

# Mind the gap

## *HIV and AIDS and older people in Africa*



Leila Amanpour/HelpAge

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By the end of 2007, more than 33 million people worldwide were living with HIV, and AIDS was the leading cause of death in sub-Saharan Africa.<sup>1</sup> Tackling HIV in Africa has become one of the major priorities for African governments and the international community. But most programmes providing prevention, treatment and care exclude a key group from their work: older people.

HIV affects older people in two main ways. Large numbers of older people are themselves living with HIV. Many are also taking on vital caring responsibilities for loved ones living with HIV and the children orphaned by AIDS.

This briefing is aimed at the European Union (EU) and member states. It sets out the need to strengthen the response to HIV in Africa by providing interventions on the basis of genuine need rather than age. It highlights the ways in which older people can be infected with HIV and the vital support that many offer to their children and grandchildren. It also cites examples of interventions that have changed the lives of older people and those who depend on them.

# Key issues

## Risk of contracting HIV

In 2006, UNAIDS stated that a 'substantial proportion of people living with HIV and AIDS are 50 years and older'<sup>2</sup> and estimated that 2.8 million people aged 50 and over were living with HIV.<sup>3</sup>

National surveys bear this out. The Kenya AIDS Indicator Survey of 2007 showed that the prevalence rate for people aged 50-54 was 8 per cent, compared with 4.1 per cent for the 'high risk' age group of 15-24.<sup>4</sup> Figures from UNAIDS in 2005 revealed that in Botswana, the prevalence rate for people in their early 50s was 21 per cent, compared with 25 per cent of people aged 15-49; and that in Uganda, the rate for men aged 50-59 was 7 per cent – the same as the national adult rate.<sup>5</sup>

Nevertheless, older people continue to be excluded from HIV prevention, care and treatment services.

HIV programmes often discriminate against older people because of a misconception that older people are no longer sexually active and therefore not at risk of HIV. In fact, they are very much at risk, through the same routes as any other population group: predominantly through heterosexual sexual contact.

In certain respects, older people are at greater risk of HIV than younger adults. For example, in older women, menopause causes a natural thinning of the vaginal walls, leading to an increased risk of internal injury during sex and subsequent exposure to HIV. Meanwhile, customs such as wife inheritance (which increases vulnerability to non-consensual sex) and ritual cleansing (in which widows are expected to have sex with family or community members following their husband's death) increase older women's risk of exposure to the virus.

## New caring duties

HIV is causing a shift in household structure and responsibilities. At a time in their lives when many older people might expect to be supported and cared for by their own children, a growing number are taking on caring roles for younger adults living with HIV, and for the orphans and vulnerable children they leave behind.

### Sick adults

Sons and daughters often come home to their parents when they become ill, and older people find themselves caring for them and their children. Surveys in seven countries in sub-Saharan Africa revealed that around 40 per cent of people living with HIV were being cared for by older people, with each older carer supporting an average of two people living with HIV.<sup>6</sup>

### Vulnerable children

Many older people also play a vital role in caring for children whose parents are sick or have died of AIDS. A recent UNICEF report refers to 'the enormous burden

that orphaning is exerting on the extended family in general and grandparents – often grandmothers – in particular'.<sup>7</sup> The report found that in Tanzania, over 40 per cent of orphaned children, and in Namibia and Zimbabwe over 60 per cent, were being cared for by their grandmothers.<sup>8</sup>

Similarly, surveys undertaken by HelpAge International and partner organisations in east and southern Africa showed that an average of 55 per cent of orphans and vulnerable children were being cared for by older people, with each older carer responsible for an average of three children. In some communities in Kenya and Tanzania, older people were caring for over 75 per cent of orphans and vulnerable children.<sup>9</sup>

These new roles are having a huge impact on older people's lives, adding to the challenges they already face, including health problems, low income and discrimination:

**Economic impact** Illnesses can cause catastrophic effects on household income. The cost of caring for people living with HIV is great, but HIV responses rarely calculate or budget for the full cost of providing for a sick dependant. The needs of any children also fall to the carer.



***My daughter  
died of AIDS***

***I want my  
grandchildren  
to live***

Many older people affected by HIV have to meet extra expenses such as healthcare, school fees and burial costs despite having no regular income. For example, in Mozambique in 2006, caring for an orphaned or vulnerable child cost an average of US\$21 a month, while caring for someone with HIV cost US\$30. However, older people had an average monthly income of just US\$12.<sup>10</sup> From these figures it is clear that most older people simply cannot meet all the costs of even one child in their care – let alone several children plus adults living with chronic diseases.

This economic burden comes at a time of life when people's earning potential is much reduced – due partly to the physical impact of ageing, but also to age discrimination. Older people with productive assets, such as land, are often forced to sell these to meet the costs of caring for a son or daughter with HIV. This leaves them with nothing to fall back on to support their own needs and those of their orphaned grandchildren.

**Health and wellbeing** Older carers may already be trying to cope with declining health related to the ageing process, leaving them physically exhausted by caring and more susceptible to the opportunistic infections of those in their care. The emotional distress of caring for one's dying child also takes its toll.

**Social isolation** Many older carers become socially isolated because they cannot afford the time or money to take part in social activities or they face stigma associated with HIV.

**Antoinette, 60, from Uganda tells her story:**

**“One of my daughters died of AIDS. My other daughter has HIV and is very weak. My seven grandchildren are now living with me.**

**I wanted to help others with AIDS in my community, so I was trained as a home-based carer by Uganda Reach the Aged Association. I visit people who are bedridden and give them counselling and advice on their health.**

**I now know how to protect myself from HIV and am teaching my grandchildren too. Since older people have learned more about HIV and can tell the younger ones about it, people have started to respect us more.”**



Kate Holt/HelpAge



# Key issues continued

## Poor access to HIV services

The UN's international commitment to achieve universal access to HIV prevention, care and treatment services by 2010 must, by definition, include older people. Under this commitment, older people have a right to access the full range of HIV services, including:

**Prevention programmes** Older people are generally excluded from prevention programmes. The UNAIDS position paper *Intensifying HIV prevention*<sup>11</sup> omits older people from the list of key groups that it recommends that prevention programmes should target. Excluding older people from prevention programmes not only increases their own risk of exposure to HIV, but also prevents them from informing the young people they care for.

**Voluntary counselling and testing** Little is known about whether older people are accessing these services and what the barriers to access may be. In one small-scale study, older people said they felt that many services were aimed at younger people, and voiced fears about discussing their sexuality with younger staff. They were concerned about a lack of confidentiality, especially if they were hard of hearing and the counsellor had to raise their voice, or if they were unable to read the results for themselves.<sup>12</sup>

**Treatment** Many older people need access to treatment for HIV and related conditions, either for themselves or for those in their care. But with data on anti-retroviral treatment rarely disaggregated by age, it is not clear how many older people are obtaining treatment or what prevents them from doing so.

**Care and support services** Older people who are sick, or caring for others, need home-based support to meet their economic, health and psychosocial needs. However, few home-based care policies, programmes and guidelines address the specific needs of older people. Meanwhile, national standards are often clinically based. Some make reference to outreach with community care, but none address the needs of older people caring for others in their homes.<sup>13</sup>

## Lack of social protection

Households consisting of older people and children are particularly at risk of poverty.<sup>14</sup> Where other forms of social assistance are limited or non-existent, universal pensions can be a straightforward and cost-effective way to improve the health and income security of children and older people (especially older women).<sup>15</sup> Pensions also increase older people's status, material security and access to health services, and make it easier for them to send children in their care to school.

In the few sub-Saharan African countries that do offer them (Namibia, Botswana, South Africa and Lesotho), non-contributory pensions are acknowledged as a vital income support. They are used by older people and other household members for healthcare expenses, such as drugs or clinic fees, or related costs, such as transport and food – helping older people to maintain their health and livelihoods.

However, universal pensions alone are not sufficient, as eligibility depends on age. For example, in Lesotho, where the minimum eligibility age is 70, pensions do not help grandparents in their forties, fifties or sixties. Universal pensions therefore need to be part of a wider package of social protection measures that includes free basic healthcare, free education, child and disability grants, community social-assistance funds, and credit schemes.



*I thought having HIV was the end*

*now I feel more encouraged*

Older people – especially older women – often need support to claim social protection and other entitlements for themselves or those in their care. They may need legal advice, help with obtaining identity papers, financial support, or access to literacy programmes.

### Exclusion from HIV data

Older people are widely excluded from systems that track the HIV epidemic and the responses to it. In 2006 UNAIDS changed its global monitoring and reporting of HIV and AIDS, moving away from the conventionally used 15-49 year age group to focus on people aged 15 years and older, with no upper age limit. Today, its

### Ashagre, 65, from Ethiopia tells his story:

**“When I tested positive I thought that meant the end, but I was given anti-retroviral treatment, as well as medication for my TB.**

**I also began receiving a range of support from the Association of Older Persons Living with HIV. They give me about BR100 [US\$2] a month, which pays for rent and flour. Every three or four days they send a home-based carer to see me.**

**Most of the carers are HIV positive too, so they understand the fear and loneliness that someone like me can feel. They give me the advice and encouragement I need.”**



Kate Holt/HelpAge

annual global epidemic updates and reports provide data on AIDS deaths, new infections and numbers of people living with HIV for all adults over the age of 15.

However, UNAIDS still collects HIV prevalence data (percentage of the population with HIV) for those aged 15-49 only. Similarly, core indicators used to track progress in the HIV response, including on access to voluntary counselling and testing, sexual behaviour and condom use, exclude those aged 50 and over.

Focusing monitoring on such a narrow age range perpetuates the myth that older people are not sexually active, and suggests that increasing access to condoms and broader prevention efforts, including testing, is not a priority for people over the age of 49.

Indicators of health and wellbeing, and measures of income and support, are vital to enable governments and NGOs to respond more effectively to the impact of HIV and AIDS. If we are to gain a comprehensive picture of the impact of the epidemic at the national and international level, data must be collected for all people and disaggregated by age, sex and socio-economic status – particularly in high-prevalence areas.

There is also limited data available on who is providing care to people living with HIV or to vulnerable children, and on what support carers need and are receiving. Several cross-country studies describe where orphans live, offering some insight into who provides care. However, they seldom include a complete description of household composition.

Because older people are so extensively excluded from HIV monitoring and reporting, the following details are still largely unknown:

- country-level HIV prevalence among those aged 50 and over
- access to voluntary counselling and testing for those aged 50 and over
- sexual behaviour and condom use among those aged 50 and over
- the number of ‘skipped-generation’ households, where older people and children live together
- within skipped-generation households, the economic status, age and sex of the household head
- the number of households with only one or few adults caring for a large number of dependants
- the percentage of older-person-headed households, in which older people are caring for others living with HIV and AIDS, and for orphans and vulnerable children.

# Policy commitments

**A number of international policy commitments to tackling HIV include older people, but few of these are being met. Key policy commitments include:**

## **2001 UN Declaration of Commitment on HIV/AIDS**

This recognises the role played by older people, and pledges to adjust and adopt economic and social development policies to address the specific needs of older carers. The resulting **2006 Political Declaration on HIV/AIDS** also recognises the role of older people as carers of orphans and vulnerable children. It commits the international community to scaling up towards universal access to prevention, treatment, care and support by 2010. Despite these commitments and recognition of the role of older people, the indicators used to track progress in implementing the declarations neglect people aged 50 and over.

## **Millennium Development Goals**

Goal 6 is 'to halt and begin to reverse the spread of HIV/AIDS by 2015 and to achieve universal access to treatment by 2010'. However, a rapid scaling up of prevention efforts is needed if this is to be achieved. HelpAge is not aware of any international, regional or national-level prevention strategies that make explicit reference to older people. UNAIDS guidelines for intensifying HIV prevention list key target groups, but older people are excluded. The focus of the prevention aspect of Goal 6 is on the 15-24 year age group. Meanwhile, data on access to treatment is rarely disaggregated by age – especially for those aged 50 and over – so access by older people remains unclear.

## **Madrid International Plan of Action on Ageing (2002)**

This global agreement promotes the full realisation of all human rights and fundamental freedoms of older people in all countries. It calls for: improvement in the assessment of the impact of HIV and AIDS on the health of older people infected and affected; provision of adequate information, training in caregiving skills, treatment, medical care and social support; and recognition of the contribution of older people in their role as caregivers. However, these calls are not supported by other UN targets and commitments on HIV, or through the monitoring and data-collection systems.

## **European Programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis through External Action (2007-11)**

The programme reinforces the EU's political dialogue with countries on key issues relating to leadership and governance. It states that the dialogue should address the need for a comprehensive strategy with an appropriate balance between prevention, treatment, care and support; and that the dialogue should address other vulnerable groups, such as injecting drug users, prisoners, older

people and people with disabilities, as well as issues around stigma and discrimination.

The programme calls for country strategies to reflect the fact that family-based and community-based care often plays a crucial role in alleviating the burden of HIV and AIDS, including as an alternative to institutional care for orphaned and vulnerable children, and to take into account the age dimension, with reference to orphaned children and older people who often care for them and may need support to this end in terms of social protection.

## **Nokwazi, 62, from South Africa tells her story:**

**"Seven of my grandchildren live with me because their parents – my children – have passed away. They all had HIV.**

**I care for my sick son too. I was very sad when he was diagnosed because he was so supportive. I receive a state pension which I spend on food and rates. The Muthande Society for the Aged are also helping me apply for grants and school fee exemptions so that my grandchildren can continue going to school.**

**My biggest fear is that everybody depends on me – I worry about what will happen if I pass away."**

***I receive a state pension***

***so my family relies on me***



# Recommendations

HelpAge is calling for a major shift in the HIV response. In order to be effective the response needs to involve and support older people. This can be done by including people aged 50 and over in prevention, treatment, care and support programmes, and by setting up social protection schemes. There must also be greater inclusion of older people at all stages of HIV responses, from design to evaluation, at the international, national and local levels.

## Recommendations for EU and government action

HelpAge calls on the EU and its member states to:

1. Develop action plans for the EU Development Cooperation and bilateral donors that recognise the pivotal role that older people play in the HIV and AIDS response, and provide the support they need.
2. Work in partnership with African governments and civil society to develop national HIV and AIDS strategies that are inclusive of older people, and to increase practical support to older people, including those with caring roles.
3. Acknowledge the social exclusion and discrimination faced by older people affected by HIV and AIDS, in line with the commitment stated in the 2005 European Consensus on Development to tackling social exclusion and discrimination.
4. Support EU country delegations to increase their understanding of how HIV impacts on older people and their role in responses, and to focus greater attention on this issue in country strategies.
5. Improve aid mechanisms to provide predictable, long-term funding.

6. Support national governments to invest in social protection systems that support older people affected by HIV and AIDS and their dependants.

7. Use influence within UNAIDS and the UN General Assembly to press for a greater focus on the impact of HIV and AIDS on older people, and on their crucial role in the response to the pandemic – in particular:

- for HIV and AIDS monitoring to include everyone, rather than only those aged up to 49, and for all HIV and AIDS data to be disaggregated at 10-year intervals at least, by sex
- for recommended indicators for national reporting on the epidemic to include older people in relation to prevention, care and treatment
- for HIV and AIDS-related research to look specifically at the interactions between age and HIV.

## Recommendations for African governments and civil society

HelpAge calls on African governments and civil society to:

1. Promote public recognition of the value, contribution and rights of older carers.
2. Collect more comprehensive data about older carers, and ensure a more sophisticated analysis and understanding of their role, so that they can be better supported.
3. Improve access to existing services and rights.
4. Set up home-based care policies and programmes, including standards-of-care guidelines to address the specific economic, health and psychosocial needs of older carers.



Leila Amanpour/HelpAge



**When older people  
care for others**

**they need support  
themselves**

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**HelpAge International helps older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives.**

HelpAge International, PO Box 32832  
London N1 9ZN, UK

Tel +44 (0)20 7278 7778

Fax +44 (0)20 7713 7993

info@helpage.org

**www.helpage.org**

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Written by Rachel Albone and Emma Cain

Edited by Eleanor Stanley and Celia Till

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