needs.'*

**Source: HelpAge International *Ageing and Development*, 9, 2001, p. 1**

**African states agree on ageing and HIV/AIDS policies**

*In meetings to develop the African Union Policy Framework and Plan of Action on Ageing 2002, poverty, rights, HIV/AIDS and gender emerged as key areas where co-ordinated planning for older people is needed.*

*There is an urgent need to protect, support and educate older people in relation to HIV/AIDS, it was stated in the meetings. Specifically, more resources should be allocated to support growing numbers of older people caring for the sick, looking after orphans, and sustaining families and communities.*

**Source: HelpAge International *Ageing and Development,* 84, 2001, p. 1.**

However, despite commitments which African governments may have made to the declarations at international summits, many of the governments are probably still a long way from fulfilling those commitments. Nevertheless, despite a scarcity of resources available to them and a lack of

capacity, most southern African country governments would construably have HIV/AIDS policy initiatives of one kind or another in place, which are being implemented in various ways, and which will be reviewed in the workshop. Examples of initiatives in Namibia and Zimbabwe are described briefly in boxes below.

**HIV/AIDS policies in Namibia**

*'Recognising the undeniable link between human rights and public health in the context of HIV/AIDS,' the Namibian Government has developed several policies as a tool for 'promoting a non-discriminatory environment in which the success of HIV prevention, care and support strategies can be optimised.'*

*The policies are reported to be the result of a broadly consultative process involving representatives of the government ministries, civil organisations, regional and international organisations, AIDS service organisations and people living with HIV/AIDS.*

*The challenge which the Namibian Government has viewed for itself and civil society was to embark on an intensified public education programme on the policies and legal instruments, and to allocate resources for the successful implementation of the policies and legal instruments.*

*Sir Abner Xoagub of the National AIDS Control Programme explains that the presence of national policies and legal instruments form the foundation of a national consensus and the way forward. The policies should not be seen as regulatory or legislatory, Xoagub states, but as tools or guidelines which provide equal opportunities for all stakeholders to work together harmoniously for the upliftment of the health status of the respective nations.*

**Source: Secure the Future Grantees Conference report, 2001.**

**The case of Zimbabwe**

*Inflation in Zimbabwe places an enormous strain on limited financial resources of poor households in addition to the impact of AIDS.*

*The Government of Zimbabwe is beginning to acknowledge the scope of the AIDS problem (Mpuli, 2001) and its negative impact on human resources. Policy makers are encouraging communities to seek ways to educate youth about AIDS as they formulate a National Policy on Youth. The advent of the AIDS levy has led to the formulation of the National AIDS Council (NAC). Home Based Care Groups, through local structures and community groups, can now access funds from the NAC to enable them to support their activities.*

**Source: Mpuli, in Secure the Future Grantees Conference report, 2001.**

Little attention has seemingly been paid in policies and programmes to addressing the generational effects of the epidemics holistically. Much clamour is heard though about the increasing numbers of so-called AIDS orphans, both realised and expected numbers, and a growing need is frequently mooted for the establishment of more orphanages. Although the role and contribution of grandparents, particularly grandmothers, as caregivers are acknowledged, it is doubtful that if any policies provide specifically for the support of older relatives (grandparents), which will assist these persons to care for affected or infected grandchildren and indeed adult children with AIDS or dying as a result of AIDS. Then, if such policies do exist, questions pertain to how effectively they are being implemented in practice.

In Africa, HelpAge International works with a wide range of organisations at community, national and international levels to examine the potential for intergenerational strategies which

include older people. It advocates, for example, for the adoption of older persons in policies to address HIV/AIDS, which include national AIDS policies, regional agreements such as the AU Policy Framework and Plan of Action on Ageing 2002, and other international mechanisms. HelpAge maintains that it is vital that clearer linkages and policy connections are made between the programmes designed to support orphaned children and possible support to the children's older relatives. (Cf. International HIV/AIDS Alliance, 2003.)

Whatever HIV/AIDS policies there are in the eight southern African countries thus, responsibility for their implementation and responsiveness is typically virtually wholly dependent on the NGO sector. Policy implementation, including the design of programmes and the delivery of services, thus falls largely in the court of non-governmental organisations (NGO's) and community based organisations (CBOs), and governments may or may not be involved in their implementation and/or subsidise such intervention or service programmes.

In a multinational Secure the Future Grantees Conference held in Johannesburg, South Africa in November 2001, delegates expressed opinion on the role and involvement of governments in home based care. Various experiences in the subregion, it was pointed out, have shown that local governments have not been able to cater (adequately) for people in need of home based care (HBC). Departments of Health, where most action has been based, tend to be already overburdened arms of government. Delegates felt that governments should be involved in HBC, and that national health departments do have the capacity to help advance care through resources and expertise. Governments should thus help to implement programmes countrywide.

**Community resources and responses**

Policies thus need to be implemented through programmes, and in the southern African countries it is noted that such implementation is largely reliant on community organisations and community resources. In addition, programmes and projects tend to target generations variously; however, overall, all generations and vulnerable social groupings are probably targeted in some way in accordance with their special needs. Hence, numerous hospices target persons who are terminally ill with AIDS, while some hospices serve only children. A large number of organisations target vulnerable children, with some offering residential care to AIDS infected or sick babies or children, often who have been abandoned. Several programmes target youth and focus on promoting anti-AIDS sexual behaviour. A majority of programmes or projects focus on the delivery of home based care services – rendered by community organisations or agents, often by volunteers. Numerous faith based organisations also target virtually all vulnerable groupings.

The majority of response organisations either serve clients at various stages of illness and need in their homes, or offer drop in facilities for advice, information, education, training, referrals, counselling, etc., or support groups. Several programmes are operated in specific settings, or geographical areas, and offer or support income generation or education activities, such as agriculture, small businesses, crèche care, primary schooling, etc. Some organisations target only AIDS sick persons: they offer home nursing, personal care and food parcels. (Ironically, food parcels are typically intended for consumption only by the AIDS sick or terminally ill beneficiary, whereas all the household's members, particularly children, may experience food deprivation and hunger.) Few programmes have thusfar probably aimed to address the needs of multiple co-resident generations afflicted with or affected by the disease integrally and holistically.

On an international or bilateral level numerous organisations and agencies are working in the subregion, frequently in partnerships with local or national organisations, to address the social and economic effects of HIV/AIDS: UNAIDS, UNICEF, USAID, UNFPA, ILO, FAO, WFP, International HIV/AIDS Alliance, Hope *worldwide*, HelpAge International, among others. On a national level growing recognition of the social and economic impact of the epidemics is spawning the formation of yet more HIV/AIDS focused NGOs and CBOs – sometimes guided by national policies, plans or programmes, sometimes as multisectoral and multi agency consortia with international involvement, and typically funded through a mix of donor and private funds. It is not clear what levels of funding governments provide for the operation of programmes, and better understanding and information are needed of such involvement.

Examples of programmes, initiatives and projects to benefit affected families operated in some of the eight countries are described briefly in the boxes below.

**Botswana's Community Home Based Care programme**

*High rates of AIDS related morbidity and hospital bed occupancy led the Botswana government in the early 1990s to establish the Community Home Based Care (CHBC) programme. An objective of the programme was to share the burden of care of persons with AIDS with families. The programme promotes caregiving to ill persons in their home, by family members supported by skilled social welfare officers and community members. The programme aims to meet spiritual, material and emotional needs of individuals and their families. A national guideline on the implementation of the programme (Ministry of Health, 1997) sets out the rights of persons who constitute the target population and what they may expect of intervention: provision of quality care services to persons with AIDS and their families; mobilisation of families and communities to support the programme; a referral system; training; information, education and counselling; monitoring; and financial issues.*

*Akinsola (1999) has questioned the extent to which the guidelines are applied in the implementation of the programme. His investigation found that only minimal social support is provided for persons with AIDS and their caregivers, mainly older women. The programme, he found, is also largely sustained by non-governmental organisations (NGOs), such as the Holy Cross Hospice which is active in Gaborone. Primary caregivers are left virtually on their own to provide care to the persons whom they are caring for. This situation is in contrast to the expectations of affected families of adequate support from government health and social agencies, and that help would be in the form of food, clothes, financial support, transport, emotional support, clinical care, information and education.*

*Akinsola concludes that the CHBC programme is yet another government initiative in many African countries which simply shifts the burden of care of persons with HIV/AIDS onto the family. He notes that in African societies, responsibility for the provision of care to socially deprived people is traditionally viewed as that of the family, particularly women and girl children. He calls for strong policy action, not only to implement the existing policy but also for various levels of government to be informed of the situation in affected households.*

**Source: Akinsola, in *Southern African Journal of Gerontology,* 1999.**

**National AIDS and Children Task Team (South Africa)**

*NACTT (National AIDS and Children Task Team) is an inter agency body representing government departments, NGOs and international bodies, chaired by the Department of Social Development and supported by Save the Children. It meets regularly to share information pertaining to children and HIV/AIDS, and to feed in its members' knowledge and experience to policy formulation. NACTT recognises the need for practical co-operation through the coalition to ensure that children's needs are met and their rights are respected, despite the ravages of HIV/AIDS.*

**Source: Save the Children Child HIV/AIDS Services directory, 2001.**

**Choose to Care: the CMMB Southern Africa AIDS initiative**

*'Choose to Care' is a joint initiative that encompasses Catholic Medical Mission Board's (CMMB) multimillion dollar commitment to more than 50 community based HIV/AIDS programmes in southern Africa. It targets the populations of five countries carrying the heaviest burden of the disease: South Africa, Botswana, Namibia, Lesotho and Swaziland. It is designed to raise awareness, relieve suffering, and restore hope and dignity to those infected and affected by AIDS. The initiative provides a broad range of services, including home based and hospice care, HIV/AIDS education, community support programmes, and orphan care and placement.*

*The initiative maintains that education and income generating activities reduce the risks of HIV/AIDS by offering more opportunities for empowerment, understanding and economic independence. Battling illness is devastating on any terms. Fear though has joined with AIDS to tear families apart, leaving many people alone in their final days.*

**Source: *Medical Mission News*, 2001, p. 4.**

**Community credit schemes in Mozambique**

*Community credit committees run by older persons and community members in Tete Province, Mozambique have so far supported over 300 AIDS carers and young people – two thirds of them women. Funds have been used to set up small businesses.*

*The credit committee allocates funds to projects that benefit the community. Interest on the funds is used to support older and most vulnerable households. Most of the older carers who have received funds have bought school items for their orphans, basic food and clothes for household members, and paid hospital and treatment costs where needed.*

*Felix, 15 years old, is the only income earner in a household of seven: he, five younger siblings, and an 80 year old great-uncle. Felix dropped out of school to earn an income herding goats. He bought the goats with funds from the credit committee. He explains:*

*'We wanted to stay together after our parents and grandparents died of AIDS. I want to go back to school but there is no money. I talk to my friends about not being bad, not stealing things to get money. I must work hard to get a good life and look after myself not to get the disease my mother and father had.'*

**Source: International HIV/AIDS Alliance/HelpAge International, 2003, p. 10.**

## Towards a policy framework and recommendations

It has not been possible within the limited time frame to carry out a comprehensive review of national HIV/AIDS policies of the eight southern African countries, but this will constitute a task for the Policy Workshop, when participants from the eight countries will table their countries' policies, and discussion, comparison and analysis will ensue. A concomitant task for the workshop will be to develop a policy framework to guide the governments of the subregion's countries in the formulation of national policies to support families affected by HIV/AIDS, and to make recommendations for the content and thrusts of such policies and their implementation, towards a resolution of key issues engendered by the epidemics and the design of effective responses. Among recommendations should be those for new research in areas where gaps in knowledge are identified, and for the capacity building of policy makers and programme managers. In the latter case, for example, an awareness should be created among policy makers and other public officials of existing policies, to facilitate existing reporting and monitoring mechanisms to ensure that policy intentions are carried out in practice.

While all countries have limited resources and governments everywhere must prioritise the allocation of resources to address numerous competing national priorities, it is hardly debatable in the southern African countries that the social and economic impact of the HIV/AIDS epidemics on family well-being and a commensurate allocation of resources be prioritised accordingly. Hence, new policy development, or in some cases simply more effective implementation of existing policies, with government involvement, must feature prominently on governments' agenda, and governments must commit to the policies and their implementation. Specifically, appropriate new or existing policies need to provide for an optimal mix of benefits to support interdependent generations within AIDS afflicted or affected family structures in practice: generationally, integrally and holistically.

A policy framework also needs to be informed by international mechanisms which are relevant to the area of HIV/AIDS and sustaining family well-being – as were indicated in the section on Policies in this report, as well as by global agencies working to address HIV/AIDS in the subregion.

In addition, existing policy initiatives and recommendations from recent international meetings and reports (cf. UNDSPD, 2003b) should be drawn upon to develop a policy framework to guide new policy development, which include:

A meeting on HIV/AIDS and Food Security organised by FAO, WFP and IFAD.
The International HIV/AIDS Alliance/HelpAge International report *Forgotten Families* (2003), which highlights new generational roles being assumed by family members, and what needs to be done to support older persons, orphans and vulnerable children at policy and programme levels.

The UNAIDS/UNICEF/USAID report *Children on the brink* (2002), which highlights the growing number of AIDS orphans, and the need to implement policies and programmes to support them.

The World Bank report *Long-term economic costs of AIDS* (2003), which recommends that more be done to support governments to develop policies to address issues of AIDS related deaths of young parents which rob children of education opportunities and undermine a basis for economic growth in the long run.

Examples of policy choices, or options to inform new policy development, in the subregion, as proposed by UNDSPD (2003b), are:

Policies aimed at reducing risk for vulnerable families (e.g. targetting prevention education efforts.)

Policies to assist and strengthen families (e.g. extending the productive life of HIV positive persons, food security, health care needs).

Policies to eradicate stigmatisation and discrimination of persons with and families affected by HIV/AIDS.

Policies to promote and facilitate community support services to affected families (e.g. schooling and health care subsidies, social safety nets, help with caregiving).

Policies to assist families with burials and with coping after family deaths.

Policies to protect and strengthen family capital overall (e.g. income generation opportunities, skills and business training, mobilisation of community resources, referrals, support groups, counselling).

Policies to support orphans and vulnerable children.

Policies that support organisations of people living with HIV/AIDS.

In all cases, it is suggested, the policies should focus on (1) reinforcing healthy family relationships; (2) protecting and increasing family resources; and (3) strengthening the resilience of families and their ability to cope (UNDESA, 2002).

Numerous recommendations to inform, or for incorporation in new policies on HIV/AIDS and the family, and/or for operationalisation in programmes in various societies and communities have been made in virtually all global and local agency reports, bulletins, etc., and in the research literature. In short, sets of recommendations have emanated from politicians, professionals, researchers, practitioners, organisations and laypersons – in policy arena, the scientific community and community contexts alike. Only a very small sampling of single recommendations made for the subregion's countries is given below, for consideration in the Policy Workshop.

Governments, NGOs and local communities need to work together in partnerships to meet the needs of whole communities and families.

Effective programmes are needed to support older persons as caregivers, to enhance their caregiving capacity and to strengthen bonds between them and other generations.
The schooling and housing expenses of orphans and vulnerable children need to be subsidised, and orphans'/childrens' psychosocial needs addressed broadly.

Awareness raising is needed among health workers on the impact of the disease on different generations and families as a whole.

Access to and utilisation of services by affected and afflicted families and persons need to be improved.

The economic independence of affected families needs to be ensured and supported.
Outreach programmes with health care personnel and trained volunteer health workers need to be established and operated.

Improved health care service delivery should include health promotion for caregivers, information and education, psychosocial support and counselling, and efforts to reduce stigmatisation.

Access to and utilisation of social security schemes need to be enhanced.

It is not feasible to attempt to represent, or indeed reproduce vastly numerous recommendations already made elsewhere in this and other reports. It is prudent however to direct workshop participants to a recent and comprehensive set of recommendations made in the International

HIV/AIDS Alliance/HelpAge International report *Forgotten families* (2003) – which report will be available in the Policy Workshop.

In all, to address the multiple issues, policies and programmes should ensure that they incorporate components which deal with, provide for or include: a balanced gender involvement (taking women's vulnerability into consideration and involving men in programmes); community participation and the involvement of all stakeholders; continuity and sustainability of programmes; the empowerment of families to take care of their own; the motivation and management of volunteers, and support systems for volunteer caregivers; recognition of the role and contribution of faith based organisations; assistance with deaths and funeral related expenses; special needs in rural settings; recognition of the role and contribution of traditional healers; the establishment of hospice networks; assistance for the creation of income generation activities; assistance with schooling for children; improved access to medical treatment; human rights and advocacy information and services; improved access to information and counselling; and sensitivity to and inculturation of different cultural, faith and customary practices. Underpinning all such needs and components is an overall need to address the psychosocial needs of affected families and persons, to strengthen intergenerational bonds, and to reduce tensions and isolation of affected families.

**Concluding remarks**

Poverty and HIV/AIDS are vast problems in Africa and are linked in a vicious circle. The epidemics and their effects cannot be adequately addressed without reducing poverty. To achieve international development targets, both poverty and the epidemics must be addressed simultaneously. HIV/AIDS cannot be separated from other issues in the subregion, but must be tackled in the context of the multiplicity of societal problems faced by poor communities and families. (Cf. HelpAge International, 2001: 7.)

Not only may the epidemics, because of the gravity of their effects and the issues that they engender – as indicated in this report, be a last straw for the subregion's peoples; the epidemics are already proving to be a last straw for frayed and overburdened traditional care and support systems (Okatcha, 1999). Despite their own vulnerability, older persons are raising increasing numbers of vulnerable children who will constitute the subregion's future adult generation. Family care is the preferred care option for orphans and vulnerable children.
However, in the context of poverty and HIV/AIDS and its impact in the subregion, family care needs to be supplemented with support from governments, NGOs and communities – and for this to be done urgently. There is likewise an urgent need for a new approach to HIV/AIDS and family well-being which will mainstream an intergenerational perspective and generational interdependence into policies and programmes (cf. UNDSPD, 2003a). The support of traditional intergenerational support arrangements in policies and response programmes can ultimately reduce the burden of AIDS care on governments, and promote family care and well-being in family environments.

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Prepared for a United Nations Department of Economic and Social
Affairs Division for Social Policy and Development Policy Workshop,
held in Windhoek, Namibia on 28–30 January 2004

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