

Stronger together

Supporting the vital role played by older people in the fight against the HIV and AIDS pandemic



Older people, particularly grandmothers, are shouldering the burden of caring for children orphaned by AIDS.

Summary

More than 40 million people worldwide are living with HIV and AIDS.¹ The number of children orphaned stands at more than 15 million and is forecast to rise to 24 million by 2010.² It is older people, particularly grandmothers, who are shouldering most of the huge emotional and financial burden as carers. Yet their vital role is going unrecognised. Older carers' strength and resilience are being put to the test and they

are not getting the support they need, either in social protection, healthcare or information. This must change urgently if the exacerbating relationship between HIV, AIDS and poverty is to be broken.

HelpAge International is calling for a major shift in the response to HIV and AIDS, one that includes older people and addresses their needs and caring responsibilities directly, through social protection and through HIV prevention, care and treatment services.

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HIV and AIDS: facts and figures

- **15.2 million children under the age of 18 have lost one or both parents to AIDS; 12 million in sub-Saharan Africa alone.**
- **By 2010, the number of orphans in sub-Saharan Africa is expected to rise to 16 million.**
- **Less than 10 per cent of children who have been orphaned or made vulnerable by AIDS receive support from outside their communities or benefit from educational or other public support.**
- **40-60 per cent of orphaned children not living with a surviving parent in Tanzania, Zimbabwe and Namibia are cared for by their grandmothers.**

Source: UNICEF 2007 *State of the World's Children*

Missed targets

In 2001 in its Declaration of Commitment on HIV and AIDS, the UN member states formally recognised the role played by older people and pledged to adjust and adopt economic and social development policies to address the specific needs of older carers. Six years on, more and more governments and agencies understand that in order to reach vulnerable children, their carers have to be targeted. Yet few national policies reflect the needs of older carers and only a relatively small number of NGOs and community-based organisations address them.

HelpAge International estimates that half of all older people in severely affected areas now care for adult children living with HIV and/or orphaned children. People over 60 make up 5 per cent, or 600 million, of the global population and are often among the poorest because of their reduced capacity to earn. As the epidemic increases, grandparents' responsibility for care will increase.

It is these vulnerable people, particularly women, who are coping with the rising costs and falling income that result from caring for orphans and other dependants. Child-focused agencies and others involved in HIV responses are failing to take this into account. HelpAge International is calling for a major shift in their approach, one that involves older people and addresses their needs directly through social protection and raised awareness.

This would not only help agencies meet their goals of improving the lives of orphaned and vulnerable children, it would also contribute to global and national HIV and AIDS objectives.

Harsh reality

Illnesses can cause catastrophic effects on household income. The cost of caring for people living with HIV is greater than the cost of antiretrovirals alone yet the full cost of providing for a sick dependant is rarely calculated or budgeted for in HIV responses. In addition, the costs of caring for children and the basic living needs which fall to the carer are rarely fully recognised. At the same time older women and men are invisible when it comes to allocating resources in the fight against HIV and AIDS.

In Mozambique women and men over 60 make up 5.4 per cent of the population³ but they care for 54 per cent of orphaned children.⁴ In 2006 HelpAge International's programme in the northern province of Tete calculated that caring for an orphaned or vulnerable child costs an average of US\$21 a month and caring for someone with HIV or AIDS costs US\$30. But with an average income for older people of just US\$12 a month, it is clear that an older person with such a low income simply cannot meet all the costs of even one child in their care, let alone several children plus adults living with chronic or infectious diseases.

'Skipped generation' households – consisting of older people and children – are on the increase. These older-headed households are emerging as a new category in several countries and the older and younger members can experience multiple layers of stigma and discrimination. Most are affected by the death or HIV status of a family member so can be subjected to AIDS-related stigma. But the impoverishment that AIDS can cause also lowers the status of the household members while older men and women face additional ageing-related discrimination or prejudice.

'Nobody in the community respects me because I am old, and my husband died of HIV. They don't see me as a human being and despise me for being here.'

Jennifer, an older woman from Kenya.

Older women and men often experience discrimination because of their age. They are considered not to be of productive working age and are refused access to HIV services and information on the assumption that AIDS does not affect them. And gender discrimination affects both male and female older carers. Women often have few or no rights to inheritance and property, which impacts particularly on older women who are widowed. And men who assume a caring role can also face discrimination by people who do not

respect them for taking on a role that is conventionally assigned to women.

It is also well documented that children who have been orphaned, who are vulnerable and who have fewer years of education are at greater risk of contracting HIV because they are more vulnerable to abuse and exploitation. Older carers assuming a parenting role need to be well informed and well resourced to provide a secure environment so that vulnerable children are less at risk.

‘I’ve talked to the grandchildren about AIDS and hope they are listening – prevention is the only way.’

Marcellina, an older woman from Sudan.

Cycle of Care

The Cycle of Care is a study of the impact of HIV on older people at household level in Thailand. HelpAge International’s partner in Thailand has developed a model which illustrates how HIV and AIDS impact on three generations over time. Because an older person can be at more than one stage of the cycle at a time, a range of responses are needed to support the whole household. HIV prevention, care and treatment services are vital, as is a social protection package: child support grants, disability grants, vulnerability grants and pensions all mitigate the financially crippling impact of AIDS.

	1. Family life before HIV	2. Weakening of family and loss of income	3. Morbidity and mortality	4. Older person as head of household	5. Grandchildren reach working age
Children Young generation	In school Cared for by parents Feel warmth and care	In school most of the time Caring breaking down Feel lack of warmth	School absentee Caring neglect Trauma of death of parents	School on/off Cared for by grandparents Loss of parents	Finish school and find work Care for grandparents Pressure to support
Parents Adult/middle generation	Economic earners Care providers for elderly and children	Work on/off Health weakening Concern for children	Stop work Sick Stress and physical pain Death	Deceased	Deceased
Grandparents Older generation	Retired from work Cared for by adult children Secure	Supplement family income Care for children and sick adults Insecure	Sole economic providers Carers for sick and children Stress of caring	Earners Carers Worried and weary	Retire Cared for by grandchildren Some security

Information gap

We know from field reports and qualitative studies that carers are overburdened. But national data must be collected and disaggregated by age, sex and socioeconomic status (SES), particularly in high prevalence areas. 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 AIDS and HIV.

The following is still largely unknown:

- The number of 'skipped-generation' households, where older persons live with children but without the middle generation, and in these households, the economic status, age and sex of the household head.
- The number of households where there are large caregiving burdens and only one or few adults to meet household needs.
- The percentage of older-person headed households where there are high caregiving burdens.

The collection of HIV prevalence data in household surveys is a recent and important advancement in quantifying the epidemic. If this data were more fully used we could better understand affected households and show:

- household composition by SES in affected families
- dependency ratios by household SES and the age and sex of the household head in affected families
- the number of most vulnerable children and people living with HIV or AIDS.

Several cross-country studies begin to describe where orphans live, lending some insight into who provides care, but they compare the world by regions, rather than fully describing the situation by country or smaller geographical areas. Also, while studies describe the relationship of orphans to the household head, a complete description of the household composition is overlooked, despite the implications for economic vulnerability.

The Tanzanian National Bureau of Statistics will include in its 2007 HIV indicators survey for the first time indicators to reveal who cares for children in the absence or sickness of parents and who cares for sick adults in the household. The results of the survey should reveal the carers of all ages and will provide important information to help inform the national HIV response.

Misconceptions about HIV and older women and men

1. HIV and AIDS do not affect older people

Older women and men are impacted severely by the HIV pandemic. UNICEF's recent 2007 *State of the World's Children* report recognises the vital role being played by grandmothers in the care of children orphaned by AIDS. 'UNICEF research in seven sub-Saharan countries⁵ reveals the enormous burden that orphaning is exerting on the extended family in general and grandparents – often grandmothers – in particular.' The scale of older women caring for the most vulnerable children ranged from 40 per cent in Tanzania to 60 per cent in Namibia and Zimbabwe. A similar burden of care emerged from surveys by HelpAge International and partner organisations, also in seven countries in sub-Saharan Africa,⁶ where older people, mainly women, were caring for 55 per cent of vulnerable children and each older carer was responsible for – on average – three children.

'I was living with my unmarried son at the time [when I tested positive for HIV] but he couldn't cope with my illness and was in denial. Because of my age, he was sure that the clinic had made a mistake. He thought HIV and AIDS was a young person's illness.'

Dorothy, 62, South Africa.

2. Older women and men are not susceptible to HIV infection

Older people are not sexually abstinent or immune from HIV. They are susceptible to HIV infection through the same routes of transmission as younger people and through specific risk factors. For example, menopause causes a natural thinning of the vaginal walls, and social factors include poverty leading to transactional or non-consensual sex (such as wife inheritance practices).

3. AIDS means there are no older people

A misconception has emerged that there are few or no older people in some developing countries because average life expectancy at birth has declined significantly in some high HIV prevalence countries due to the number of early adult deaths and, most significantly, due to child mortality. However, for those who do survive into adulthood, life expectancy is greatly increased. In Mozambique, for example, average life expectancy at birth is just 38 years but at 60 it is 14.5 years.

Universal access to HIV prevention, care and treatment for older women and men

To improve the quality of life for the countless millions of children, people living with HIV and AIDS (PLWHA) and older carers worldwide, policies and resources must be targeted at older women and men. The commitment to achieve universal access to HIV prevention, care and treatment services by 2010 must therefore embrace older people.

Because HIV information is largely targeted at younger people, older women and men have been indirectly, and in some cases actively excluded. A group of older women from Cambodia reported being turned away from HIV prevention sessions being run by local NGOs or governments because they were 'too old'. This story is repeated across developing countries. Older women and men have an equal right to HIV information and services that are age-appropriate and accessible. Given their crucial role in caring for sick adults and children, they should be provided with (and involved in the design of) appropriate care-giving information and training, including in the delivery of ARVs.

Much of the care that older people provide is considered home-based. However, most home-based care policies and programmes, including guidelines on standards, do not address the specific economic, health and psychosocial needs of older carers. National standards are often clinically-based and although some make reference to outreach with community care, none are sufficient and comprehensive enough to support those older women and men in their homes who care for sick adults and children.⁷

In addition to HIV-related services and information, older carers, especially women, must be given the necessary support including legal advice, financial support and literacy programmes, to access entitlements for themselves and those in their care. Older women's rights to food, shelter, land, equal recognition before the law and income must be realised so that they can support

themselves and their dependants. Denial of these rights exacerbates insecurity, poverty, and psychosocial trauma, which harm their own wellbeing and their ability to care for others.

Agencies designing and implementing HIV and AIDS programmes must ensure that older women and men with caring responsibilities are systematically involved in the design, implementation and monitoring of prevention, care and treatment interventions at household and community level. HelpAge International and its partner organisations can play a vital role here.

Pensions and social protection

In many African countries affected by HIV and AIDS, households comprising older people and children are particularly vulnerable to poverty. Many older people have no regular income, and yet face the often catastrophic extra expenses of healthcare, school fees and burial costs when they are affected by the pandemic. They are therefore disproportionately affected by poverty and HIV. A proven way to ease the extra financial burden experienced by older women and men as carers of the most vulnerable children and people living with HIV and AIDS (PLWHA) is through implementing social protection measures.

A range of these measures is required to support families, including cash transfers, health and social services, food or living subsidies, and work programmes. One form of social protection which would be relatively straightforward and cost-effective to implement, and at the same time would particularly benefit older women, is social pensions.

Direct support in the form of a cash transfer to older people alleviates the impact of HIV and AIDS by providing financial resources for the care of very vulnerable children and orphans, enabling HIV-positive people to access treatment, and reducing the demands on older people who frequently care for their HIV-positive children in addition to grandchildren.

Where there are high proportions of children and PLWHA being cared for by older women and men, and particularly where other forms of social assistance are limited or non-existent, social pensions can be an effective way to support living standards among older

people and children simultaneously. Regular cash transfers (such as social pensions, child benefits or disability grants) can be used for healthcare expenses, such as drugs or clinic fees, or related costs, such as transport and food. Where transfers facilitate antiretroviral treatment, this can enable HIV-positive people to regain or maintain health, look after themselves and continue in remunerative work, strengthening livelihoods and reducing the likelihood of children being orphaned. Social pensions can enable older carers to better provide for themselves and their dependants, and reduce anxieties about making ends meet.

‘Without a pension I wouldn’t be able to buy food, pay bills or send my grandchildren to school.’

Emily, from South Africa, aged 74.

Universal social pensions are increasingly recognised as a win-win policy, not only for reducing the poverty of older people and their dependants but also for increasing older people’s status, material security and access to services. Pension income often goes towards children’s health, education and better nutrition, therefore contributing to meeting the Millennium Development Goals on hunger, education and health. In the few sub-Saharan countries that do offer this in the form of a social (non-contributory) pension (Namibia, Botswana, South Africa and Lesotho), it is acknowledged as a vital income support.

In addition to the direct benefits for older people and their families, the wider community and economy are helped too. Small cash injections into cash-poor areas can have substantial benefits to local businesses and trades without a negative inflationary effect. In the longer term, a regular predictable cash transfer can interrupt the cycle of poverty and increase the health and wellbeing of the next generation.

Pensions in action

Lesotho, the mountainous country contained within South Africa, introduced a universal old-age pension in November 2004. Two thirds of the population of 2.1 million live below the poverty line and there are about 100,000 orphaned children.⁸ Most grandparents in remote areas look after several grandchildren.

Those aged 70 and above are eligible for the monthly sum of M150 (US\$25) – some 70,000 people, according to the Bureau of Statistics, or 3.6 per cent of the population. The benefit is equal to the official national poverty line for a single person, and is explicitly intended to eliminate old-age poverty.

The Ministry of Finance and Development Planning has acknowledged that the monthly pension is modest. However, the plan is to increase it in line with any economic growth in the coming years. And extending Lesotho’s social pension to all eligible citizens over 65 would increase the cost to a still affordable 2.5 per cent of GDP from around 2 per cent now.

Pensions are paid directly in cash through the post offices, in the presence of the military and police officers. Other public buildings such as health centres, courts, chiefs’ offices and schools are used as additional pay centres. The involvement of the military and the police in the delivery of cash to the pay centres has brought a sense of safety to the pensioners, the government says. A military helicopter is used to reach some remote areas that are inaccessible by road.

International commitment to social protection

Several international commitments recognise the right to social protection. The Universal Declaration of Human Rights states that 'everyone has a right to a standard of living adequate for the health and dwelling of himself and his family... and to security in the event of unemployment, sickness, widowhood, old age or other lack of livelihood in circumstances beyond his control'.

This is reiterated in the Madrid International Plan of Action on Ageing (MIPAA 2002) and in the 2002 African Union Policy Framework and Plan of Action on Ageing (AUPF and PoAA 2002). More recently the Livingstone Call to Action in 2006, signed by representatives of 13 African governments, called on all AU members to develop national social protection plans.

Broader and deeper social protection

Non-contributory pensions make a significant impact on reducing poverty and vulnerability among households with older people. The appeal of the pension is its universality. However, even when a social pension is in place, grandparents in their forties and fifties are obviously not eligible if the minimum age is 60 or even 70, as it currently is in Lesotho. And where pensions are modest and do not cover all the usual expenses faced by parents or carers, a broader social protection package is required to reach carers of all ages.

Social pensions therefore need to be part of a wider package which includes free and appropriate basic healthcare, free education and other social transfers including child and disability grants.

Other social protection tools

Pensions are not the only benefit that can make a big difference in tackling the impacts of HIV and AIDS. In South Africa, foster-care and child-support grants also alleviate the financial, social and emotional strain on older people and carers who take in orphans and vulnerable children.

However, it is vital that those who are eligible for such grants know

their rights and understand how to apply. Public awareness campaigns have seen the take-up rates for these grants increase dramatically, although 1 in 5 eligible older people are still not accessing pensions. Agencies and governments must ensure that the most vulnerable are reached. A benefit is no use at all if complicated administrative procedures or problems with documents mean it is not accessed.

Other social protection mechanisms that can alleviate the financial stress on households affected by HIV and AIDS include burial societies and community social-assistance funds. Schemes that make credit and low-interest flexible loans available to older carers and young people can also be invaluable.

In Mozambique, older people have set up support groups to cut the costs of care and increase income. Small businesses raise money that goes into a social fund run by older people's committees. It pays for transport to testing centres and ART clinics. Living Together, a project run by HelpAge International since 2002 with UNICEF funding, reaches almost 70,000 people in Changara District.

Also in Mozambique, poverty certificates exempt holders from all school fees and costs. Living Together has raised awareness of these and helped people apply.

Conclusion

Every nation affected by the HIV pandemic – every community – must find its own way to ease the financial and emotional burden on carers. But there is clearly a need for greater awareness of the impact on older men and women and of possible support mechanisms. Governments and civil society must adopt policies and practices that support and assist older carers and the children and PLWHA in their charge.

HelpAge International is advocating for resources and support for older carers, particularly women.

HIV prevention, care and treatment services do not currently cater for older women and men, yet they have the same right to them for themselves as well as for those in their care. Social protection, cash transfers, targeted information and explicit policies for older people are the most effective way for governments and agencies to reinforce these vital efforts in caring for orphans and other dependants affected by HIV.

Older women and men are providing a huge amount of care to children and adults in resource-poor settings with little or no external support. Social protection can have a positive impact on poverty, AIDS impact mitigation and HIV prevention. It can enhance someone's ability to parent and protect the children in their care. It therefore makes clear sense to link these two issues: targeting social protection at older carers could reach big proportions of AIDS-affected and poor and vulnerable households. The many millions of older women and men who are caring with strength yet silence are long overdue proper recognition and support.

Action

HelpAge International is calling for:

- **Public recognition of the value, contribution and rights of older women carers to reduce stigma and discrimination against them.**
- **More sophisticated analysis and understanding of the role of older women and men in caring for vulnerable children, and for adults and children living with HIV, so that urgent support can be targeted at these older carers.**
- **Better support to access existing services, for example, help with transport costs, identity papers, legal paperwork, access to ARVs, waivers and subsidies such as school grants.**
- **Home-based care policies and programmes, including standards of care guidelines that address the specific economic, health and psychosocial needs of older women carers and support them in their care giving roles.**
- **Agencies designing and implementing HIV and AIDS programmes to ensure that older women carers are systematically involved in the design, implementation and monitoring of prevention, care and treatment interventions at household and community level.**
- **Further research and collection of age and gender-disaggregated data, on infection rates and on access to treatment, including for people over 50, to design and implement appropriate HIV and AIDS policies and programmes that meet the rights and needs of older women carers.**
- **Older carers to be provided with economic support, in the form of a social pension or other cash transfer, to help with the costs of care, to avoid distress sales of assets, and to compensate for the time taken away from income earning activities and allocated care.**
- **Older people's rights to food, shelter, land, equal recognition before the law and income be realised so that they can support themselves and their dependants. Denial of these rights exacerbates psychosocial trauma which negatively affects their own well-being and their ability to care for others.**
- **Older carers to be provided with the necessary support including legal advice, financial support and literacy programmes, obtaining documentation needed to access entitlements for themselves and those in their care.**
- **Older women carers' rights to information on HIV prevention, transmission, care and treatment which is age-appropriate and accessible be recognised, in order to protect and care for themselves and their dependants. Older women carers must be provided with and involved in the design of appropriate care-giving information and training, including in the delivery of ARVs.**

- 1 UNAIDS December 2006
- 2 UNICEF 2007 *State of the World's Children*
- 3 There are one million people over 60 in Mozambique
- 4 From evidence and data from eight communities in Changara District in Mozambique (January 2007)
- 5 Burkina Faso, Cameroon, Ghana, Kenya, Mozambique, Nigeria and Tanzania
- 6 Ethiopia, Kenya, South Africa, Sudan, Tanzania, Zimbabwe and Uganda
- 7 Miller C, *Counting Carers*
- 8 Lesotho Ministry of Finance and Development Planning, 2006

HelpAge International is a global network of not-for-profit organisations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives.

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