

Forgotten families

Older people as carers of orphans and vulnerable children



HelpAge International is a global network of not-for-profit organisations working with and for disadvantaged older people worldwide to achieve lasting improvements in the quality of their lives. Web: www.helpage.org

The mission of the **International HIV/AIDS Alliance** is to support communities in developing countries to play a full and effective role in the global response to HIV/AIDS. Web: www.aidsalliance.org

Acknowledgements

The authors would like to acknowledge the valuable inputs from UK and international staff of HelpAge International and the International HIV/AIDS Alliance, Gertrude Mwape, Shyam Sundar, Simon Tunkanya and Thomas Varghese for the reports developed in Zambia and India, and to the International HIV/AIDS Alliance Zambia for their support with this work. Many thanks also to Nec Chipfupa and HelpAge International Mozambique, Maisoon Bukhari and HelpAge International Sudan, Amleset Tewodros of the HelpAge International Africa Regional Development Centre and Godfred Paul and Usa Khiewrord of the HelpAge International Asia Pacific Regional Development Centre.

The case studies draw from fieldwork undertaken by the international offices and partners of HelpAge International and the International HIV/AIDS Alliance. First names have been used in order to protect anonymity. If you would like further information on any of the programmes or stories, please contact the authors of this report.

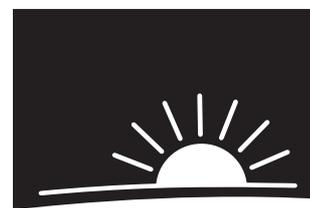
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Registered British charity numbers 288180 & 1038860
ISBN: 1 872590 187

Front cover photograph: John Cobb/HelpAge International
Back cover photograph: Brent Madison/HelpAge International

This publication was made possible through the generous support of both the US Agency for International Development (USAID) under the terms of the International HIV/AIDS Alliance's Award Number HRN-G-00-98-00010-00, and Help the Aged (UK). The opinions expressed herein do not necessarily reflect the views of these donors.



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As the HIV/AIDS epidemic strikes at the heart of family and community support structures, large numbers of older people are assuming responsibility for bringing up orphans and vulnerable children. Family structures are changing. Often the middle generation – both men and women – is completely absent, leaving the old and young to support each other. This means that families of older carers and orphans and vulnerable children are compelled to take on new roles.

- Current global figures estimate that 16 million children under 15 have already lost either one or both parents to HIV/AIDS.
- Recent studies found that in South Africa and Uganda, 40% of children were living with their grandparents, and in Zimbabwe, over half.

Older people make up a significant proportion of the poorest, and HIV/AIDS exacerbates the extreme poverty faced by older-headed households. This compromises the ability of older carers to care adequately for children (as they face difficulties obtaining sufficient food, clothes and shelter), and limits their access to health care and education services. The financial burden of caring for children means older carers are often forced to sell their assets or borrow money.

The scarcity of HIV/AIDS information for older people limits their ability to protect themselves and their families. Older people should be playing a key role in HIV/AIDS prevention within their communities and families. To date, the role of older people as counsellors and educators has not been sufficiently recognised in community-based and national HIV/AIDS prevention programmes.

The trauma resulting from the loss of family members and the stigma of being affected by HIV/AIDS can result in high levels of exclusion, for older people and for orphans and vulnerable children, leaving them feeling ashamed and alone. Many older people feel they are failing in their role as a carer because they are unable to protect their family from social isolation.

Nevertheless, mutually supportive relationships between older carers and orphans and vulnerable children are being forged as a result of the epidemic. While difficult economic conditions can undermine these relationships, the advantages of keeping children with their remaining family members, whenever possible, are evident.

'Our grandmother is so wonderful. She helps us in so many ways. She feeds us, dresses us and brings us up properly. When we see her, we see our mother. If she were not here, we would have been scattered around other families and would not be treated in the same way. We are so grateful that she is still with us.' Catherine, 15, the eldest of eight grandchildren being cared for by Irene, 80 years old, in Malawi.

This report shows that – provided appropriate support is available – older people and orphans and vulnerable children can overcome some of the challenges posed by the HIV/AIDS epidemic. The case studies featured in this report describe innovative ways of dealing with some of the difficulties faced by older-headed households. These community-driven programmes powerfully demonstrate the impact that minimal additional resources and appropriate technical support can have. They cover a wide

range of responses, including the use of non-contributory pension schemes in South Africa, home-care services in Zambia (which have enabled families to stay together), and training for older people to be counsellors in Sudan. In Vietnam, older people's clubs, led by local leaders, are helping older people to cope with the stigma and discrimination in their communities.

Collaborative action is required to ensure that the intergenerational and socio-economic impacts of HIV/AIDS are fully recognised. There are different, but important, roles for all actors:

- National governments have a key role in prioritising funds for social spending and ensuring there are progressive legislative frameworks in relation to HIV/AIDS (in anti-discrimination, inheritance rights and income support).
- International development institutions, such as the UN and the World Bank, should ensure access to sustainable funds.
- International non-governmental organisations need to develop innovative and community-driven programmes, as well as being key partners for supporting, and advocating for, improved governmental programmes.
- Community-based organisations have a vital role in articulating and designing programmes, as well as implementing them.

If international commitments on HIV/AIDS and poverty reduction are to be met, the following recommendations need to be implemented at local, national and international levels:

1. Provide direct income support to address the financial needs of older carers of orphans and vulnerable children.
2. Ensure policies and programmes designed to meet the health needs of families affected by HIV/AIDS include older people and orphans and vulnerable children.
3. Ensure access to universal and flexible education services for orphans and vulnerable children that recognise their changing roles, time commitments and financial constraints.
4. Provide older people with information and training on HIV/AIDS and the rights of children and older people.
5. Develop policies and programmes that address the psychosocial needs of older carers and orphans and vulnerable children.
6. Ensure the involvement and participation of older carers and orphans and vulnerable children, in community structures, and in formulating national policy for poverty reduction and supporting families affected by HIV/AIDS.
7. Undertake research and collect comprehensive age-disaggregated data on the needs and roles of older people and orphans and vulnerable children, to design HIV/AIDS interventions that are inclusive of older people.

These recommendations form the basis of an agenda for action. There is a 'moral imperative' for those responsible to care 'for all whose lives have been devastated by HIV/AIDS',¹ to ensure that families of older carers and orphans and vulnerable children are not forgotten.

¹ UNAIDS, *Declaration of Commitment on HIV/AIDS*, United Nations General Assembly Special Session on HIV/AIDS, fifth priority, 2001, p. 2.

Introduction

'If the parents leave the children, you just carry on with it. You have no choice.'
Pauline, aged 87 years, Pretoria, South Africa. Her daughter died of AIDS two years ago.
Now she has three young grandchildren to look after.

The extent of the crisis

HIV/AIDS is striking at the heart of family and community support structures for the old and young, and is leaving a whole generation of children to be brought up by their grandparents. Current global figures estimate that 16 million children under 15 have already lost either one or both parents to HIV/AIDS, and that another 40 million children will lose their parents within the next 10 years.² Millions of children are living with parents who are sick, and many more are living in households headed by older people³ who are struggling to provide care for a number of orphans.

Older people have always been involved, to some extent, in the care of children. However, as a result of HIV/AIDS, the problem now is the increased extent of this care. The numbers of older people who are now taking full responsibility for the care and upbringing of orphaned children is alarming.⁴

Recent World Bank studies found that in 20 out of 28 countries in Africa and Latin America, more than one-fifth of orphaned children were living with their grandparents. In South Africa and Uganda it was 40%, and in Zimbabwe, over half. In Zambia, Uganda and Tanzania, grandparents made up the single largest category of carers of orphans.⁵ A programme supporting older people affected by HIV/AIDS and caring for orphans in five villages in Tete Province, Mozambique, since September 2001 identified 774 older people caring for a total of 2,187 orphans, most of them under the age of 10.

Research indicates that older people make up a significant proportion of the poorest of the poor, and even without the added threats created by HIV/AIDS, many older people struggle to survive and suffer poverty, social exclusion and age discrimination. In most countries of Africa and Asia, older people have few forms of support outside their families.⁶ Contributory pensions are only available to the relatively small numbers who have had jobs in the formal economy, while non-contributory pensions exist in only a handful of countries. Often, these pensions are not index-linked to inflation.

Nevertheless, people the world over continue to work and support themselves and their families well into old age. Despite the exclusion they face, older people provide a vast pool of social capital as knowledge bearers and educators, as well as taking on the triple roles of caregiver, homemaker and income earner in many households.⁷

Until recently, one of the main responses to the growing numbers of orphans and vulnerable children has been the development of orphanages and childcare institutions. However, experience shows that institutional care does not cater for all the developmental needs of children, and that they develop better in a family environment.⁸ In addition, this response fails to recognise that orphans and vulnerable children can provide older people with economic security, and emotional and psychosocial support. As a result, the institutionalisation of orphans and vulnerable children can have a negative impact on older people too.

² While *Children on the Brink* defines children as those under 15, a more frequently used definition is those under 18. This report focuses on children affected by HIV/AIDS although the principles that underpin it could be applied to other vulnerable children, for example children who are living with sick or dying parents or in households that have taken in orphans. *Children on the Brink. A joint report on orphans, estimates and program strategies*, UNAIDS/UNICEF/USAID, July 2002.

³ The United Nations defines older people as those over 60 years of age. Definitions vary, however, depending on culture, life expectancy and people's own perceptions of age. Some may include all adults over 50.

⁴ 'Supporting children in need, through a community-based, orphan visiting programme', Foster G., Makufa C., Drew R., Kambua S. and Saurombe K., *AIDS Care*, 8, pp. 389–403, 1996.

⁵ *Poverty, Children, Schooling and HIV/AIDS: A targeting dilemma*, Ainsworth, M. and Filmer, D., Policy working paper No. 2885, World Bank, Washington, DC, 2002.

Orphans in Sub-Saharan Countries: A framework for public action, Subbarao, K. and Coury, D., Africa Region (Human Development) and Human Development Network (Social Protection), World Bank, Washington, DC, 2003.

⁶ *Chronic Poverty and Older People in the Developing World*, Heslop A. and Gorman, M., Chronic Poverty Research Centre Working Paper no 10, HelpAge International, 2002.

⁷ *State of the World's Older People*, HelpAge International, 2002.

⁸ *Building Blocks: Africa-wide briefing notes – Overview*, International HIV/AIDS Alliance, 2003.

A Last Resort. The growing concern about children in residential care, International Save the Children Alliance, 2003.

Meeting international commitments

Public policies at national and international levels have not yet acknowledged sufficiently the significance of older people and orphans and vulnerable children in efforts to combat poverty and HIV/AIDS. Current understanding of the role of older carers and the profile of households that are absorbing orphans and vulnerable children is incomplete.

Despite the declarations made at international summits (see below), many governments are still a long way from fulfilling their commitments. Few national HIV/AIDS policies pay adequate attention to the growing numbers of orphans and vulnerable children affected by HIV/AIDS, and even less make provision for their older carers and guardians.

Declarations made at international summits

- The Declaration of Commitment on HIV/AIDS signed at the United Nations General Assembly Special Session (2001) commits member states to implement by 2005 'national policies and strategies... [that] provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS.' It further commits governments to 'review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers.'⁹
- The Madrid International Plan of Action on Ageing (2002) also commits member states to 'introduce policies to provide... support, health care and loans to older caregivers to assist them in meeting the needs of children and grandchildren in accordance with the Millennium Declaration.'¹⁰
- The Millennium Development Goals commit UN member states to halving, by 2015, the number of people living in extreme poverty and halting and reversing the spread of HIV/AIDS.¹¹

The purpose of the report

This report by HelpAge International and the International HIV/AIDS Alliance is motivated by a shared understanding of the role of older carers in supporting orphans and vulnerable children, and a recognition of the economic and social importance of this relationship in combating poverty and HIV/AIDS. It draws on evidence collected from programme experience in Africa and Asia, in order to provide policymakers and other actors tackling the HIV/AIDS epidemic with:

- an overview of the issues identified by older people and orphans and vulnerable children themselves;
- good practice examples from community-based programmes that are improving the lives of older people and orphans and vulnerable children;
- recommendations that will help to prioritise orphans and their carers within HIV/AIDS and wider development policies, programmes and research.

⁹ Declaration of Commitment on HIV/AIDS. *Global crisis – global action*, United Nations General Assembly Special Session on HIV/AIDS, New York, 2001, Articles 65 and 68 respectively.

¹⁰ Madrid International Plan of Action on Ageing 2002, United Nations Report on the Second World Assembly on Ageing, 8–12 April 2002, A/CONF. 197/9, Paragraph 81 (b).

¹¹ The Millennium Development Goals are available at: www.un.org/millenniumgoals/index.html

'It wasn't supposed to be like this. These children's parents were supposed to be taking care of me. Now they are dead and I am nursing their children.' Akeyo, 74 years old, looking after 10 grandchildren in Kenya.¹²

Over the past decade, the HIV/AIDS epidemic has had devastating economic, social, health-related and psychological impacts on entire families, particularly in the world's poorest communities in Africa and Asia. These are fully recognised as long-term development issues.

What is not so clearly understood is the impact that HIV/AIDS has on family and household structure – especially where parents and the other adults, who would normally be there to care for orphans and vulnerable children and support older relatives, are absent.

The case studies presented in this report show clearly that family structures in communities affected by HIV/AIDS are changing, as in the case of Ramu and Leela. Ramu, aged 60, is a grandfather of 11 children, four of whom live with him and his wife Leela, in Tamil Nadu, India. They have been looking after the grandchildren since the father, and then the mother (their daughter), died of AIDS. Other family members were unwilling to take them in. Ramu says, *'It is our duty to make sure these children have a good future but we need money to provide it.'*¹³

Although the presence of many generations under one roof is not necessarily new, there are several distinctive characteristics in communities affected by HIV/AIDS. Often the middle generation – both men and women – is completely absent, leaving the old and young to support each other. Usually, there are large numbers of orphans and vulnerable children living with grandparents or older people in a single household. *'In the good old days, when there were deaths of parents it was easy to incorporate one or two orphans. But when you have nine, what can an old man like me do?'* says John, 76, of Katuba in Zambia, who lives with his son, niece and nine orphans.

An increasing number of these households are headed by older women. In Juba, Sudan, older women headed two-thirds of the households interviewed. This trend, combined with women's traditional role in childcare, leaves many older women in communities affected by HIV/AIDS with the primary responsibility for caring for the orphaned children of their deceased adult children or other relatives.

As family structures change, the roles of older people and orphans and vulnerable children adjust to meet the impacts of the HIV/AIDS epidemic. The stories presented in this report show that the main impacts are felt in the economic, health, education and psychosocial aspects of their lives.

¹² 'Where homesteads are turning into graveyards', Kendo, O., *East Africa Standard*, Kenya, 21 February 2001.

¹³ *Study Report on Older People and Child Care*, Sundar, T.R.S. and Varghese, T., International HIV/AIDS Alliance, Tamil Nadu, India, 2003.

Economic vulnerability

HIV/AIDS is placing tremendous strain on the already limited resources and capacity of older people who are caring for orphans and vulnerable children. It is widely acknowledged that the loss of the middle generation of adults severely reduces the income and consumption capacity of families affected by HIV/AIDS. This is particularly the case for older people and orphans and vulnerable children. Most of the older-headed households surveyed in Juba, Sudan, were living on less than US\$1 a day – far below the income required to provide for the needs of multiple household members.¹⁴

A recent study of older people in communities affected by HIV/AIDS in Kenya shows that, although the average minimum required household expenditure was approximately 6,800 Kenyan shillings per month (approximately US\$91), the average income of most of the older-headed households was nearer 2,400 KShs (US\$32).¹⁵

Older people are selling land, property, cattle and other assets in the struggle to meet their own basic needs, and to care for their grandchildren. Additional costs include food, health care, school fees and uniforms. Finances are stretched even further due to the lack of affordable medicines for people living with HIV/AIDS. Households are spending their meagre resources on treatment for sick family members, and funerals. This depletes the family resources, and often jeopardises the livelihoods or inheritance of the children and other family members.

In Tamil Nadu, India, older carers reported selling their property, or pledging it with money lenders for interest rates ranging between 36 and 120% per annum, to provide health care to treat family members.¹⁶ A young woman from Battambang province, Cambodia,¹⁷ relates how her family sold all their assets in search of treatment for her husband and two young children, all of whom have since died of AIDS. She too is HIV positive and her remaining child, aged eight years, will be left in the care of the grandmother, Insaran, aged 60 years.

The economic strain placed on these families and household members means that older people are under pressure to engage in income-earning activities, and that children often drop out of school to find work.

'I am caring for eight children and they have to have food, clothes, and medicines when they are ill; they have to go to school. My husband is working as a casual labourer and I brew beer and sell food. I get up early in the morning, make tea, cook porridge, get the kids ready for school and prepare what I am taking to the market. I sit for a long time in the Souk [market] and come back home about 3.00pm to prepare beer and cook dinner. I always feel tired, as I am too old to do all these things, but there is no alternative.' Juliana, aged 60, Juba, Sudan.

The additional financial responsibilities come at a time when older people's capacity to earn an income is severely compromised by their physical health, and gender and age discrimination in employment opportunities. Older people are also routinely excluded from obtaining the credit they need to start a small business, because of age discrimination and lack of assets to offer as security. Community members in Tamil Nadu, India, identified unemployment – for both old and young, especially in rural areas

¹⁴ *Older people as Caregivers for HIV/AIDS Orphans*, HelpAge International Sudan, Juba, Sudan, 2003.

¹⁵ *Feasibility Study on Viable Income Generating Activities for Older Persons Taking Care of HIV/AIDS Orphans Conducted in Ahero, Nyando District and Asumbi, Homabay District, Kenya*, Liaison Development Consultants, HelpAge Kenya, November 2002, p27.

¹⁶ *Study report on Older People and Child Care*, Sundar, TRS. and Varghese, T., International HIV/AIDS Alliance, Tamil Nadu, India, 2003, p7.

¹⁷ *HelpAge International Cambodia Trip Report*, Platt A, HelpAge International, 2003 (unpublished).

– as a cause of their poverty. Ageing, with the related deterioration of health status, was perceived to contribute to this problem. Older people interviewed in Zambia and Mozambique talked about difficulties in farming their plots and blamed lack of support from government for agriculture, as well as poor yields due to disease or failed rains.

'Most older people are frail and cannot go far to grow crops. Some of us are caring for orphans who are also suffering from hunger.' Leria, 56, widowed with two orphaned grandchildren, Tete Province, Mozambique.

Older people's income-earning capacity is further compromised when they are caring for their dying adult children and/or very young children, leaving them little time to earn. Furthermore, they are often unable to access resources that they are entitled to. For example, many older women, in particular, lack inheritance rights to land and property, and orphaned children may have no knowledge of, or may be refused, information about their deceased parents' shares in community savings schemes.

In many societies, children have been active in supporting households. The impact of HIV/AIDS has led to increasing numbers of households that are child or youth-headed, and in older-headed households children are supporting the efforts of their grandparents or other older relatives.

A recent study in Zimbabwe found that 76% of respondents had household members under the age of 15 contributing to household income through waged work. Those under 15 years are usually employed as casual labourers at nearby farms (especially during school holidays), work as herd boys or housemaids for well-to-do members of the community or in urban areas, or work as labourers for the rural district councils or in schools in the surrounding areas.¹⁸

Creating a safety net

Social protection, in the form of a low level of income guarantee, would go a long way to offset the additional financial burdens experienced by older people as carers of orphans and vulnerable children.

Of the countries most affected by HIV/AIDS, only three in sub-Saharan Africa (Namibia, Botswana and South Africa) have comprehensive social protection measures for older people, in the form of a basic non-contributory pension. In Asia, India has a means-tested, non-contributory scheme that provides people of 65 and above who are 'destitute' with a sum of 75 rupees (US\$1.50) per month.

In South Africa, non-contributory pension programmes reach a large number of poor older people (1.9 million) at relatively low cost (1.4% of GDP).¹⁹ The programme is financially sustainable, and attracts a large measure of political support. The 640 Rand (about US\$75) old-age pension is acknowledged as providing an important complement to – if not the only – income support to older people. It is a vital contribution to the household economy, securing older people's basic needs and, in households with orphans paying for school fees, clothes or medicines.

¹⁸ *Viability Study of Income Generating Activities in Karoi and Makoni Districts, Zimbabwe*, Zimbizi, G., HelpAge Zimbabwe, November 2002, p. 8.

¹⁹ and ²⁰ *Non-Contributory Pensions and Poverty Prevention: A comparative study of Brazil and South Africa*, Institute for Development Policy and Management, University of Manchester/ HelpAge International, DFID Project R7897, Pensions and Poverty Prevention, 2003.

Research suggests that non-contributory pension programmes have a significant impact on reducing poverty and vulnerability among households with older people.²⁰ However, in low-income countries with a limited tax base, the introduction of non-contributory pension programmes will require international financial and technical support.

In parallel, in South Africa, foster-care and child-support grants are available for age-eligible co-resident grandchildren, and these are alleviating some of the financial burden on older people and other carers who take in orphans and vulnerable children. However, take-up rates of these grants are low (not just by older people), with only 7% of those who are eligible claiming the grants.²¹ Older people expressed their concern about how difficult it was to obtain the grant, due to complicated administrative procedures and the need to provide appropriate documentation.²² For older people, general awareness of the availability of these grants is poor, and problems are exacerbated by ageist attitudes of social workers who believe that older people are unsuitable carers for children, and recommend alternative, younger, carers for foster care roles.

Other social protection mechanisms that can alleviate the financial stress on households affected by HIV/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 provide a lifeline for families.

Case study: Pensions and community support in South Africa

Pauline has been looking after three grandchildren since her daughter died of AIDS two years ago – the last of her four adult children to die. *'If the parents leave the children, you just carry on with it,'* she says. *'You have no choice.'*

At the age of 87, Pauline finds that being a parent again is not easy – especially without her husband, who died almost 40 years ago. *'It's been an uphill struggle,'* she admits.

The family, who live on the outskirts of Pretoria, live on Pauline's pension of 640 Rand a month (about US\$75), of which almost two-thirds goes on rent, and a foster-care grant of a similar amount, secured for her by local voluntary organisation Tateni Home Care Services.

Tateni volunteers have also brought food parcels, helped find school uniforms, cared for the family when Pauline was sick, and negotiated with the local school to waive school fees until the foster-care grant came through. At 120 Rand, school fees are equivalent to almost three weeks' pension money. *'I spend every cent I have. There is nothing to save,'* says Pauline.

²¹ *Impact of HIV/AIDS on State-Administered Social Security Grants*, Schierhout, G. and Soderlund, N., South Africa, Report prepared for the Department of Welfare, Pretoria. Abt Associates, Johannesburg 1999.

²² *Chronic Poverty and Older People in South Africa*, May, J., Chronic Poverty Research Centre, University of Manchester, HelpAge International, 2003.

Case study: Community credit schemes in Mozambique and Thailand

Community credit committees run by older people and community members in Tete Province, Mozambique, have so far supported over 300 older carers and young people – two-thirds of them women. Funds have been used to set up various small businesses, including trade in small animals, used clothes, fresh-river fish, traditional beer making, and producing local foodstuffs, such as tomatoes and green leaves. Some older carers received skills training in basket making, pottery, knitting and shoe making.

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

Amina, aged about 65, has looked after seven grandchildren since the death of her daughter and son-in-law from AIDS. Amina explains what she did with the money from the credit committee: *'We bought flour in Tete to make bread, which is the most popular food I sell. I dream of one day having a store, but know that I must make profits to buy one in the future. Most of my profits now go to buy food for the children.'*

Felix, 15 years old, is the only income earner in a household of seven, in which he lives with five younger siblings and 80-year-old great-uncle. Felix dropped out of school to earn an income herding goats. He bought the goats with funds from the credit committee. *'We wanted to stay together after our parents and grandparents died of AIDS. I want to go back to school, but there is no money. I talk to my friends about not being bad, not stealing things to get money. I must work hard to get a good life and look after myself not to get the disease my mother and father had.'*

Similarly in Chiang Mai, Thailand, loans issued by older people's associations form part of a range of interventions that have helped to improve the lives of older people affected by HIV/AIDS who are caring for children. The project was developed with the Thai non-governmental organisation Mother Child Concern Foundation (then known as Women Against AIDS). Kamol, a 79-year-old widow living with her HIV-positive daughter and two granddaughters, runs a business making pork crackling. With her loan of 5,000 Baht (US\$115) she has been able to expand her business, as well as pay for her daughter's medical costs and her granddaughters' school fees.

Poor health status

'It is easy to identify the house of an older person, as it is often dilapidated and of poor quality.'²³

The increased stress on family members living in older-headed households has an impact on their health and wellbeing. Health consistently ranks alongside material security as a priority concern for older people.²⁴ Older people's poverty often manifests itself in poor quality housing and living conditions, which impact on their health, and that of those living with them. Older people's health may be further compromised by increased responsibilities in caring and providing for others, as they often forgo food and medicines for other members of the household, while continuing to undertake many additional tasks and responsibilities to try and make ends meet.²⁵

'I am getting older and weak. I have rheumatoid arthritis and the daily activities are becoming harder. I get up in the morning with very painful joints. And yet I clean the hut, bring water, prepare tea and get the kids ready for school. I go to work, then to the market and come back home to prepare food.' Salome, aged 65, Juba, Sudan (lives with her six orphaned grandchildren).

Despite its importance, health care remains inaccessible to many older people. Hospitals tend to be concentrated in urban centres, far from the rural areas where the majority of older people live. Older carers cannot afford to pay for transport to reach the health services, let alone the medical fees. Even in countries like Zambia and Kenya, where fee exemption policies exist for those under five and over 60 years of age, these policies are often not implemented due to lack of resources and discrimination against older people.²⁶ Orphans and vulnerable children and their older carers are often stigmatised by health care providers due to their association with HIV/AIDS. This means that older people find it hard to access treatment for themselves and children in their care, causing them great distress as they worry about the future of the children:

'The children are in poor health and one has malnutrition. I can't provide the needed care because I have no money and none of my relatives or friends help me. Sometimes there has been no money and the kids are ill and hungry and I've felt I just wanted to leave. Oliver, aged 65, Juba, Sudan (lives with his wife and six children, and two orphans aged four and seven).

In these situations, many older people still prefer to use traditional medicine. Traditional healers have considerable influence in the community. They continue to provide more accessible and more familiar health care options to poor families – especially in Africa. Yet they lack up-to-date accurate information on HIV/AIDS, making it difficult for them to respond to the needs of families affected by HIV/AIDS.

²³ *Report of a Consultation with Older People in the Lead up to the Second World Assembly on Ageing*, HelpAge International Africa Regional Development Centre and HelpAge Kenya, 2001 (unpublished).

²⁴ *State of the World's Older People 2002*, HelpAge International, 2002.

²⁵ *Coping with HIV/AIDS and Ageing in the Family*, Project Child, Committed Community Development Trust, Mumbai, India, 1995 (unpublished).

²⁶ *Elder Abuse in the Health Care Services in Kenya*, HelpAge International Africa Regional Development Centre and HelpAge Kenya, 2001 – country study for *Missing Voices: Global response to elder abuse*, International Network for the Prevention of Elder Abuse and the Ageing and Life Course Unit, World Health Organization.

Creating accessible health care services

Community-driven processes are beginning to address these problems through home-based care and support to families affected by HIV/AIDS. So far, this has concentrated largely on support to people living with HIV/AIDS, but recent efforts are broadening the focus to include children and older people in families affected by HIV/AIDS. Training older carers and volunteer home visitors, and providing health kits and basic medicines are all effective ways in which to support families to meet their health needs. HIV/AIDS education programmes in South Africa are encouraging dialogue between conventional health professionals and traditional healers, which makes it easier for older people to access appropriate health services.

Ensuring that health policies that favour older people are properly implemented is also important, and in countries such as Tanzania and Kenya, older people are monitoring local health policies. The Older Citizens Monitoring Project²⁷ is providing support to older people in collecting data, and is assisting with disseminating strategies that will challenge some of the local obstacles to policy implementation.

Case study: Home care services Katuba, Zambia

Josephine is 76 years old and lives in a very small hut in Katuba, Zambia, where she cares for her granddaughter Edna (in her 30s), who suffers from tuberculosis (TB), and two great-grandchildren. When Edna needed to go to hospital to be tested for TB, Josephine resorted to harvesting wild grass to sell to local people, to raise the necessary transport costs. When asked how the family is coping with her granddaughter's illness, she says, *'When there is money, we borrow a bicycle and push her on it to the clinic.'*

Josephine is not well herself, complaining of sore legs and malaria. Her sight is bad, and she regrets not being able to work. She would like to do so many things. Her greatest problem is hunger. She wishes they could eat more than once a day. As she is over 60 years of age, Josephine has been receiving food aid from Care International, but it is not enough. *'I would like to be able to have breakfast, lunch and supper.'*

The Moomba Home Care Project, a community-based organisation, has formed a partnership with the Katuba Child and Family Project to support families such as Josephine's. The project provides families with a monthly ration of basic provisions, education talks on immunisation, nutrition, malaria, and HIV/AIDS-related diseases, a voluntary counselling and testing service, and a food security programme. The Moomba Home Care Project also supports orphans and vulnerable children to enable them to live with relatives after the death of their parents, and provides them with food and funding for school uniforms and shoes.

Reduced access to education

'We like to dance and play, but we should help our grandmother cleaning, brewing beer and bringing water. We all go to school, except Suzy and Ali, because there is not enough money.' Anna, aged 10, Juba, Sudan (lives with her 60-year-old grandmother and her eight siblings).

Orphans and vulnerable children experience great difficulty accessing education services. The lack of free primary education in many HIV/AIDS-affected countries in Africa and Asia means that school fees are often unaffordable for vulnerable households, including those headed by older people. In Katuba, Zambia, out of 22 orphans and vulnerable children in households affected by HIV/AIDS and headed by older people, only eight were attending school.²⁸ Similarly in Juba, Sudan, less than half of the identified orphans and vulnerable children were attending school.

'Our grandma is really caring and supporting us. She is doing her best to provide what we need, but I am in third grade, my brother in the first, and my youngest brother in pre-school. I am not sure my grandmother will be able to pay our school fees when we go to higher class.' Jackeline, aged 14, Juba, Sudan.

Even if older carers manage to find funds for school fees, they are often unable to cover other essential items such as uniforms, books and the child's transport costs to and from school. As a result, orphans and vulnerable children are often unable to take up their right to education.

Creating flexible education services

To ensure that all children, including orphans and vulnerable children, have access to education, many communities are working together to create alternative, flexible services. A project run by ActionAid in Uganda offers flexible timetables so that working children can attend during non-traditional hours. Other examples of innovative schooling projects include evening classes, schools that adapt their terms to fit agricultural seasons to allow working children to attend, community schools that use informally trained teachers and charge minimal, or no, fees, and distance and home-based school courses.²⁹

In other instances, community-based or non-governmental organisations are working with schools and older carers to subsidise the school fees for orphans and vulnerable children. Older people's committees from the Living Together programme in Tete, Mozambique, are lobbying the local education authority and schools to help re-integrate orphans and vulnerable children into schools. In just over a year, the programme has managed to get 982 children living with older people in five villages into school by lobbying the local directorate of education and individual schools to waive school fees, and by providing support for school materials and uniforms.³⁰

²⁸ *The Role of Older People as Carers of Orphans and Vulnerable Children in Katuba Area of Chibombo District, Zambia* by Gertrude K. Mwape, International HIV/AIDS Alliance, April 2003.

²⁹ *Building Blocks: Africa-wide briefing notes – Education*, International HIV/AIDS Alliance, 2003, p. 12.

³⁰ *Living Together Programme*, HelpAge International Mozambique, 2002.

Case study: Innovations in alternative schooling

Community schooling is a popular approach in some areas affected by HIV/AIDS. Local communities or churches run schools and do not charge fees, require no uniforms, provide educational materials, and use local teachers, often on a voluntary basis. Other successful models exist and have proven to be replicable in Mali, Malawi, Uganda and Zambia, among other countries.³¹

Case study: Interactive radio education in Zambia

In Zambia, a pilot programme involving interactive radio education (IRE) is currently in operation in areas affected by HIV/AIDS. The pilot is specifically designed to reach vulnerable children who are currently out of school and provide a less costly alternative to formal education. Interactive lessons in elementary English and maths skills are broadcast for a limited number of hours per day targeting out-of-school youth in community centres. Minimal support from printed materials is offered and literate community mentors – most of whom have completed secondary school and participated in a three-day training programme – are matched with students to provide instructional support. Families are expected to contribute in cash or in kind to provide for the upkeep of the educational centres.

The programme follows the Zambian curriculum, and the objective is to cover the entire Grade One mathematics and English language curriculum in 100 x 30-minute radio lessons. Students meet for a short time each day and receive instruction from both the radio and the mentor. Mentors are also provided with lesson plans and instructions on how to prepare.

³¹ *Building Blocks: Africa-wide briefing notes – Education*, International HIV/AIDS Alliance, 2003, p. 12.

Primary Education in Eastern and Southern Africa: Increasing Access for Orphans and Vulnerable Children in AIDS-Affected Areas, Hepburn, A.E., Stanford Institute of Public Policy, Duke University, 2001. Available at: www.usaid.gov/pop_health/dcofwwf/reports/edreps/hepburnfinal.doc

Community Mobilization to Mitigate the Impact of HIV/AIDS, Donahue, J. and Williamson, J., Displaced Children and Orphans Fund, 1999.

Exclusion from prevention programmes

'As older people, society considers us more knowledgeable about issues, our grandchildren and people in general will listen to our words of wisdom. We want to be part of the prevention of HIV/AIDS.' HelpAge Zimbabwe, grassroots consultations with older people in preparation for the Second World Assembly on Ageing, Madrid 2002.

Older people seldom have access to information about HIV/AIDS. Prevention and awareness programmes are almost exclusively targeted at young people, and rarely reach out to older age groups, either as carers or as a possible 'at risk' group. Literacy levels of older people are low too, limiting their access to the written information that is available. This leaves older people ill-informed about HIV/AIDS and how it is spread, reducing their own risk perception, and compromising their ability to protect themselves and those in their care.

Within communities, older people often act as educators and moral guides. Without the correct information about HIV/AIDS, they are often unaware that some traditional practices (such as wife inheritance and sexual cleansing)³² carry the risk of HIV infection.

In discussions with older people in Zimbabwe, 59 out of 76 older people associated HIV/AIDS with adultery. If older people were informed, they could help reshape practices and beliefs in the family and community. In terms of obtaining information, many were unable to read or write, and 98% of the publications were only available in English, which was not their first language.³³ They also noticed that the messages were not meaningful to older people and that most of the pictures showed young men and women.

In another study, in Kenya, there was general consensus that the channels and processes of communication between older people and development organisations and/or national governments were inadequate and ineffective.³⁴

An analysis of older people's access to media in Asia showed that older women, in particular, find it harder to access print media. This is due partly to lower rates of literacy among women, partly to the cost, and partly because newspapers are usually available in public places that are not accessible to them.³⁵

Targeting HIV/AIDS information at older people

Older people's roles as leaders and educators must be harnessed to support HIV/AIDS education and prevention efforts. Seeing the impact of HIV/AIDS on their communities, many older people are keen to receive information and education about it in order to protect their families and themselves. According to one of the clinical officers interviewed at a Rural Health Centre in Chibombo district, Zambia, *'They are the ones looking after the orphans. If they are taught about HIV transmission, they could be instrumental in teaching about HIV/AIDS prevention.'*

Older people should be involved in developing awareness programmes on HIV/AIDS at community and national level, including disseminating materials and messages appropriate for older people as carers of orphans and vulnerable children. For older people, oral communication is still preferred, and television and radio are becoming increasingly important as they overcome the exclusion caused by low literacy levels.³⁶

³² The practice in which a widow has sex with another man following the death of her husband, to 'purge' the husband's spirit.

³³ *Supporting Older Women and Men Affected by HIV/AIDS in Karoi and Makoni, Zimbabwe*, Help Age International Africa Regional Development Centre and Help Age Zimbabwe, 2003.

³⁴ *Report of Analysis of Communication Opportunities for Older Persons in Kenya*, HelpAge Kenya, 2003. This was produced as part of audit phase of Older Citizen's Monitoring Project, and 41 older people were surveyed from Nairobi and its surrounding areas.

³⁵ and ³⁶ *Older People and the Media: A community survey, Asia Training Centre on Ageing (ATCOA), HelpAge International Asia and Pacific Regional Development Centre, 2003.*

Case study: Older community counsellors in Sudan

Older people's committees within 23 displaced people's centres in Juba, Sudan, are being supported to inform older people about HIV/AIDS. A meeting of 115 older people from the committees chose 10 to be trained as community counsellors. Their training covered the basic facts about HIV/AIDS, counselling, community mobilisation, problem solving, gender, older people's issues and rights, co-ordination, data collection, public awareness raising and reporting, and living positively with HIV/AIDS. According to one of the trained older counsellors: *'Before this training I thought HIV/AIDS was the concern of doctors, but later I discovered... it has become our problem and concern.'*

The older counsellors now make house-to-house visits and discuss HIV/AIDS at social gatherings, held at the displaced people's centres. Issues discussed include child care, referral to schools and health services, and testing and counselling services, as they become available. The counsellors, who are paid expenses, also identify older people caring for children or sick adults who need material support, such as clothes, bedpans or money for school fees. Reverend, 65, who lives with his wife and nine orphans, says *'I am concerned about HIV/AIDS prevention. I educate in the church and keep telling them to go for a voluntary test.'*

Psychosocial trauma

'All I needed was someone to listen to me and tell me I could still be loved even after my mother had died.'³⁷

In many countries, a major problem for those affected by HIV/AIDS is the stigma and discrimination they face. HIV/AIDS has often been considered a form of punishment for wrongdoing, and is associated with promiscuity and witchcraft.³⁸ This can result in acute levels of exclusion for older people and orphans living with, or related to, people living with HIV/AIDS. Social ties and traditional support mechanisms can be weakened when ignorance and stigma marginalise a family affected by HIV/AIDS, leaving them feeling ashamed and alone. Many older people feel they are failing in their role as a carer because they are unable to protect their family from this kind of isolation.

'I am facing a hard time. I am repelled from my family and the children keep on telling me about the relentless comments they hear from their peers because of their parents' illness and death.' Szerina, aged 60, Juba, Sudan.

Both children and older people need interaction and acceptance from their local community and peers. Many older people find themselves so busy with the efforts to provide for their families that they lose touch with their peers and have no one with whom to discuss the difficulties they are facing. Similarly, children can be isolated and excluded. Seven-year-old Viola, from Juba, Sudan, lives with two older siblings and her grandmother. She says *'I am not happy. I don't have a mother and have little food. Every day I talk to my mother but I don't hear her voice. I want to have a mother, like my friends do.'*

Alongside the stigma and exclusion, orphans and vulnerable children and their older carers experience grief and possible confusion following the loss of their parent, child or, in many cases, multiple family members. Older people often play an important role in comforting young children on the death of their parents, and in providing support and guidance. Yet the older carers themselves are under tremendous pressure, with psychological problems of their own following the death of their children – grief, loss, anger, fear – and the worry of bringing up orphaned children who may also be HIV positive. The key concerns, as reported by older people interviewed in India who had taken over the role of primary carers, were stress, worry and sleeplessness. One grandfather describes supporting his granddaughter at the funeral ceremony for his son who had died of AIDS:

'My granddaughter, who was then only five years old, dragged a chair over in front of the coffin and just sat there, alone. It was such a pitiful and heartfelt sight to see. My wife and I could not bear it. We went up to hug her and console the little girl, feeling her sorrow that she should lose both her parents in such a short time. I also felt angry at the cruel fate that I was facing. In my life I didn't do any bad things – why should my family and I suffer from such a cruel and ugly fate? Losing my loved ones, money, losing respect, losing friends.' Duangkaew, aged 72, Thailand.³⁹

³⁷ Masiye Kids Club, Zimbabwe, in *Building Blocks: Africa-wide briefing notes – Psychosocial support*, International HIV/AIDS Alliance, 2003.

³⁸ *Building Blocks: Africa-wide briefing notes – Psychosocial support*, International HIV/AIDS Alliance, 2003.

³⁹ *Coping Mechanisms of Poor Older Men and Women Affected by HIV/AIDS*, HelpAge International workshop report for the World NGO Forum on Ageing at the Second World Assembly on Ageing, Madrid, Spain, 2002 (unpublished).

Older carers also worry about what will happen to the children when they themselves die. *'My fear is if I am not here, there will not be anybody to take care of them. I pray to God to tend my health till the kids are able to care for themselves,'* says 67-year-old Betty, taking care of three grandchildren aged 14, eight and six in Juba, Sudan.

Worries over inheritance disputes and a lack of succession planning can create a great deal of stress for older carers. Lyndia is 61 years old. Her daughter died of AIDS, and she lives with her three orphaned grandchildren aged three, seven and 12.

'When my daughter was ill I had to take care of her and her belongings, because so many of her husband's relatives were trying to take these possessions after his death. Not one of our relatives helped us. We have gone through all this alone.' Lyndia, aged 61, Juba, Sudan.

Building awareness and planning for the future

Open community discussions led by local leaders, as well as awareness-raising campaigns at a national level, can go a long way to improve understanding of the causes and impacts of HIV/AIDS. Some community initiatives are developing innovative ways to express openly the issues related to HIV/AIDS. They aim to integrate affected children and older people through community events such as storytelling, drama and children's drawings. For family members in households affected by HIV/AIDS, having a space in which to openly discuss with others the situations they face is often a big support in itself.

Most development programmes for families affected by HIV/AIDS focus on meeting material needs. They must also consider the psychosocial effects on children or older people of caring for a sick parent or child, living in a household affected by HIV/AIDS, or losing parents or children. Counselling services should work with families to help them come to terms with their grief and plan for the future.

Faith-based organisations and church communities are an important source of support, and many older people take comfort from their personal faith. Sophia Ngwira, 52 years of age, from Zambia, says that she prays to keep herself calm. She says that when her husband died there was a lot of talk, and that if it had not been for prayer, she might have gone mad.

Home visiting and counselling services provided by community volunteers or members of church groups offer vital emotional support. Older people and community members in Tete, Mozambique have formed a network of *ouventes* (listeners) who visit families affected by HIV/AIDS, to provide them with emotional support and guidance, and refer them to relevant services. Experience with traumatised children in Mozambique, and children in areas of Uganda that are worst affected by HIV/AIDS shows that community-based activities such as playgroups can help children recover and develop social skills. The FOST project in Zimbabwe has set up clubs to ensure that orphans integrate with other children.⁴⁰

³⁹ *Coping Mechanisms of Poor Older Men and Women Affected by HIV/AIDS*, HelpAge International workshop report for the World NGO Forum on Ageing at the Second World Assembly on Ageing, Madrid, Spain, 2002 (unpublished).

⁴⁰ *Building Blocks: Africa-wide briefing notes – Psychosocial support*, International HIV/AIDS Alliance, 2003.

Case study: Older people's clubs in Vietnam

In Hanoi in May 2002, a group of older people participated in a consultation on their role as carers and the impact of HIV/AIDS on their lives. They found the experience so useful that since then they have taken action for themselves. With the help of the Vietnam Women's Union, the older women and men established an older people's club in Thai Nguyen.

At the meetings, they can freely talk about their experiences and problems, and can seek support from others in a similar situation.

'People in this group suffer the same pain and the same circumstances, and we can sympathise with each other. Other people cannot – they do not understand,' says one older woman at the consultation meeting. The change for these older people has been tremendous. *'This has been the best period in our lives for a long time. We are so much healthier and happier now,'* says one of the women members of the club. The local leaders are now planning to start similar clubs in other villages.

Case study: Coping with loss and planning for the future

Parents have helped their children before they die by making a memory book with them. A memory book includes important information about where the child grew up, family events and traditions, and a family tree to show who is who and where they live. Some parents include information about their memories of the child, the child's health, education and favourite things. An alternative approach is a memory basket, which includes important personal items to help children remember things. Memory books or baskets help to strengthen a child's sense of belonging and to know about their roots, especially if he or she moves to another area, or lives with a different family.⁴¹

Case study: Getting to know extended families in Uganda

In the National Community of Women Living with HIV/AIDS (NACWOLA) project in Uganda, while parents are still alive, they encourage children to visit and socialise with as many relatives as possible so that they get to know their extended family. This helps strengthen the bonds between these relatives, so that when the parents die and the children move in with their relatives, they are not seen as strangers but as part of the family. This promotes confidence and a sense of belonging.

⁴¹ *Building Blocks: Africa-wide briefing notes – Psychosocial support*, International HIV/AIDS Alliance, 2003.

HelpAge International and the International HIV/AIDS Alliance urge non-governmental organisations, national governments and international development institutions to place family and community-based support at the heart of the response to the HIV/AIDS epidemic. The recommendations in this report complement global campaigns calling for HIV/AIDS prevention, access to treatment, universal primary education for all, and breaking the silence on HIV/AIDS. They do, however, emphasise that families of older people and orphans and vulnerable children need to be given more specific attention in policy and programme interventions. A co-ordinated response is required that recognises the strengths and roles of different actors.

1. Provide direct income support to address the financial needs of older carers of orphans and vulnerable children.

- National governments should develop and expand social protection mechanisms such as non-contributory pensions and foster-care and child-support grants for orphans and vulnerable children.
- International development institutions should provide financial and technical backing to start social-protection schemes in countries that have a limited tax base.
- National governments and non-governmental organisations should ensure that older-headed households have access to credit schemes and the appropriate training to ensure the viability of small business ventures.

2. Make sure that policies and programmes designed to meet the health needs of families affected by HIV/AIDS include older people and orphans and vulnerable children.

- National governments, with the support of international development institutions, should provide accessible and appropriate health care services for older people and vulnerable children.
- National governments and non-governmental organisations should develop strong partnerships for scaling up the provision of home-based care and community outreach programmes.
- Local and national governments should include older people in monitoring programmes that evaluate the appropriateness of health measures for older-headed households.

3. Ensure access to universal and flexible education services for orphans and vulnerable children that recognise their changing roles, time commitments and financial constraints.

- National governments should incorporate into their education policies and systems some of the flexible and alternative education services that are being developed by the non-governmental sector, such as community schooling, informal education and skills-training programmes.
- International donors should provide support and financial backing for the development of innovative education programmes.
- National programmes should ensure that school vouchers, subsidised uniforms, materials and transport are available for orphans and vulnerable children to enable them to be integrated into schools, and ease the pressure on older-headed households.

4. Provide older people with information and training on HIV/AIDS and the rights of children and older people.

- National prevention programmes should include a greater emphasis on developing older people's roles as community counsellors and educators, to enable them to provide guidance and support to affected families.
- Non-governmental organisations should involve older people in developing effective community-based HIV/AIDS programmes – especially in developing materials and messages that are appropriate for older people as carers of orphans and vulnerable children.
- Community-based organisations should provide practical support services within HIV/AIDS programmes, such as training in parenting skills, legal assistance and advice on inheritance rights.

5. Develop policies and programmes that address the psychosocial needs of older carers and orphans and vulnerable children.

- Governments and non-governmental organisations should initiate and support programmes and policies to reduce the stigma and discrimination that families affected by HIV/AIDS experience – particularly open community discussion, led by local leaders, which directly influences the messages of national campaigns.
- Community-based organisations should support the formation of community carer and orphan peer-support groups, and provide training for counsellors and bereavement specialists on the particular needs of these two groups.
- Community-based organisations should involve older people in developing end-of-life planning methods, such as memory books, with people living with HIV/AIDS and their children.

6. All actors should ensure the involvement and participation of older carers and orphans and vulnerable children, in community structures, as well as in formulating national policy for poverty reduction and supporting families affected by HIV/AIDS.

- Actively seek the views of older carers and children in discussions about HIV/AIDS and its impact on communities, and bring them into policy and programming processes that impact on their lives.
- Include orphans and vulnerable children and older people in needs-assessments and consultation mechanisms in designing interventions to prevent and mitigate against the impacts of HIV/AIDS.
- As HIV/AIDS programmes are reviewed and developed, ensure that monitoring and evaluation processes include older carers and orphans and vulnerable children.

7. All actors should undertake research and collect comprehensive age-disaggregated data on the needs and roles of older people and orphans and vulnerable children, to design better HIV/AIDS interventions that are inclusive of older people.

Additional information is required on:

- the nature and composition of households affected by HIV/AIDS, details of who the primary caregivers and guardians of orphans and vulnerable children are, and their coping strategies
- the poverty impacts of HIV/AIDS, including asset depletion, and links to national and international poverty monitoring systems
- the health needs and health-seeking behaviour of older carers and orphans and vulnerable children, in particular, the ways in which to engage effectively and innovatively with traditional healers
- the information needs of older people, and the effectiveness of formal and informal education for orphans and vulnerable children
- the effectiveness of older people as educators, and any impact on the understanding and behaviour of orphans and vulnerable children
- the psychosocial impacts of HIV/AIDS on children and older people's wellbeing.

The voices and experiences presented in this report provide a valuable starting point for discussion and debate on the issues of older carers of orphans and vulnerable children. International commitments on HIV/AIDS and poverty reduction will only be met if agencies, national governments and the international community involve older people and orphans and vulnerable children in strategies to support families affected by HIV/AIDS.

With appropriate support, older people and orphans and vulnerable children can confront the challenges they face from the HIV/AIDS epidemic. Collaborative action is required to ensure that the intergenerational nature and widespread socio-economic impacts of HIV/AIDS are fully recognised.

For HelpAge International and the International HIV/AIDS Alliance, the intergenerational nature of HIV/AIDS is now a priority in policy and programme work. In addition, policy and advocacy activities will continue to raise awareness of the issues:

- The International HIV/AIDS Alliance is preparing a briefing note on older carers for its *Building Blocks* resource kit. These briefing notes are intended for people supporting children in Africa and Asia who are orphaned or made vulnerable by HIV/AIDS. The new booklet on older carers will be published in 2004 and will also be available at: www.aidsalliance.org
- HelpAge International is holding a workshop in Nairobi in September 2003 (preceding the 13th International Conference on AIDS and STIs in Africa). The purpose of the workshop is to explore community-based models of care that support older people in their role as carers of orphans and other vulnerable children. The workshop report will be available at: www.helpage.org in October 2003.
- In 2004, at the XV International AIDS Conference in Bangkok (11–16 July), the organisers have included a sub-track on social and economic issues on HIV/AIDS and older people. Plans are underway to see that older people and orphans and vulnerable children can participate in this and other key international development fora.

These activities aim to engage a broad range of actors already tackling the issues of HIV/AIDS and sustainable development, so that the families of older carers and orphans and vulnerable children are not forgotten.

Papers

Building Blocks: Africa-wide briefing notes, International HIV/AIDS Alliance, 2003.
Available at: www.aidsalliance.org/building_blocks.html

HIV/AIDS and Ageing: A briefing paper, HelpAge International, 2003.
Available at: www.helpage.org/publications/publications.html

State of the World's Older People 2002, HelpAge International, 2002.

Ageways 61: HIV/AIDS and older people, HelpAge International, December 2002.

Principles to Guide Programming for Orphans and Other Children Affected by HIV/AIDS, UNICEF, 2002.

'Supporting Community Efforts to Assist Orphans In Africa', Geoff Foster, *New England Journal of Medicine*, June 2002.

Web links

www.orphans.fxb.org./indexeng.html

www.hopeforafricanchildren.org/about.htm

www.synergyaids.com/documents/COB2002.pdf

www.unicef.org/publications/index.html

www.savethechildren.org.uk/index.html



This report by HelpAge International and the International HIV/AIDS Alliance is motivated by a shared understanding of the role of older carers in supporting orphans and vulnerable children, and a recognition of the economic and social importance of this relationship in combating poverty and HIV/AIDS. It draws on evidence collected from programme experience in Africa and Asia in order to provide policymakers and other actors tackling the HIV/AIDS epidemic with:

- an overview of the issues identified by older people and orphans and vulnerable children themselves;
- good practice examples from community-based programmes that are improving the lives of older people and orphans and vulnerable children;
- recommendations to help prioritise orphans and their carers within HIV/AIDS and wider development policies, programmes and research.

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