

HelpAge International

Leading global action on ageing

The Impact of HIV/AIDS on Older People in Africa

Workshop Report

23rd – 25th January 2002

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1 Foreword

A workshop, bringing together AIDS service organisations, organisations working with older people, the private sector, WHO, ADB and the public sector took place between 23rd and 25th January 2002 to discuss an urgent, long overdue but extremely pertinent issue: the impact of HIV/AIDS on older people.

The HIV/AIDS pandemic has played havoc among the lives of African populations. By 2000, of the 34.3 million people estimated to be living with HIV, 24.5 million or 10% of the world's population and 14 million out of the 18.8 million that had died were from Sub-Saharan Africa. It is reported that before AIDS, 2% of all children in the developing world were orphans. By 1997, this figure had risen to between 7 and 11%. Out of a total of 13.2 million children that have been orphaned by AIDS, 12 million are in Sub-Saharan Africa.

These figures are alarming, but what is even more frightening is the immense impact that HIV/AIDS is having on older people as they shoulder the responsibility of providing care and support to those that are sick and the children orphaned by AIDS. A survey conducted in Zimbabwe in 1992 found that 90% of those caring for orphans were older people and most of them were women. A study carried out in the same country in 1996 found that 143 out of 292 people caring for orphans were aged 50 years and above with 125 of them being aged 60 years and above. A WHO sponsored research in Zimbabwe in 2001 found similar results.

Yet, almost without exception, the role that older people are playing in supporting the sick, the dying and those who are orphaned goes unrecognised and unsupported. Older people are routinely excluded from HIV/AIDS education and awareness campaigns, as a result of the misguided belief that older people are not sexually active and a failure to appreciate the risks that they run when caring for those with HIV/AIDS. The prejudices that older people face in so many areas of their lives are compounded when they are affected by HIV for example, poverty and social exclusion increase. The burden of care places massive stresses on the physical health and psychological well-being of older women and men.

Misunderstanding of facts about life expectancy projections in Sub-Saharan Africa result in issues relating to older people being overlooked further. Many people incorrectly assume that, as life expectancies are dropping in many countries, there will no longer any older people. However, the reality is that the impact of HIV/AIDS is likely to speed-up population ageing as past high birth rates and significant declines in infant mortality have resulted in high numbers of middle-aged adults in Africa. The vast majority of people are not infected with HIV and they will, inevitably, grow older, and they will in all probability live longer than previous generations. By 2030, there will be 25 million people aged 60 - 64 up from the current 11 million. Steep declines in fertility throughout the continent will further enhance population ageing.

Bringing together AIDS service organisations and organisations working with older people, the workshop sought to increase understanding about the full impact of HIV/AIDS on older people as well as identify strategies that can most usefully be employed to tackle the problem. The issues have now been clearly identified and priority areas for intervention defined. It is now the responsibility of those who attended the workshop, those who read this report and those who are interested in ageing issues to push for change and encourage others to play their part in addressing the impact of HIV/AIDS on older people.

Tavengwa M. Nhongo
Regional Representative

2 Summary

The HIV/AIDS and Older People workshop, 23-25th January 2002, brought together 27 participants from older people's organisations, AIDS service organisations, regional bodies, other non-governmental organisations and the private sector.

At the opening event, Muthoni Mwithiga of the National AIDS Control Council (Kenya) spoke of the Council's efforts to increase awareness and understanding of HIV/AIDS within Kenya and gave a commitment to work with organisations of older people to ensure that the needs of the older population are addressed. Ambassador Pamela Mboya, Chair of HelpAge Kenya and Board Member of HelpAge International, spoke of how the impact of HIV/AIDS on older people is not receiving the attention it deserves. She highlighted how, despite the facts about the impact on older people, policy makers, development agencies and donors do not factor older people in their policies and programmes.

Three days of intense discussions identified the many different ways that HIV/AIDS impacts on the lives of older women and men. The full impact of caring for those who are sick was highlighted, with many examples of how older people are adversely affected in terms of their social, health and economic well-being. In many cases, older people become the guardians for children who are orphaned as a result of AIDS. This role begins when those with HIV become sick, and older people then take on the full social and economic responsibility for multiple grandchildren when they die of AIDS. The massive role that older people play in the care of the sick and for the children who are left as orphans is largely ignored in HIV/AIDS policy and programme responses. As a result, older people are left to cope alone.

The health, social and economic consequences of HIV/AIDS on older people were explored in detail. Differences in impact were identified for older women and older men. It was recognised that overall, older women are more involved in the day to day care of those who are sick. On the other hand, the older men who are carers often have more difficulties coping with the responsibility as they are not so used to the role and tend to have fewer support structures.

The work that is currently being implemented in relation to older people affected by HIV/AIDS was reviewed. In the process, it became acutely apparent just how little is being done. Whilst generic HIV/AIDS programmes may provide some support to older people, it was recognised that this is more by accident than design and that, in most cases, the needs of older people are simply overlooked or ignored. However, it was encouraging that some programmes are being implemented and it was recognised that there is need for sharing of information about lessons learned and good practices identified.

The 'way forward' was mapped out with practical suggestions in terms of policy and programme activities. It was agreed that older people specific programmes are needed as well as promoting the mainstreaming of older people's issues into existing HIV/AIDS policies and interventions.

3 Workshop Methodology and Report Structure

The workshop was designed to promote the sharing of experiences and ideas related to the impact of HIV/AIDS on older persons. During the workshop, participants:

- Discussed the impact of HIV/AIDS on older persons and identified the key issues that arise
- Considered how HIV/AIDS impacts on older men and older women differently
- Reviewed current programmes designed to address the impact of HIV/AIDS on older people – assessing what works well and what does not work so well
- Mapped out and agreed strategies that could be used to address the impact of HIV/AIDS on older persons

For most sessions, participants worked in small groups and then presented their findings that were then discussed in plenary sessions.

This report seeks to present the discussions that took place – taking a thematic approach to the presentation of the issues.

4 Ageing

A short introduction to ageing was given at the beginning of the workshop. During this session, participants were asked to think about their own ageing and consider how they would be living when they were older; where they would get their money from; who would be caring for them and what their concerns would be. Participants highlighted their future concerns as being:

- Worries about mobility due to physical weakness and sight failure
- Caring for orphans
- Lack of income to sustain self and dependants
- Exclusion due to negative attitudes
- Isolation due to loss of family and friends
- Disease and sickness such as arthritis and hypertension
- Senility and death
- Apprehension as to whether their contributions be welcome
- Fear of adapting to a new lifestyle – moving from urban to rural areas
- Loneliness and lack of care as their children may neglect them
- Inability to meet the financial expectations of family members as pension is little

5 The Impact of HIV/AIDS on Older People in Africa

The workshop highlighted the ways in which HIV/AIDS impacts on the lives of older people. Whilst the consequences of HIV/AIDS are presented below as a series of issues, workshop discussions highlighted that, in reality, the issues are strongly interrelated and that the nature of the relationship between the different issues also needs to be understood.

5.1 The Care-Giving Toll

Many adults who are sick with AIDS related illnesses return to their parents' homes when they are no longer able to manage by themselves. Older people, particularly older women, take on primary responsibilities for the day-to-day care of their sick sons and daughters. The workshop discussions highlighted the consequences of this role on older people – impacting,

as it does, on their physical and mental health, draining their resources and, in many cases, making them feel isolated.

Older people often start caring - socially and economically - for their grandchildren as soon as the son or daughter who is sick moves into their home. With the death of their children, the grandparents often become the sole carers of the grandchildren.

Traditionally, older people, particularly older women, play an important role as carers of grandchildren and so, arguably, this is not a new role. However, what has changed is the burden of care. In the past, grandparents would have cared for their grandchildren some of the time and, in many cases, would have received support from the parents of the child in return – either through remittances if s/he was living elsewhere, or through the provision of food and care if the son/daughter was still living in the same community. With HIV/AIDS however, many older people are now the primary carers of many grandchildren with absolute responsibility for their welfare. Again and again, the magnitude of the caring responsibilities was highlighted during the workshop.

Research in Tanzania highlights dissatisfaction on the part of the grandparents and the grandchildren, in relation to the quality of care provided to the orphans. Some orphans feel they are not well supported and that their needs are not met by their grandparents. Older people echoed these sentiments, saying that as they care for the sick and later strive to generate sufficient income to meet food and other basic needs, they are unable to care for the grandchildren in the way they would like.

Workshop participants reported how older people often speak of their fear for the future, wondering who will care for their grandchildren when they, themselves, die.

The toll of caring is exacerbated by the sheer economic cost (as highlighted in more detail below), which means that older people are unable to buy the drugs needed to care for the sick or meet the costs of caring for the orphans.

The physical and emotional strain involved in caring for the sick means that the health of older people themselves is compromised in the process of caring for others. The role of care brings with it risks of infection, both from HIV and other communicable diseases like Tuberculosis (TB). In many cases, older people are ill equipped to protect themselves from the risk of infection. Even if the cause of the illness is known (most people do not disclose their HIV status), older people may not know how to protect themselves or may choose not to. Participants highlighted how, for example, older people would not use gloves, even if they could afford them, as they would not want to be seen to shun their sons/daughters.

It was noted that all the data that is routinely disseminated relates to prevalence. In all cases, the graphs show lower rates of infection among the youth and the ageing, with high rates among the 15-49 age group. However, such graphs show only one side of the pandemic; but fail to show the impact in terms of those who provide the care and support for the sick.

5.2 Economic Impact

The enormous economic impact of HIV/AIDS on older persons was highlighted. Caring for the sick involves considerable expenditure on medical support, both from traditional and hospital based practitioners. In many cases, older people find it a challenge meeting the cost of food for those who are sick.

The economic cost of supporting the grandchildren often starts as soon as the children start living in the households, but becomes the full responsibility of the older persons following the death of the parents. Whilst meeting the costs of basic needs such as food and clothing is challenging enough, for many, school fees and the associated costs (uniform, books, etc) are impossible.

Prior to becoming sick, some people may have been remitting money to support their ageing parents. When the son or daughter becomes sick, they are no longer able to provide that support and the older person faces a situation of increasing costs and decreasing income.

In many cases, those caring for the sick stop their income generation activities to provide the full-time care that is needed. Participants from all the countries represented, highlighted how older people sell their assets to meet the costs of caring for the sick. The economic development of the older person stagnates as resources are channelled into caring for the sick. With time, their economic base, which is often very limited to begin with, is depleted and the older persons and their grandchildren are left impoverished. In many cases, assets that used to generate an income (e.g. livestock and land) are sold, and as a result, following the death of the person with AIDS, the older parents are not able to restart their income generation activities.

The question of how to support the income needs of older people caring for the sick and the orphans was discussed in detail. In many cases, research is highlighting that lack of time is a major problem whilst, at the same time, there is a call for support of income generation activities. It was felt that, in many cases the burden of care is most extreme when caring for the sick and very young orphans, but that time devoted to care is less when the orphans are older.

Income generation activities that can be undertaken within the home or that do not require much labour, such as keeping locally bred chickens, were seen in many cases as better options than more involving activities. In situations where strong community groups exist, group members may help others who are too busy to be involved in income generation activities. In other cases, it was noted that co-operatives are very difficult and failure to participate in the activities and meetings results in exclusion from the benefits of the projects. The debate about income generation continued and may questions related to the profitability of activities, how activities can be adapted to meet the needs of older age groups, how we define 'success' and the challenges of accessing funding for income generation work with older people remained. It was acknowledged that there is need for further sharing of ideas and good practice in relation to income generation work.

5.3 Older People and the Risk of HIV Infection

In many societies, there is a denial of older people's sexuality and, as a result, little acknowledgement that older people are at risk of HIV infection through sexual intercourse. Almost without exception, HIV prevention campaigns target the youth, using language and imagery that serve to exclude older people.

Older persons are also at risk of infection from the caring roles that they perform. Day to day care practices mean that older people cut the boils to release pus, they help bathe the very sick and tend those with diarrhoea. For those caring for grandchildren, some of whom are HIV positive, it was reported that in several countries older people traditionally clear nasal passages by sucking the mucus. Such caring roles mean that older people are in direct contact with various bodily fluids, many of which may contain blood when people are very sick. In this way, not only are older people exposed to HIV, but are at a great risk of contracting other opportunistic infections such as TB.

Social attitudes towards older people and sex mean that it is very difficult for older people to seek treatment for STDs. If an older person is sick, health workers seldom consider the possibility of HIV. However, it was noted that in Uganda (and possibly in other countries), anyone with TB is automatically tested for HIV. In most countries in Africa, when someone tests HIV positive, there is little support and people are not able to access treatment as drugs, both to boost health and treat infections are prohibitively expensive. It was noted that the health of older people who are HIV positive tends to deteriorate faster than younger persons who are positive.

Some practices traditionally performed by older people also expose them to HIV. Most traditional birth attendants (TBAs), traditional healers and those who perform ritual cuttings are older women and older men. In all these roles, they may become infected or may inadvertently infect others as a result of poor hygiene practices.

In Uganda, 60% of pregnant women give birth in the village and most are attended to by TBAs – in many cases TBAs will have wounds on their hands and do not use protection and so are put at risk. In Kenya, a programme supported by WHO supplied pregnant women with birth kits (a blade, thread, soap and gloves) which were given to the TBA at the time of delivery. These kits are no longer supplied, but can be put together cheaply by the TBA.

The failure to target older people in HIV/AIDS education not only puts them at risk, but also puts others at risk. As carers for orphans, older people are responsible for providing education about HIV to their grandchildren. If older people are not well informed, they may provide the wrong information to those in their charge, or even counter HIV prevention messages targeted at the youth. The lack of information means that many older people are not able to protect themselves as they perform their caring tasks.

5.4 Physical and Mental Health Consequences

Not only are older people at risk of infection in the same way as others, but there are also specific health issues that impact heavily on older persons.

The physical and emotional demands placed on older people by the caring role that they perform impact on their health. The research carried out in Zimbabwe (2001), highlighted the many hours devoted to care responsibilities and the physical strain of feeding, bathing and lifting the person who is sick. In the same study, older people spoke of the physical problems they face transporting the person with AIDS to hospital when they need treatment. In Tanzania, discussions with older women emphasised the emotional strain of the role, both in terms of caring for the sick and supporting the orphaned grandchildren. The constant emotional strain results in depression and self-neglect. Their inability to care for the sick and the orphaned as well as they would like to, leaves some older people feeling a loss of self-worth.

The stress of caring for the sick and the orphaned is heightened by the stigma attached to HIV in many communities. Whilst it was reported that in Uganda communities tend to offer support when someone is sick with AIDS, in other countries stigma and rejection seemed to be the norm. In some cases, the stress leads to negative coping mechanisms by some older people with increased use of drugs and alcohol.

When the health of older persons suffers as a result of the impact of HIV/AIDS, they are not able to access the support they need from health services. A problem facing older people across the continent is the attitude of health workers who actively discourage them from

seeking treatment – viewing their health problems as simply ‘old age’ and ‘a waste of resources’.

5.5 Community Attitudes

In many countries, HIV/AIDS remains poorly understood – especially in rural areas. As a result, people with HIV are often discriminated against and so do not reveal their status.

The stigma associated with HIV/AIDS can result in older people being victimised in a variety of ways. It was reported that in Mozambique and Tanzania, older women are particularly vulnerable to allegations of witchcraft linked to the death of young people. Such allegations often result in social isolation and violence against the older persons.

In some situations, beliefs have developed that raping an older woman will cure HIV/AIDS. Such crimes have been reported in South Africa and other countries in the continent.

It was reported that in Ethiopia, the stigma does not end with the death of the person who was sick. In some cases, older people stopped their grandchildren playing with others so that they would not have to face the ordeal of being called names or rejected by their peer group.

The sense of isolation not only comes as a result of stigma but also because, when caring for the sick, older people do not have the time to engage in their usual social and family duties. Reports were cited of older people gradually being excluded from family decision making and becoming less involved in wider family affairs.

In Tanzania, older women felt that the strengthening of community networks would help address their isolation and make them better able to deal with the stress they endure. However, it was reported that in Ethiopia some of the traditional social networks have loosened and, in some communities disintegrated. For example, the number of deaths has put the traditional idhar (burial society) under great pressure and, in some communities, they have collapsed.

In Uganda, where HIV/AIDS awareness and action has been in operation since early on in the pandemic, it was reported that there is now little stigma associated with HIV. In most cases, if someone is sick with HIV/AIDS it will result in increased community support. That said, it was felt that in some cases people create a feeling of stigma for themselves – with fear leading them to withdraw from some social activities.

Traditionally, older people are viewed as the custodians of customs and practices. Whilst there are traditions and cultures that need to be changed in the light of HIV/AIDS, it is important to recognise that every tradition has a function, and that when trying to change a practice, the role of the tradition should be understood and older people’s involvement in changing attitudes sought.

6 The Impact: Differences Between Older Women and Older Men

Participants identified some of the ways in which the impact of HIV/AIDS differs between older women and older men. However, such differences vary between matriarchal and patriarchal societies and within communities. As programmes are developed to mitigate the impact of HIV on older people, there is need for a context specific analysis that looks at the degree, causes and consequences of the differing impacts on older men and older women. That said, the discussions that took place highlighted some of the different impacts and issues that need to be considered.

6.1 Impact of HIV/AIDS on Older Women

Older women tend to have more responsibilities in terms of caring for those who are sick, and in relation to the family as a whole. Although rates of HIV infection are lower among older women, the care roles they perform expose them to more risks of infection than men.

It was felt that, in many cases, older women tend to consult traditional healers, counsellors and advisors more than older men. This can have positive or negative consequences depending on the quality of the advice received. In some cases, this tendency means that older women are better able to access support than older men, but it can also mean that they receive misinformation from some of these informal support networks.

Caring for people with HIV/AIDS results in increasing household costs, as additional medical and food expenses need to be met. At the same time, care responsibilities mean that older women have less time to participate in activities that would generate income. In most cases, older women tend to have fewer resources than men and so the sale of assets may have a greater impact on them. Many women turn to petty trading to generate income, but this activity only generates a minimal income for the household.

In most societies, sons and daughters give remittances to their mother rather than their father. As such, older women are more likely to feel the impact of loss of remittances following the sickness or death of their son/daughter from AIDS

The stigma, psychological trauma and isolation associated with HIV/AIDS affects both older men and older women. In some cases, the impact seems to be greater for older women. It is a fact that more older women live alone than older men (as women tend to live longer and, in most cultures, marry men older than themselves) and, as such, more women take on care responsibilities alone.

Abuse and victimisation are more frequently directed towards older women than men. For example, work in Tanzania and Mozambique has found that older women are more likely to be accused of witchcraft and more likely to be affected by inheritance issues than men.

There was considerable debate about older people's health-seeking behaviour, and the impact of care responsibilities on the health of older people. It was felt that older women's health often suffers as a result of their care responsibilities. When caring for others, many older women neglect their own care needs. Whilst it was felt that older women tend to have wider social support networks, these networks often diminish when they are involved in daily care of the sick as they have less time to participate in community activities.

There was considerable, unresolved debate about when older women access health care. In many cases, older women are higher users of health services, but workshop participants also cited cases of older women who do not seek medical care until they are very sick. In many societies, a woman who is sick will go back to her family home to be cared for. Many only take this course of action when they are very sick. In the meantime, they continue caring for others at the expense of their own health.

Workshop participants debated issues related to power within the household and community. However, it remained unclear how HIV affects the power of older women. In some ways, it might reduce their power in the community as they devote more time to caring and they may be affected by stigma, but within the home it may increase their power since they become the main decision-makers.

Both older women and older men are likely to take on roles related to sex and HIV education for the children under their care. These roles vary between cultures.

6.2 Impact of HIV/AIDS on Older Men

Participants highlighted that, from their experience, older men tend to find it harder to adapt to day-to-day care responsibilities, as this is not a role they are used to. In general, older men tend to be less well informed about food and nutrition, and so are less able to care for themselves and the orphans in their charge.

Participants highlighted that older men tend to have fewer coping mechanisms than older women, and are socially conditioned not to show their emotions. As a result, older men find it harder to access the emotional support they need to cope with social and economic impacts of the pandemic. The stress of dealing with HIV/AIDS seems to result in more cases of alcohol and drug abuse among older men than among older women. In addition, cases of violent behaviour have been recorded and cases of sexual abuse of orphans in their care have been noted in some countries.

Older men face many economic issues as a result of the impact of HIV. Generally, they are likely to feel more pressure from “breadwinner” expectations and the need to provide. Whilst they tend to have more assets than older women, this also means that they sell more when HIV hits their family. The loss of assets may bring with it loss of dignity and self-esteem. The death of their sons and daughters not only brings immediate grief and hardship, but also leaves some older men with concerns about who will inherit their remaining property.

Older men tend to be greater supporters of traditional behaviour and are less willing to change than women. Yet, older men are generally the final decision-makers in the event of family/community conflicts related to traditional practices. In communities heavily impacted by HIV/AIDS, older men are likely to take on greater responsibility in community issues and decisions.

As mentioned above, if a woman becomes sick, she returns to the family home to be cared for. During this period, the older man remains alone and has to cope by himself.

Rates of HIV infection appear to be higher among older men than women.

7 Key Challenges

Having looked at the impact of HIV/AIDS on older persons, workshop participants discussed and identified key issues.

As outlined above, the economic, social, health and psychological impact of HIV/AIDS on older people is enormous. There are multiple ways in which older people are not taken into account by HIV/AIDS prevention and care programmes.

The enormous role older people play in caring for the sick and dying, as well as the care they provide for the orphaned grandchildren, is often unrecognised and undervalued. Yet, in many communities it is older people who ensure that those with HIV/AIDS receive support, and that orphaned children have a home. In many cases, the potential of older people to be involved in prevention programmes is ignored. Older people could be involved in peer education that would help increase understanding and reduce stigma.

In many cases, older people are the custodians of culture. In communities where they are still respected, older people can promote or inhibit change. In this respect, as well as many others, their inclusion in general HIV prevention and care programmes is vital.

The many disadvantages that older people normally face are exacerbated in the context of HIV/AIDS. In most countries, social security systems are either very limited or non-existent, and most people enter older age with very limited resources. With HIV, the sale of resources means an increase in poverty with no formal social security on which to fall back. HIV/AIDS stagnates development as resources are channelled to HIV/AIDS activities, yet the ability of poor older people and poor communities to mobilise resources is limited. In the case of older people, this is made worse by the fact that they have little access to credit or other livelihood promoting programmes as the private, government or non-governmental sectors exclude them on the basis of age and perceptions about their abilities.

The mapping exercise (see Appendix 1) demonstrated that older people are generally excluded from existing HIV/AIDS policies. This exclusion serves to aggravate the impact of HIV on older people. In some cases, HIV/AIDS policies talk of vulnerable groups but do not specifically mention older people. In Tanzania, the issue of care is mentioned but is not linked to older people. As much as there is need for HIV policies to specifically include older people. It is also important that policies that are developed on ageing include HIV/AIDS. It was noted that the draft OAU Policy Framework and Plan of Action on Ageing includes HIV/AIDS and so offers a basis for this.

8 Interventions Related to HIV/AIDS and Older People

Prior to the workshop, participants were asked to prepare information related to their existing HIV/AIDS work. The information was displayed and used as the basis for discussions about the types of programmes being implemented, what is working, and what is not working. Copies of all the presentations are attached in Appendix 1.

The displays and the subsequent discussions highlighted that although there is some work being implemented in relation to HIV/AIDS and older people, much of it is relatively new and little has been evaluated in detail to determine ideas of good practice. During the discussions, experiences from other areas of work with older people and from other HIV programmes were drawn on to inform debate about what might and might not work.

8.1 Types of Programmes

The programmes that are being implemented were discussed, and various types of programmes and approaches identified as outlined below:-

- Integrated programmes
- National multi-sectoral approaches
- Programmes that indirectly benefit older people
- Small projects
- Policy initiatives at country and regional levels
- Information, education and communication, including training, theatre, resource materials and so on.
- Caring and support programmes including community-based support, home based care, home visiting/counselling.
- Work with traditional healers, traditional birth attendants, male/female circumcision practitioners – projects include education and provision of equipment for infection control

- Income generation activities. For example, those who practice female circumcision are encouraged to start other income generation activities, payment of school fees for orphans and micro-credit

8.2 What Works and What does not Work

Based on discussions about existing programmes and drawing on other experiences from work with older people or work on HIV/AIDS programmes, participants identified factors that contribute to the success or otherwise of programmes working with HIV/AIDS and older people. In addition, gaps were identified within existing work.

What works

- Integrated approaches
- Empowerment
- Involvement of older people
- Direct benefits to all older people
- Clear identification of needs/contribution of older people
- Ownership of the programme
- Working with existing groups
- Spiritual voluntary services, weekly or monthly visits
- Established referral systems
- Recognition of the services of volunteers
- Voluntary home visits supported by social workers
- Older peoples homes are only appropriate for the most destitute or those with no support
- Partnerships, information sharing and networking
- Influencing other NGOs, the private sector and public sectors
- Involvement of all stakeholders
- Surprise check ups to assess families
- Building capacity both financial and human resources
- CBOs initiated by the local community and linked to local religious organisations
- UNAIDS has examples of good practise. Even though they are not related to older people, some of the lessons could be used in work with older people
- Using qualitative and quantitative data collection approaches to get older people's views
- Developing a well documented African perspective

What does not work

- Exclusion of older people and the local community
- Lack of ownership of the programme by the community
- Older people's homes do not promote inclusion/family care and can become a dumping ground
- Programmes that are not a product of a felt need
- Programmes that do not involve the local community
- Information and research on its own does not provide a solution. It must be supported/followed by an intervention
- Unsustainable programmes
- Dependency on a single source of funding
- "Handout approach", creates magnets with "false positives", e.g. Uganda
- Problems of dependency in relation to school fees
- Poorly managed projects

8.3 Challenges

- Lack of sufficient Africa focused perspectives
- The current programmes are not reaching many older persons
- Lack of capacity at the community level
- Lack of concern/commitment by governments and institutions
- Resource allocation towards older persons' HIV/AIDS programmes
- Lack of research and information
- Lack of monitoring and evaluation
- Political interference
- Donor driven agendas
- IGP for older people and orphans is a challenge.
- Group formation or co-operatives are a challenge
- Sustaining voluntary work
- Low level impact
- Developing a sense of responsibility within communities
- Good follow up and monitoring of different pilot approaches needed

9 The Way Forward

Working in groups, participants identified key priority areas for action, what needs to be done and strategies that need to be adopted to move forward. In a plenary session, the priority areas were discussed and consensus reached about the way forward.

Five priority areas were identified, namely: -

- a) Information, education and communication
- b) Advocacy
- c) Policy
- d) Research
- e) Direct support for immediate and longer term needs of older people

In addition, it was agreed that there was need to address issues of capacity building and gender throughout, and that indicators should be established.

| Priority Area: Information, Education and Communication | |
|--|---|
| Action Needed | Strategies |
| <ul style="list-style-type: none"> • Development of IEC strategies at national level and guidelines at regional level. • Baseline survey with focus on older people's infection risk, caring risk and their role as educators • Co-ordination/working with existing HIV/AIDS agencies • Develop and disseminate information • Training • Lobbying of policy makers, the private sector, governments, the communities • Networking/consensus building • Best practice sharing | <ul style="list-style-type: none"> • Building partnerships with sustainable community groups – co-operatives, associations, burial groups, support groups, clans, etc., as change agents. • Collaboration with the media • Work closely with local and religious leaders, teachers, health care workers, development workers and traditional healers. • Develop and deliver culturally sensitive, appropriate and timely messages • Invite guest speakers from other communities to share lessons learned • Community exchange visits |

| Priority Area: Advocacy | |
|--|--|
| Action Needed | Strategies |
| <ul style="list-style-type: none"> • Lobbying at regional and international conferences • Networking and building links with governments, non-governmental organisations, donors and the private sector • Development and dissemination of advocacy tools e.g. videos, briefs and posters. • Self advocacy by older people | <ul style="list-style-type: none"> • Mainstream ageing and HIV/AIDS in development initiatives • Partnerships with HIV/AIDS agencies, NGOs, CBOs, government ministries and the private sector • Mobilisation of local human and material resources • Sharing information networking & regional co-ordination • Promoting greater involvement of older persons • Start with small interventions and grow |

| Priority Area: Policy development | |
|---|--|
| Action Needed | Strategies |
| <ul style="list-style-type: none"> • National policies on ageing need to include HIV/AIDS • HIV/AIDS policies must include ageing • Advocate the inclusion of HIV and ageing issues in poverty alleviation processes • Research/baseline data • Consensus building • Sharing of best practices • Implementation, monitoring and evaluation | <ul style="list-style-type: none"> • Target donors to include ageing and HIV/AIDS related issues in their programmes • Implementing agencies should include older people in their projects • Networking and collaboration of organisations working on HIV/AIDS issues |

| Priority Area: Direct Support | |
|--|--|
| Action Needed | Strategies |
| <ul style="list-style-type: none"> • Initiate pilot programmes with strong monitoring and evaluation components specific to HIV/AIDS e.g. care of the adult child • Mainstream older people's issues into HIV programmes • Mainstream HIV/AIDS into existing programmes • Needs assessments • Allow people access to existing training and services | <ul style="list-style-type: none"> • Learn, advocate, find resources, scale-up • Identify community support/network groups • Working with other institutions (CBOs, NGOs, the private sector, governments and international organisations) • Closely link community work with advocacy – highlighting what works, what are the issues, and experiences from the ground |

Priority Area: Research

| Action Needed | Strategies |
|--|--|
| <ul style="list-style-type: none">• Research areas (risk of infection for care givers; extent of the care role; economic impact; health impact; psychosocial issues; use of different health approaches; attitude of health workers; rights issues related to HIV)• Literature review and adapting information for different audiences• Disaggregate data by age and sex• Surveys and participatory appraisals• Influence academics to include ageing• Resource centre at local, national and global levels | <ul style="list-style-type: none">• Collaborative planning to avoid overlaps, minimise gaps and learn from others• Build strong alliances before starting research, between planners, policy makers, older people and implementers• Build on what has been done in terms of research, methodology, coverage and relevance• Effective dissemination to include advocacy and community action |

Appendix 1: HIV/AIDS and Older People – Mapping Experience

Prior to the workshop, participants were asked to prepare information about HIV prevalence in their countries and details of the work being implemented by their organisations in relation to HIV/AIDS. The information was displayed during the workshop and used as the basis for discussions relating to work being implemented in relation to HIV/AIDS and older people.

Mozambique

HAI-Mozambique, MONASO and the National AIDS Control Council compiled the following information.

a) Prevalence Data

| | |
|--|-------------------------|
| National HIV prevalence end of 1999 (adult) | 14.5% |
| National HIV prevalence 2000/01 (adult) – majority being people between 15 –29 | 16.0% |
| Number of infected people 1998 | 1.1 Million |
| Number of infected people 2002 | 1.9 Million |
| Estimated new infections (1999) | 700 per day |
| Deaths among adults (between 1998 – 2002) | 118,000–388,000 |
| Total number of adults over 50 years living with HIV/AIDS | 112,152 (8.7% of total) |
| People over 50 years living with HIV/AIDS | 112,152 |
| Females over 50 years living with HIV/AIDS | 51,962 |
| Males over 50 years living with HIV/AIDS | 60,189 |

Source: Impacto demografica do HIV/SIDA em Mozambique

| | |
|--------------------------------|-----------|
| Orphans due to HIV/AIDS – 1998 | 123,000 |
| Orphans due to HIV/AIDS – 2002 | 400,000+ |
| Orphans due to HIV/AIDS – 2010 | 1,134,169 |

Source: National Strategic Plan to combat STD/HIV/AIDS, 2000 – 2002

b) Policy and Strategy

- There is no national AIDS policy but there is a national strategic plan to combat STD/HIV/AIDS for 2000-2002 produced in March 2002. There is no mention of older people in the strategy.
- Each Ministry also produces its own strategy. Work with older people links to the Ministry of Women and Co-ordination of Social Action (MMCAS) policy which aims to:
 - Reduce the impact of HIV/AIDS on most vulnerable groups namely women, children and older people
 - Strengthen the capacity of families and communities to care for orphans from AIDS related deaths
 - Respond to the needs of the vulnerable groups within the existing mandate of MMCAS

Strategies

- Create positive/favourable attitudes in communities/agencies

- Strengthen institutional capacity
- Develop community capacity
- Implement micro-finance projects

Note: MMCAS strategy is supported by UNICEF

c) Programmes addressing the impact of HIV/AIDS on older people

Project: “Living Together” (targets orphans and vulnerable children living in households headed by older people in Changara District, Tete Province, Mozambique).

Project Implementer: HelpAge International – Tete

Project Partners: Community Based Organisations (existing): Provincial Directorate for Women and the Co-ordination of Social Action, National Association of Disabled Mozambicans, others (government and non-government).

Project Funder: UNICEF

Project Duration: 2 years (October 2001 – September 2003)

Project context:

- Older people (predominantly women) care for households affected by HIV/AIDS – both sick adult children and grandchildren
- HIV campaigns exclude/ignore older people
- Older people already vulnerable due to poverty and social exclusion
- Children with one parent dead are termed “orphans” as two parents are needed for ‘normal’ life and security.
- HIV/AIDS prevalence rate in Tete is one of the highest in the country (19.8-22.6% compared to 16% nationally) - “Tete corridor”
- Older people still have an educating role in the community
- HelpAge International is already in the second year of a three-year poverty alleviation programme working in 24 communities – the UNICEF project will start in 5 of them.
- CBOs, local resources etc already exist and the new project links with them → mutual strengthening.

Project Goal:

To strengthen the quality and ability of CBOs, family and community members to support vulnerable people caring for the terminally sick and orphans, and improve responses to needs and concerns of older people and orphans in the fight against HIV/AIDS in Changara district.

Project Purpose:

To enable older people living with the terminally ill and orphans to cope with the realities of HIV/AIDS, improve care of the sick, orphans and older people, and facilitate communities to support these vulnerable groups.

Project Outputs:

- Strengthened ability of older people, sick people and orphans to meet immediate needs – including family/community support and other resources
- Raised awareness on HIV/AIDS and civic rights.
- Community response to HIV/AIDS linked to key agencies at all levels
- Inclusion of older people, the sick and orphans in community life.

Project Activities:

- Meeting immediate needs – health, education and shelter
- Training and income generating activities via access to credit
- Information, education and communication via CBOs and partners
- Advocacy and lobbying at district, provincial and national levels
- Developing community networks

Project Key Strengths:

- Links HAI into UNICEF supported Ministry of Women and Co-ordination of Social Action (MMCAS) strategy
- Targets older people – specifically older women (previously ignored)
- Uses/based on an intergenerational approach
- Links with existing community development initiatives, local structures and resources
- Strengthens our advocacy position to lobby the inclusion of older people in future national policy
- Addresses needs of orphans – which national strategy identifies as a gap.

Project Key Challenges:

- To ensure needs and contributions of older people are included/addressed by other agencies – not just seen as a “one off”
- To operate successfully with staff and material resources (constraints)
- To be ‘exemplary’ as a model and pilot type project
- To disseminate lessons learned

ActionAid Kenya**Vision:**

To see poor and marginalised communities empowered to gain control over the causes of their vulnerability to HIV, secure basic rights and needs, live with dignity and achieve sustainable development in the face of AIDS.

Mission:

To create an acceptable environment for and to complement preventive activities, and to improve the capacity of communities to cope with the effects of the HIV epidemic using local resources through community initiatives.

Objectives:

- To reduce the rate of HIV transmission
- To mitigate the impact of HIV on society, particularly the poor and marginalised
- To lobby and advocate for pro-poor policies/practices addressing the rights issues of the epidemic, promote effectiveness of the national response.
- To integrate HIV/AIDS objectives into development and emergency work
- To promote participatory approaches to HIV, sexual reproductive health and gender.

Horizons Programme – Population Council

Horizons is a global programme designed to identify components of effective HIV/AIDS programmes and policies, test potential solutions to problems in prevention, care, support, treatment, mitigation and service delivery, and disseminate and utilise findings with a view to replication and scaling up of successful interventions.

Horizons started as a five-year programme (1997–2002) but has now been extended for another five years (2002–2007).

Horizons is implemented in partnership with ICRW, PATH, International HIV/AIDS Alliance, Tulane University and the University of Alabama. It works closely with local research and service delivery organisations to design and implement or undertake studies that address various aspects of HIV/AIDS. The project which involves a problem solving process comprises of five steps:

- problem identification and diagnosis
- strategy selection
- strategy experimentation and evaluation
- information dissemination and result utilisation

As a research programme, Horizons does not have an explicit geographic focus. Instead, it has a research agenda that it seeks to implement in one or more countries where the conditions for addressing priority questions and implementing study activities are favourable. There are currently programmes in Africa, Asia and the Latin America/Caribbean regions.

Summary of Horizons Research Agenda

The table below summaries the research areas of approaches of the Horizons project. In all this work, there are various cross-cutting themes namely gender roles; NGO capacity; community mobilisation and involvement; involvement of people living with HIV/AIDS; scaling-up strategies; behaviour change communication; cost issue and cost-effectiveness and addressing vulnerability.

| Research areas | Activities |
|---------------------------------------|--|
| Prevention | <ul style="list-style-type: none"> • Test gender-sensitive strategies to promote dual protection barrier methods and sexual risk reduction • Expand sexually transmitted infection prevention and management programs • Add Voluntary Counselling and Testing (VCT) in different settings • Scale-up prevention of mother to child transmission programmes • Test strategies to maintain safe sex behaviour |
| Access to treatment, care and support | <ul style="list-style-type: none"> • Service delivery – provide competence, infrastructure • Behaviour – adherence to anti-retroviral drugs, risk, behaviour • Equity – non discriminatory access to anti-retroviral and other drugs • Community – role of people living with HIV/AIDS/community groups • Private sector – involvement in treatment • Cost-effectiveness of providing treatment • Psycho-social care and support needs of people living with HIV/AIDS and care givers |
| Youth | <ul style="list-style-type: none"> • Add youth oriented components to adult programmes • Focus on high rate of infection of young women • Decrease girls dependence of transactional sex • Address the needs of youth living in households with infected adults • Change negative norms of gender and sexuality that put young men and women at risk • Test ways to provide youths with counselling and testing |
| Mitigation | <ul style="list-style-type: none"> • Address needs of OVC in urban areas • Strengthen community responses to caring for OVC • Develop interventions for assisting family care givers • Minimise burnout/dropout and stress among volunteers and |

| | |
|-----------------------------------|--|
| | professional caregivers. <ul style="list-style-type: none"> • Examine community based strategies to reduce property grabbing and violation of human rights • Access impact of economic strengthening programmes for vulnerable groups |
| Stigma and discrimination | <ul style="list-style-type: none"> • Test multifaceted community interventions to reduce stigma and discrimination • Assess approaches for creating people living with HIV/AIDS friendly health care settings • Work with the private sector to reduce stigma and discrimination through work place policies. |
| Determinants and policy responses | <ul style="list-style-type: none"> • Expand studies of structural approaches to ensure 100% condom use in sex establishments • Focus on understanding the inputs and processes to replicate and scale up successful interventions |

Elim Hlanganani Care of the Aged – South Africa

a) Prevalence Data

The prevalence rate among the over 50 years of age are:

| Age | Percentage |
|-----------------|------------|
| 50 – 59 Females | 7.0% |
| 50 – 59 Males | 5.5% |
| 60 – 65 Females | 5.0% |
| 60 – 65 Males | 5.0% |

b) Policy and research

- The national AIDS policy does not include older people
- No research carried out on HIV/AIDS and older people
- Older people do become infected and affected by HIV/AIDS

c) Programmes addressing the impact of HIV/AIDS on older people

Home Based Care and Support

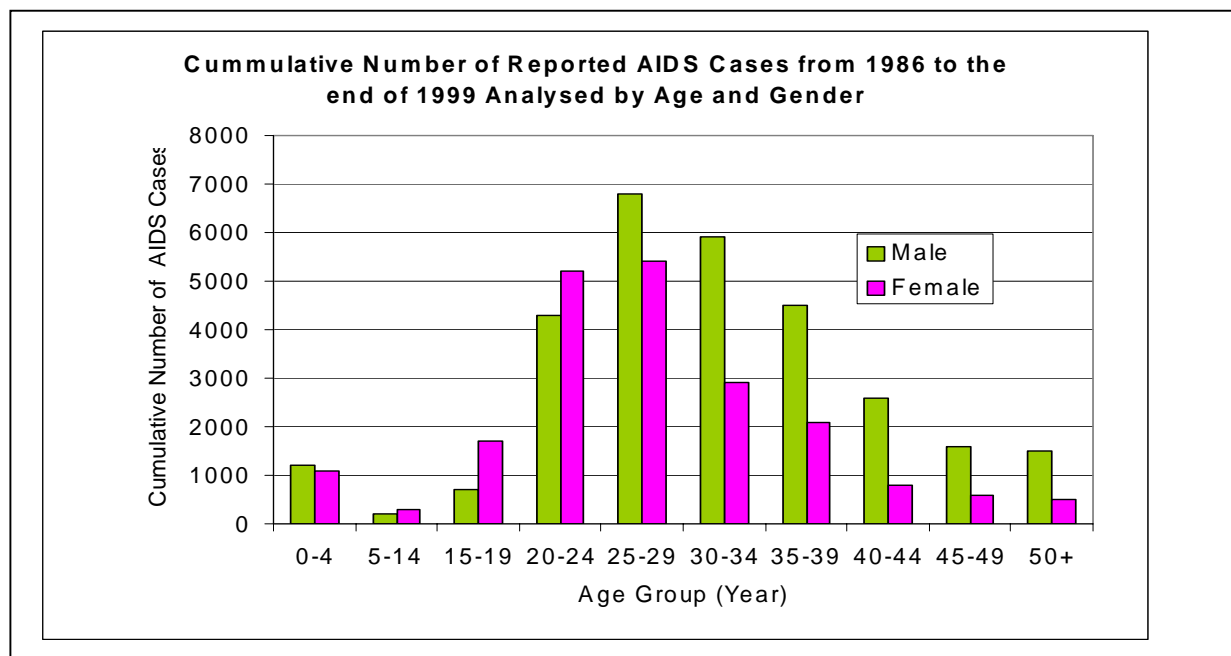
- Some of the aged (mostly literate and retired nurses) are trained to render home care nursing to fellow sick aged.
- Workshops and training of trainers who will render home care nursing
- Older people also render home based care for terminally ill patients who have been discharged from hospitals including HIV/AIDS clients
- The home care givers work in collaboration with the clinics and hospitals for the provision of home care e.g. treatment such as Panadol, gloves, bandages and solutions for cleaning wounds and food supplements in the form of mealie mix packs containing proteins, vitamins and minerals.
- Older people at Elim Hlanganani offer social support services to HIV/AIDS orphans and other poor children in the community (with the help of social workers, business and private sectors)

Income Generating Projects

- Activities include sewing, knitting and gardening so they get funds to help in the care of orphans and the poor.

HIV/AIDS Awareness

- Older people are given information on HIV/AIDS and the prevention thereof.
- They are involved in peer education and also visit schools providing health education - teaching the pupils how to care for their grannies.
- During events and celebrations the opportunity is taken to disseminate information on HIV/AIDS and prevailing diseases and how to prevent them.



d) Recommendations

- Include older people in our national policy on HIV/AIDS.
- Render more awareness campaigns for the elderly.
- Identify more suitable strategies and plans in giving health education to the aged on HIV/AIDS e.g. consider their culture, beliefs and maintain dignity.
- Promote and provide more funding for home care projects.

African Development Bank

a) Policy Level Responses

- The African Development Bank (ADB) has developed a strategy on HIV/AIDS to guide its operations and provide support to regional member countries (RMC).
- HIV/AIDS issues are included in the Bank's sectoral policies (agriculture, health, education, gender, governance, population, civil society).
- The bank has played an advocacy role through preparation of symposia/workshops and participation in the organisation of major regional and global conferences (Abuja, UNGASS, ICASSA)

b) Operational Level Responses

- Since the early '90s the Bank has been funding HIV/AIDS control activities in RMCs.
- Bank funded HIV/AIDS control interventions are stand-alone projects and components integrated in other sectoral projects/programmes.

- To date, it has invested US\$250 million in 23 countries and many are in the pipeline.
- The Bank funded operations include: institution building; enhancing the safety of blood transfusion; improving access to therapy; sensitising and educating population through information, education and communication.
- The Bank has also been engaged in raising awareness on HIV/AIDS among its own staff through preparation of briefs, organisation of events such as World AIDS Day, etc.

c) Main Features of the Bank Strategy

Conceptual Framework:

The strategy is based on the rationale that HIV/AIDS is a multi-sectoral development issue having a causal-effect relationship with all sectors including health

Institutional Framework:

The Bank, as a development finance institution having close collaboration with UN specialised agencies, NGOs/Civil Society, bilateral and multilateral organisations, can support HIV/AIDS control activities in Africa as part of its development operations.

Objectives of the Strategies:

- To assist RMCs in their efforts to develop and implement multi-sectoral HIV/AIDS control activities.
- To support the programs prepared and led by UN specialised agencies and other partners in the fight against the epidemic

Priority areas for Bank Group Intervention:

- Promotion of political commitment
- Support sectoral responses promoting decentralisation, community participation and ownership
- Strengthening of co-ordination to promote synergy

Strategies to achieve the objectives:

- Advocacy and policy dialogue
- Mainstreaming of HIV/AIDS issues in Bank operations
- Partnership development

Institutional measures for the implementation of the strategy:

- Strengthening of Bank internal capacity on HIV/AIDS through training
- Co-ordination of Bank HIV/AIDS control activities through a focal point
- Dissemination of information and preparation of progress reports annually
- Preparation of PRSPs and country strategy papers

Operational Measures

- Inclusion of HIV/AIDS issues in project preparation phase
- Monitoring and evaluation of implementation of the strategy
- Support to operational research in socio-cultural behaviour area to expand knowledge base on local circumstances and best practices

Rwanda

Prevalence Data

| | |
|---|---------------------------------|
| HIV prevalence rate among pregnant women in urban areas | 19 – 28% |
| HIV prevalence rate among pregnant women in non urban areas | 7.5 – 12% |
| HIV prevalence rate among people coming for consultation of STI | 41.8 – 54.9% |
| HIV prevalence rate among adult population | 11.2% |
| Estimated number of people (total) infected as at mid June 2000 | 370,000 – 400,000 |
| Estimated number of women infected as at mid June 2000 | 210,000 |
| Total number of AIDS orphans | 270,000 |
| Total numbers of deaths in 1999 | 40,000 – 50,000 |
| Risk of mother to child transmission | 25 – 30% |
| Prevalence rate among the young (12 - 24 years) in 1997 | 4.1% |
| Prevalence rate among age group 20 - 34 years | Women 1.5 – 2% more than men |
| Prevalence among boys aged 15 -19 years - school going | 9.4% |
| Prevalence among boys aged 15 - 19 years - non school going | 12.5% |
| Prevalence rate in the age group 15 - 19 years (urban) | 8.5% |
| Prevalence rate in the age group 15 - 19 years (rural) | 3.4% |
| Prevalence among girls of age 12 - 14 years - school going | 9.4% |
| Prevalence among girls of age 12 - 14 years - non school going | 5.0% |

Zimbabwe

a) National prevalence data

- First case identified in 1985
- 1.5+ million Zimbabweans infected, 400,000+ have developed AIDS
- More than 1,000 Zimbabweans die every week from AIDS
- 500,000+ orphans due to AIDS
- 25% of adults are living with HIV

b) AIDS Policies

Key issues

- Prevention is the only effective intervention to limit the spread of HIV/AIDS
- Health is key to development and growth
- Multi-sectoral response is required
- Encourage active participation
- Correct information is essential for behaviour change

Gender: Policies

- Provide equal opportunity for education and advancement
- Understand and respect sexuality
- Promote gender-sensitive HIV/AIDS programmes
- Encourage partner notification
- No tolerance of gender violence

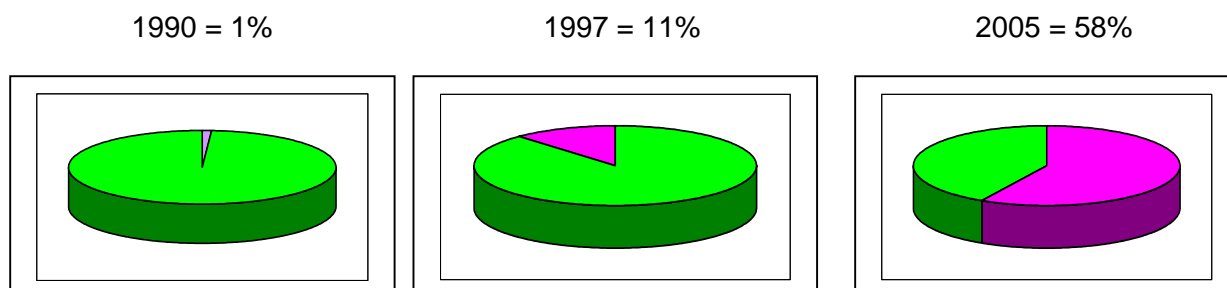
Gender: Strategies

- Change structures that perpetuate vulnerability of women
- Increase income-generating opportunities for women

- Promote equal access to education, land, equipment, and technology
- Promote equity in laws and practices

c) Cost of HIV/AIDS Care

Percent of MOHCW Budget devoted to HIV/AIDS care:



Sudan

a) Prevalence data

The official figures, taken from the AIDS/HIV Surveillance Report of October 2001 are given below.

| Number of cases | AIDS | Asymptomatic HIV | Total |
|---------------------|-------|------------------|-------|
| During this quarter | 138 | 118 | 256 |
| Cumulative total | 4,004 | 3,683 | 7,687 |

Total reported cases by the end of 2001 was 4,004. Report by year as follows:

| To '86 | 87 | 88 | 89 | 90 | 91 | 92 | 93 | 94 | 95 | 96 | 97 | 98 | 99 | 00 | 01 |
|--------|----|----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| 2 | 2 | 64 | 122 | 130 | 188 | 184 | 198 | 201 | 250 | 221 | 270 | 511 | 517 | 652 | 492 |

Number of AIDS cases by Age and Sex

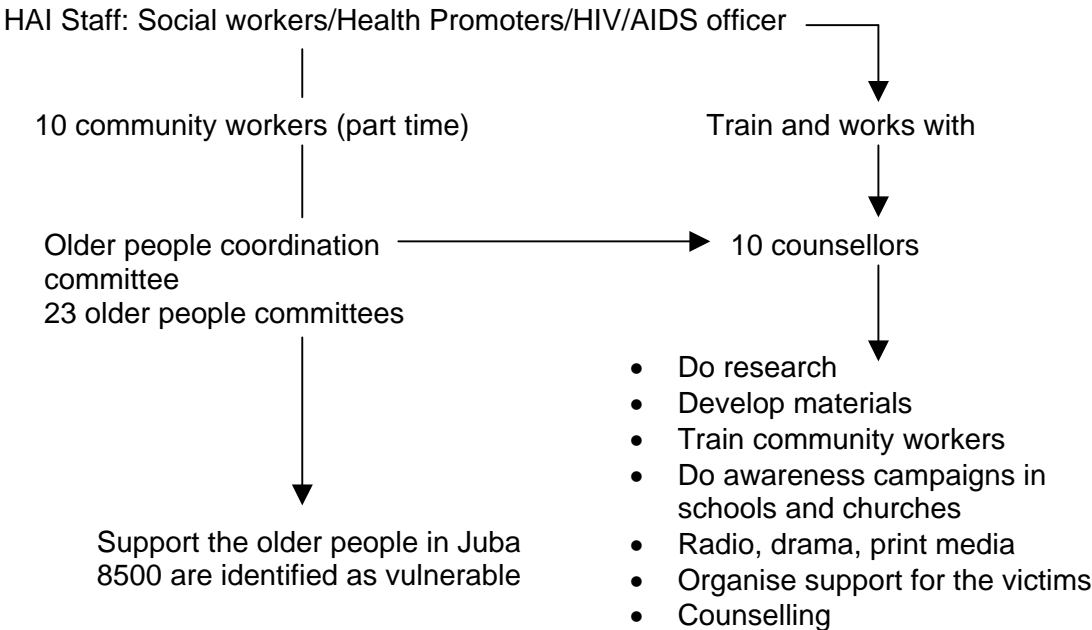
| Age | During this period | | | | Cumulative Total | | | |
|--------------|--------------------|-----------|---------|------------|------------------|--------------|-----------|--------------|
| | Male | Female | Unknown | Total | Male | Female | Unknown | Total |
| 0-4 | 3 | 1 | | 4 | 44 | 16 | | 60 |
| 5-9 | 2 | 1 | | 3 | 36 | 17 | | 53 |
| 10-14 | - | 1 | | 1 | | | | |
| 15-19 | 1 | 1 | | 2 | 90 | 33 | | 123 |
| 20-24 | 7 | 6 | | 13 | | | | |
| 25-29 | 17 | 7 | | 24 | | | | |
| 30-34 | 18 | 5 | | 23 | 1178 | 481 | | 1,659 |
| 35-39 | 15 | 6 | | 21 | | | | |
| 40-44 | 19 | 5 | | 24 | | | | |
| 45-49 | 9 | 3 | | 12 | 402 | 103 | | 505 |
| 50-54 | 6 | - | | 6 | | | | |
| 55-59 | - | - | | - | 150 | 41 | 2 | 191 |
| 60+ | 5 | - | | 5 | | | | |
| Unknown | | | | | 4 | - | 43 | 47 |
| Total | 102 | 36 | | 138 | 2,762 | 1,197 | 45 | 4,004 |

Results of HIV tests

| Groups Tested | During this Period | | Total during this year | |
|-----------------------------------|--------------------|------------|------------------------|------------|
| | Tested | Positive | Tested | Positive |
| High risk groups: | | | | |
| Prostitutes | | | | |
| Bar girls | | | | |
| Homosexuals | | | | |
| Injecting drug use | | | | |
| Blood recipients | | | | |
| Sexual contacts of AIDS | | | 5 | 4 |
| Prisoners | | | | |
| Suspected AIDS patients | 394 | 138 | 1,082 | 412 |
| Kidney donors | 17 | | 36 | |
| TB patients | | | | |
| Long distance truck drivers | | | | |
| Voluntary counselling and testing | 60 | 9 | 135 | 22 |
| Others (<i>specify</i>) | | | | |
| <i>Subtotal</i> | 471 | 147 | 1,258 | 438 |
| Low risk groups: | | | | |
| Blood donors | 13,340 | 79 | 36,559 | 320 |
| Pregnant women | | | | |
| In-migrants | 695 | 3 | 1,016 | 5 |
| Out-migrants | 9,221 | 27 | 27,340 | 179 |
| STD patients | | | | |
| Premarital | | | | |
| Other (<i>specify</i>) | | | | |
| <i>Subtotal</i> | 23,256 | 109 | 64,915 | 504 |
| Total | 23,727 | 256 | 66,173 | 942 |

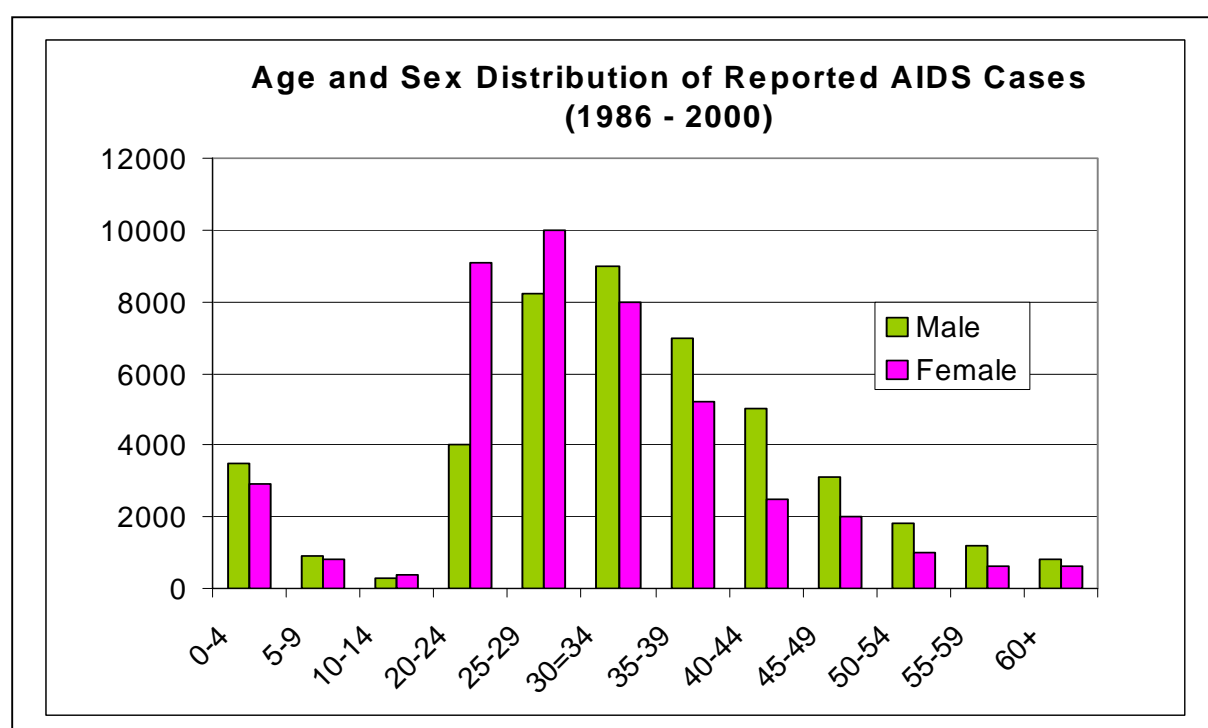
The above table presents the official figures for HIV prevalence, but may be underestimated because of war; geographical location; high population movements; 4 million internally displaced people of which more than 3.5 million live in Khartoum; immigration for work and migration.

b) Programmes addressing the impact of HIV/AIDS on older people



a) National prevalence data

- Adult HIV prevalence rate rose from 5.3% in 1990, to 13.2% in 1999. By the year 2000 it had stabilised at 14%. By the end of 2000, with the efforts of National AIDS Control Council and other programmes it had dropped to 13%.
- HIV spreads rapidly in Kenya, mainly through sexual contact (90% of infections)
- Prevalence is higher in urban areas (16–17%) compared to rural areas (11–12%)
- 80–90% of infections are among young people aged 15–49 years.
- Most AIDS deaths occur between the ages of 25–35 years for men, 20–30 years for women.
- HIV prevalence varies markedly between different regions, but all regions are affected



b) AIDS Policy

Older people are not mentioned specifically in the national AIDS policy. However the National AIDS Control Council takes a multi-sectoral approach, so community based programmes cover the burden of HIV/AIDS on the older people.

c) Research addressing the impact of HIV/AIDS on older people

Findings of the survey carried out by Family Planning Private Sector on the burden of care and support on grandparents for HIV/AIDS orphans, 1999–2000:

- Older people taking care of orphaned children are poor and worry about the children they cannot help. The responsibilities of finding food for orphans, counselling and disciplining them is a burden that older people do not have the strength to cope with.

- Despite many people dying of AIDS, older people in some communities still believe that their sons and daughters are dying of chiira (curse).
- The survey revealed that the major problems of orphans is lack of education due to financial difficulties as the burden of education support falls on the older people; older siblings and uncles. Orphans also need emotional support and adult guidance, food and income to meet their need for clothes, health and future prospects.
- AIDS creates insecurity and psychological problems amongst affected families, especially for children and elderly caregivers.
- The burden of care is thrust on older people, their inability to cope, the lack of alternative strategies arrived at coping with the burgeoning numbers of AIDS orphans in the socio-cultural systems and society's apparent belief that grandparents will take care of orphans.

d) Programmes addressing the impact of HIV/AIDS on older people

- HelpAge Kenya has recently (January 2002) conducted consultative fora with older persons in Nyando and Rangwe (Asumbi) districts. This is being developed into a proposal.
- HelpAge Kenya and HelpAge International in conjunction with UNIFEM held a two-day workshop in Kisumu in November, 2001. Theme: on community responses to HIV/AIDS "issues affecting the older persons".

The Family Planning Private Sector conducted a survey (1999–2000) on the "Burden of Care and Support on Grandparents for HIV/AIDS Orphans in Rural, Peri-urban and Urban Areas of Kenya" (see above).

WHO Activities

a) Ageing and HIV/AIDS in Africa - Project Objectives

- Create a body of evidence on the needs of older care givers
- Provide baseline information to inform policy makers on setting priorities and allocating resources
- Identify the barriers that prevent the provision of support in their care giving roles.
- Collaborate on programme interventions with government agencies, NGOs and the academia to maintain the health of older care givers.

b) Research reports

- Impact of AIDS on older people in Africa: Zimbabwe Case Study. Second draft report: December, 2001. World Health Organisation: Non-communicable Disease Prevention and Health Promotion (NPH), Ageing and Life Course (ALC).
- A methodological toolkit on the use of qualitative – quantitative methods to assess: The burden of AIDS related care on the older population. Research Guide (Draft)

Tanzania

a) Prevalence Data

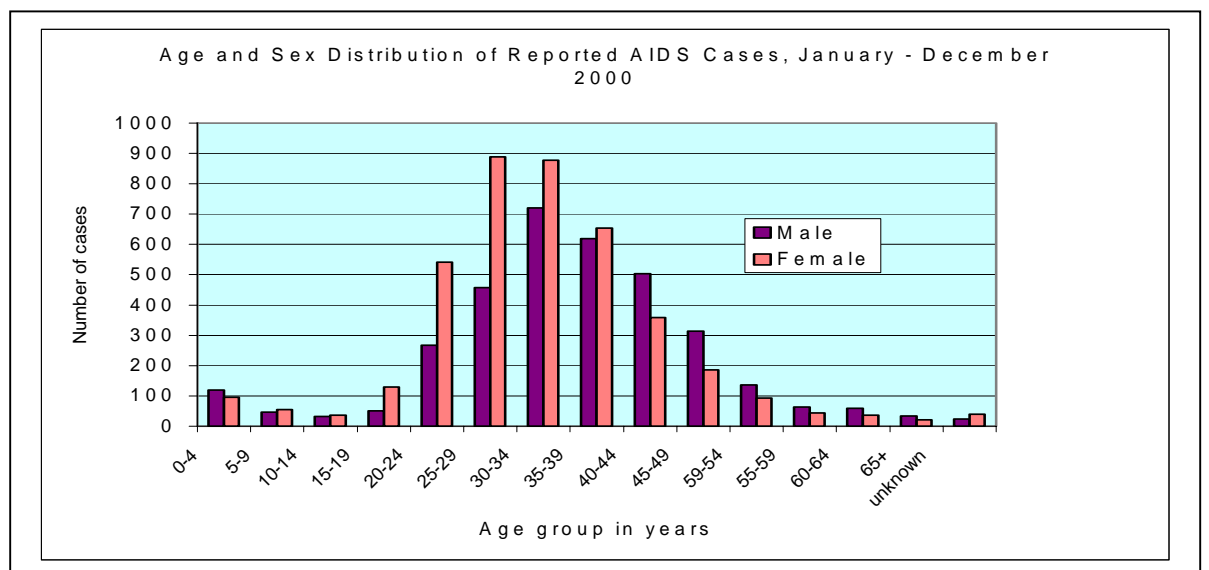
Distribution of reported AIDS cases by age and sex during 2000

Between January 1st and December 31st 2000, a total of 11,673 cases were reported to the National AIDS Control Programme (NACP) from the 20 regions of Tanzania mainland. This resulted in a cumulative total of 130,386 cases since 1983 when the first AIDS cases were diagnosed in Tanzania.

| Age | Male | % | Female | % | % Total |
|---------|-------|------|--------|------|---------|
| 0 – 4 | 209 | 3.7 | 182 | 3.2 | 3.7 |
| 5 – 9 | 69 | 1.2 | 70 | 1.2 | 1.3 |
| 10 – 14 | 44 | 0.8 | 52 | 0.9 | 0.8 |
| 15 – 19 | 81 | 1.4 | 198 | 3.5 | 2.4 |
| 20 – 24 | 389 | 6.8 | 812 | 14.2 | 10.3 |
| 25 – 29 | 741 | 13.0 | 1,236 | 21.6 | 17.0 |
| 30 – 34 | 1,091 | 19.2 | 1,143 | 20.0 | 19.2 |
| 35 – 39 | 890 | 15.7 | 868 | 15.2 | 15.1 |
| 40 – 44 | 708 | 12.5 | 473 | 8.3 | 10.2 |
| 45 – 49 | 425 | 7.5 | 232 | 4.1 | 5.7 |
| 50 – 54 | 196 | 3.5 | 120 | 2.1 | 2.7 |
| 55 – 59 | 99 | 1.7 | 54 | 0.9 | 1.3 |
| 60 – 64 | 84 | 1.5 | 42 | 0.7 | 1.1 |
| 65+ | 77 | 1.4 | 60 | 1.0 | 1.2 |
| Unknown | 577 | 10.2 | 177 | 3.1 | 7.9 |
| Total | 5,680 | 48.7 | 5,719 | 49 | 100.0 |

From: National AIDS Control programme: HIV/AIDS/STI Surveillance Report for 2000.

The NACP estimates that only 1 out of 5 AIDS cases are reported due to under-utilisation of health services, under-diagnosis, under-reporting and delays in reporting. Despite these limitations however, the data is believed to reflect the trend of AIDS cases in the country. According to the 2000 data, the region with the highest cumulative case rate was Mbeya followed by Dar-es-Salaam and Coast. The region with the lowest case rate was Mara.



| Marital status of Reported AIDS Cases for the Year 2000 | | Possible sources of infection for the reported AIDS cases for the year 2000 | |
|---|-------|---|-------|
| Married | 42% | Heterosexual | 77.2% |
| Single | 24.2% | Mother to child | 3.4% |
| Divorced | 6.6% | Blood | 0.4% |
| Separated | 4.2% | Not stated | 19% |
| Cohabiting | 1.9% | | |
| Widowed | 1.3% | | |
| Not stated | 17.6% | | |

Prevalence rate among the 50 age group

| Years | Females | Males | Total | % of total |
|-------|---------|-------|-------|------------|
| 50-54 | 120 | 196 | 317 | 2.7% |
| 55-59 | 54 | 99 | 154 | 1.3% |
| 60-64 | 84 | 42 | 126 | 1.1% |
| 65+ | 60 | 77 | 139 | 1.2% |

According to data of 2001, WAMATA registered 24 HIV+ people ranging from 50-58 years of age. 10 female and 12 males, in addition two of them are within the age range 60-68 years.

b) National Aids Policy

The national policy was released in November 2001. There is no mention of older people. The term "adults" is used throughout.

c) Research carried out on HIV/AIDS and older people

None known. HAI Tanzania is proposing some research as a means to identify focused areas of work.

d) Programmes addressing the needs of older people affected by HIV/AIDS

WAMATA is a national NGO supporting people living with HIV/AIDS and the affected. This includes "guardians" of orphans, many of who are older people.

HAI Tanzania is proposing a possible area of work, a draft outline is given below.

| Title Proposed Partners, locality: | Methodology/ Objectives: | Indicators | Constraint /support required |
|---|--|--|--|
| Tentatively known as: HIV/AIDS and Older People | The overall goal is to improve the daily lives of older people and of those they care for. | Research report, highlighting key issues which can be incorporated into components 2 and 3, and can be considered for integration into HAI's national programme. | No funds available as yet |
| Potential partners: Institute of Child Health (ICH) for component 1 | <u>Component 1:</u> Research: through use of surveys and focused discussions with older people, identify issues arising for older people in their role as carers (risk of transmission, emotional well being, resilience to vulnerability, | Increase in awareness of older people of the risks of transmission and older | If funds secured, need to include cost of additional staff member to |
| WAMATA (a national HIV/AIDS counselling support NGO) and, | | | |

| | | | |
|---|---|--|--------------------------------|
| <p>possibly, the Sukumaland Older Women's Programme (SOWP) in Magu District for component 2</p> <p>A range of national HIV/AIDS policy and service provision organisations for component 3</p> <p>Locality: component 1 could be undertaken in Magu and Dar-es-Salaam. Need to decide if component 2 will also take place in Magu and Dar-es-Salaam (there is potential to incorporate the work into the SOWP programme in Magu).</p> | <p>quality of care provided to orphans, sustaining community support).</p> <p><i>(at this stage from the findings we could identify aspects of the work which could be mainstreamed into the broader HAI programme in Tanzania).</i></p> <p><u>Component 2:</u> A practical community based project in collaboration with a local partner, addressing issues of older people's vulnerability within the context of HIV/AIDS. Inputs might focus on older people's need for education, income generation, and for safety networks based on social inclusion, support groups etc <i>(the aim being to strengthen resilience, reduce stress, increase capacity for care provision).</i></p> <p><u>Component 3:</u> Awareness raising: input into the national AIDS arena in terms of increasing awareness of the needs and rights of older people vis-à-vis national policies and practices on HIV AIDS.</p> | <p>people able to identify and use preventative measures</p> <p>Increase in number of older people able to generate some income to support themselves and those they care for.</p> <p>Increase in number of older people who are part of a social network of support from within the community (friends, neighbours, religious groups, other support group).</p> <p>Increase in numbers of AIDS awareness programmes that include the needs of older people within their work.</p> | <p>implement this project.</p> |
|---|---|--|--------------------------------|

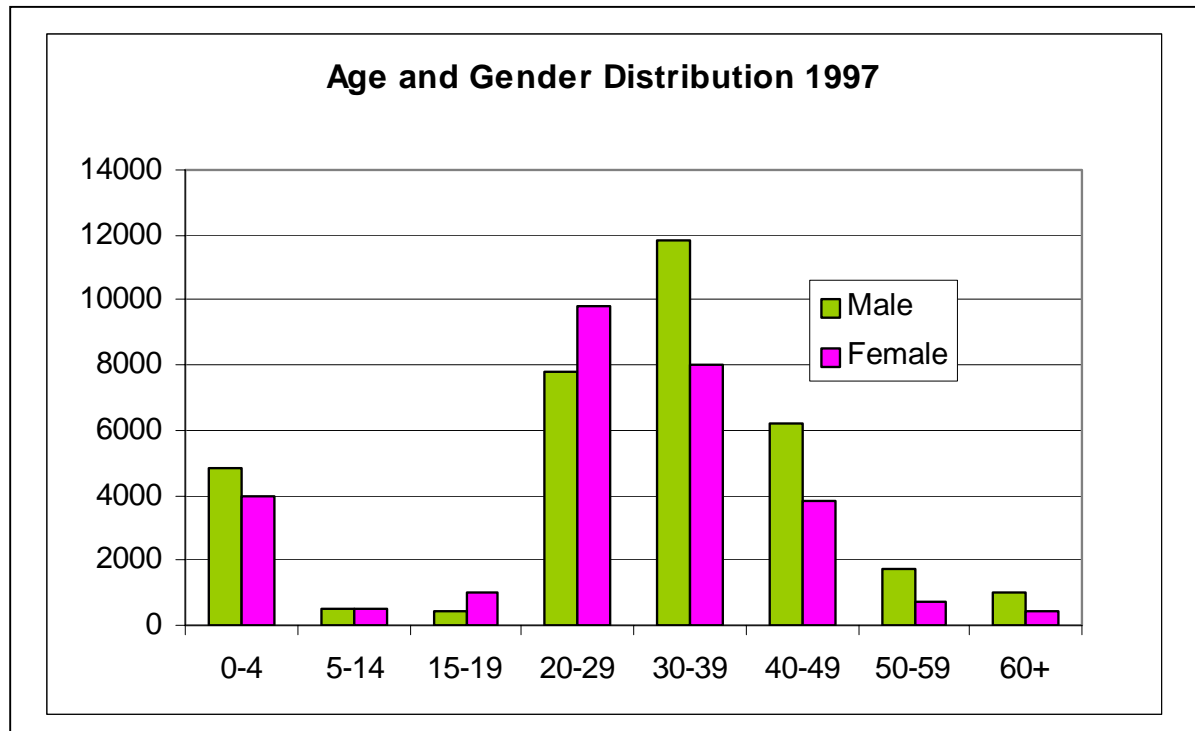
Africa Regional Development Centre

Current work related to HIV/AIDS and older people includes:

- Consultative workshop with older people in Kisumu, Kenya – supported by UNIFEM
- Dissemination of information on ageing and HIV
- Press releases – UN Day for Older Persons, World AIDS Day and others.
- Participation in UNGASS meeting resulting in older people being included in the outcome paper
- Participation in local and international fora to raise issues affecting older people
- Collaboration with WHO on HIV research in Zimbabwe and in other countries in future
- Supported development and resource mobilisation for HIV programme in Uganda
- Inclusion of HIV/AIDS in OAU Policy Framework and Plan of Action and Africa Common Position for WAA2
- Section on HIV in new training manual
- HIV an issue of older people in Africa video
- Feature issue at Africa regional workshop – Harare
- A topic at the Age Training Course (July 01, January 02).
- This Workshop!

a) National HIV/AIDS Prevalence Rates

- By the end of 1997 an estimated 1.5 million people had been infected with HIV since the beginning of the epidemic
- 1 in 4 adults is infected with HIV – overall, 20% of the population is HIV positive
- It is estimated that 2,000 people are newly infected with HIV each week.
- An average of 320,000 developed AIDS
- An average of 200 people die of AIDS each day.



b) National AIDS Policy

The National HIV/AIDS Policy does not very clearly mention older people

c) Research carried out on HIV/AIDS and older people

HelpAge Zimbabwe is the only organisation in Zimbabwe specifically focusing on issues affecting older people. In 1992 it carried out a survey in Karoi District to assess the impact of AIDS on older people. Results of the research indicated that the majority of older people care for at least two generations: their children first, and subsequently their grandchildren when their children die of AIDS. In Zimbabwe, older women carry the largest burden in caring for the HIV infected and affected (orphans).

d) Programmes that address needs of older people affected by HIV/AIDS

- Income generation programmes (HelpAge Zimbabwe)
- Payment of HIV/AIDS orphans school fees and uniforms (HelpAge Zimbabwe, NAC, ZNNP)
- Community home based care programmes (generalised care)
- HelpAge Zimbabwe/MOHCW/NAC/NGOs

Ethiopia

a) HIV/AIDS Situation in Ethiopia

1980s HIV began to spread in Ethiopia
 1984 the first 2 HIV infections evidenced
 1986 HIV prevalence estimated 7.4% of the total population
 2000 3.2 million people infected with HIV (70% rural, 13.4% urban)
 2000 750,000+ AIDS orphans

Prevalence in major towns

| | | | |
|-------------|-------|----------|-------|
| Addis Ababa | 16.8% | Bahirdar | 20.8% |
| Awassa | 11.5% | Diredawa | 13.6% |
| Gambella | 19% | Dilla | 11.7% |
| Desse | 7.5% | | |

Age and Sex Distribution of AIDS Cases

| Age group | Male | Female | Total | % |
|-----------|-------------------|------------------|--------|------|
| 0 – 4 | 173 | 165 | 338 | 1.6 |
| 5 – 14 | 23 | 25 | 48 | 0.2 |
| 15 – 19 | 256 | 845 | 1,101 | 5.1 |
| 20 – 29 | 4,894 | 4,511 | 9,405 | 43.6 |
| 30 – 39 | 4,846 | 1,949 | 6,795 | 31.5 |
| 40 – 49 | 2,169 | 647 | 2,816 | 13.0 |
| 50 – 59 | 670 | 203 | 873 | 4.1 |
| 60+ | 160 | 33 | 193 | 0.9 |
| Total | 13,191 (61.2%) | 8,378 (38.8%) | 21,569 | 100 |

Average age for female = 28 years
 Average age for male = 33 years

b) National HIV/AIDS Policy

National Policy issued in 1998 and Strategic Framework for Response to HIV issued in June 2001, but NO mention of older people.

c) Research on older people and HIV/AIDS

- Malualem Gurmess, “The Social Effects of AIDS on the Elderly: A Senior Essay”, Addis Ababa University, 1999.
- BRDC, “The Socio-economic Impacts of HIV/AIDS on KAP of HIV/AIDS STD Among Older People in Addis Ababa”, May 2001

HelpAge International Ethiopia supported both researches.

d) Priority given population groups:

- Youth
- Women
- AIDS orphans
- Farmers

- Commercial sex workers
- Mobile labour force
- Workers
- Uniformed people
- Refugees and internally displaced people
- PLWHA

e) Organisations implementing programmes

The Government agencies under Ethiopia multi-sectoral AIDS projects (EMSAP) are National HIV/AIDS Council (NAC), 12 regional (HIV/AIDS) councils, a zonal level HIV/AIDS co-ordinating committee and the Woreda/District/Level HIV/AIDS council.

NGOs are increasingly involved in HIV/AIDS work from time to time. They provide social support to orphans, PLWHA and affected families through health care, food, shelter, clothing, school materials, finances and counselling. HAI Ethiopia is actively involved with the Christian Relief and Development Organisation (CRDA), an NGO umbrella organisation, where they promote HIV/AIDS and older people awareness into their programmes. As a result, a few have developed posters depicting the impact of the pandemic on older people.

f) National Policy and Programme focus

Priority intervention areas:

- Information, education and communication, and behaviour change communication
- Condom promotion and distribution
- Voluntary counselling and testing services (VCT)
- Management of STI
- Blood safety
- Universal precautions
- Prevention of mother-to-child transmission (PMTCT)
- Care and support
- Legislation and human rights
- Surveillance and research

Ministry of Labour/Social Affairs with Ethiopian Elderly Pensioners Association (EEPNA) conducted an awareness raising workshop on older people and HIV in Ethiopia.

Uganda

a) Introduction

- AIDS in Uganda was first identified in 1982
- HIV Prevalence climaxed to about 18.5% among adults in 1992 but has declined to 6.1% in 2000 as reported from selected sentinel sites.
- There has been considerable reduction in the initial fear, panic, denial, myths and misinformation, stigma and discrimination.

b) Context

Progress attributable to:

- Enabling environment created by an attitude of openness and commitment from the highest levels of political leadership.
- Contribution of multiple partners: individuals, organisations, networks
- An overall supra-sectoral co-ordinating body
- Mainstreaming HIV/AIDS activities in all sectors
- Identifying priority areas and addressing them with appropriate strategies

c) Prevalence data

| National Prevalence of HIV | | Distribution of Adult AIDS cases by Age and Sex ('000s) | | |
|----------------------------|------------|---|----------|------------|
| Year | Percentage | Age (Years) | Male (%) | Female (%) |
| 1995 | 18.5 | 12-14 | 0.2 | 0.2 |
| 1996 | 15.25 | 15-14 | 0.4 | 2 |
| 1997 | 14.7 | 20-24 | 3 | 7 |
| 1998 | 9.51 | 25-29 | 6 | 7.2 |
| 1999 | 8.3 | 30-34 | 5.5 | 5 |
| 2000 | 6.1 | 35-39 | 3.5 | 3 |
| | | 40-44 | 2 | 1.7 |
| | | 45-49 | 1 | 0.8 |
| | | 50-54 | 0.7 | 0.5 |
| | | 55+ | 0.5 | 0.3 |

Source: HIV/AIDS Surveillance Report – June 2001

d) National AIDS Policy and Older People

- Not yet specifically targeted as a critical vulnerable group
- Addressed indirectly through general HIV/AIDS Strategies: Information, education and communication; voluntary counselling and testing, care, etc
- Examples of programmes: home based care, clinical management and follow-up, income generation activities, nutritional support, material and education support for orphans, psycho-social support
- Poverty Eradication Action Plan where AIDS is mainstreamed, favours the poor.

e) Key Implementers

- Government: MoGLSD, MoH, MoLG
- Faith Based Organisations, Catholic Secretariat, UMSC, UPMB...
- International NGOs: Action Aid, Meeting Point, LWF, World Vision,...'National NGOs; UWESO, TASO, NACWOLA, AIC, MACI, ...
- CBOs: numerous countrywide

f) Conclusion

- Older people are a critical group in HIV/AIDS
- Roles are crucial but vulnerable
- Uganda is scaling up the response broadly
- Older people should be a new special focus area

- This meeting on the topic is critical, timely and welcome
- Uganda delegation will learn and influence future strategies in NSF.

Barclays Bank of Kenya Limited

HIV/AIDS - PERSONNEL POLICY

a) Preamble

AIDS, though a disease like any other disease, has the unique feature that it has no cure. It is however as easy to contract AIDS as it is to prevent contracting it. The bank's policy on AIDS is based on this understanding.

The bank does not discriminate in any way against staff who are HIV positive or have developed AIDS. The emphasis is to provide information on preventive measures and to take possible and acceptable measures to protect themselves from contracting the disease.

The following is the bank's policy statement on HIV/AIDS:

b) Information, Education and Other Preventive Health Measures

The bank is to provide staff with updated information to enable them to protect themselves from HIV and to cope with the presence of AIDS. To this end the bank will:-

- Publish a general HIV/AIDS manual to be distributed to all staff.
- Introduce the subject of AIDS in locally organised training sessions. This will be through invitation of experts on the subject to lecture to course participants. One or two in service staff to go through training for that purpose.
- Invite NGOs and anti-AIDS groups to cover the bank in their anti-AIDS programmes.
- To cover the subject in staff meetings where staff discuss, in general terms, issues related to AIDS. The purpose here is to keep staff actively aware of the presence of AIDS so that they continue to take preventive measures.
- Introduce the subject in management meetings and conferences.
- Publish HIV/AIDS related topics in staff magazines.

c) Other Preventive Measures

The bank will in addition:-

- Have in place measures to reduce the frequency of motor vehicle accidents which are noted to play a role in the spread of AIDS through victims coming in contact with other passengers' blood or through transfusion of unscreened blood.
- Make condoms accessible to staff. These will to be initially supplied through the bank clinic.

d) Counselling Service

Human Resources Division to arrange AIDS counselling as follows:-

- Counselling by a senior officer in the welfare unit.
- Consoling through counselling bodies outside the bank.

This service is to be conducted in confidence. The service will also be available to staff who only require more information on AIDS. They need not be infected with the AIDS virus.

e) HIV/AIDS Testing

While the medical aid scheme covers AIDS ailments as it does any other disease, the bank shall in addition meet the charges of, at most, one AIDS test per any staff who strongly suspects he/she is infected.

This will however be on prior request by staff and will apply in cases where AIDS is clinically suspected. Such tests will be conducted on appointment by or through the bank's doctor and the results to be treated with confidentiality.

f) HIV/AIDS : The Terms of Employment

AIDS is to be treated like any other medical condition for purposes of medical aid cover and the granting of sick leave. The bank:-

- Is to allow HIV positive staff or AIDS patients to perform their normal duties as long as they are fit to work.
- Will not terminate the employment of such staff by the mere fact that they are HIV positive.
- Will not subject staff to HIV screening except upon their request or with their consent.
- Will not test pre-recruitment candidates for HIV or disqualify a candidate merely on the basis of being HIV positive. Fitness to perform bank functions is what counts.
- Will abide by requirements of other countries prior to posting staff in those countries for training or secondment. Where the said countries require testing prior to posting, then this shall be done, but again with the consent of the affected employee.
- Will make alternative working arrangements if ability to work is impaired by HIV related illness.
- Will consider retirement on medical grounds - with full benefits in accordance with the bank's pension scheme - if impairment due to AIDS renders staff completely incapable of carrying out bank duties.
- Will ensure that staff members with AIDS enjoy health and social discretion in the same manner as other employees suffering from other illness.
- Will continue to monitor the administrative, personnel and financial implications of the AIDS policy.

- Will ensure confidentiality regarding all medical information including HIV/AIDS status.
- Will endeavour to protect HIV/AIDS affected staff from stigmatisation and discrimination by co-workers, union or clients, where this is possible.
- Statistics and not names of reported cases will be maintained.
- Will train internal HIV/AIDS counsellors.

g) Barclays Staff AIDS Programme

Overall Purpose: Prevention and treat AIDS as a medical condition similar to other medical conditions.

Information: seminars, videos, booklets, talks/lectures - invited guests.

Protection: condoms.

Infected/affected: counselling, medical support.

Facilities available: staff clinic, counselling opportunities by staff and others, staff have the opportunity to elect beneficiaries in the event of death.

Other support: funeral support; coffin, transport (covers staff and immediate dependants irrespective of cause of death), death gratuity where applicable.

HelpAge International – UK Secretariat

- Global co-ordination of HelpAge International HIV/AIDS work
 - Policy/programme planning framework
 - Knowledge management
 - HIV/AIDS working group
- Policy development and advocacy
 - Mapping key development partners work and strategies on HIV/AIDS (UNAIDS, UNICEF, World Bank, regional development banks, Oxfam, ActionAid etc)
- Input to UK and EU government policy
 - UK all party Parliamentary group on HIV/AIDS
 - UK select committee on HIV/AIDS and international developments
 - EU Parliament through MEPS
- Ageing and Development seminar session on HIV/AIDS, attended by some 20 people from NGOs, academia and government (December 2002)
- UNGASS HIV/AIDS – held a side event IFRC lobbying delegates and organisations present, distribution of papers and HAI materials, achieved good press coverage and older people as carers are mentioned in declaration (June 2001)
- Member of UK AIDS consortium and STOP AIDS Campaign.

- Second World Assembly on Ageing Preparation
 - Workshop on HIV/AIDS at NGO forum
 - Side event to assembly
 - Input to declaration on international strategy for action on ageing
- Programme support/funding
 - Application of Framework to programme plans
 - Support to international offices programme development
- Review and support to annual plans
 - Active projects – Caribbean St. Vincent
 - Seeking funds – Sudan, Kenya, Zimbabwe, Cambodia
- Ongoing review of donor interest and call for proposals include Global Fund for AIDS, TB and Malaria
 - Support on proposal development and donor liaison

Appendix 2: Participants List

| | |
|---|---|
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