

SUPPORT WOMEN CAREGIVERS: FIGHT AIDS



A UNAIDS Initiative

**The Global Coalition
on Women and AIDS**

WHAT'S REAL

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The AIDS epidemic is taking a devastating toll on families and communities worldwide. In its wake lies a growing burden of caring for the sick, the dying, and those left behind. In countries hardest hit, most of the care for people living with HIV takes place in the home, and up to 90% of

Due to the demands of caring for others, many female caregivers have less time to earn an income, produce food, go to school, and maintain the rest of the household.⁴ This creates a vicious cycle, whereby women and their families are more likely to be malnourished, in poor health, or



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that is provided by women and girls.¹ The inability of health systems to care for all those living with HIV who are in need of services has led many governments to rely on home-based care to fill the gap. Most of those who provide this care are unpaid and already quite poor, and the additional financial and emotional burden of administering care frequently pushes them into destitution. Therefore, caregivers, particularly women and girls, need more economic, technical, and social support for providing this essential yet too often unrecognized service – and this support must be made central to AIDS strategies.

“Policy makers need to be clearer who the home and community-based carers for orphaned children are, and what resources they have, and provide them with adequate financial, social, and emotional support....”

Fiona Clark, International Policy Officer, HelpAge International

That is why the UNAIDS-led Global Coalition on Women and AIDS is making greater support for caregivers a top priority.²

The social and economic burden of care on women

AIDS-affected households face both increased expenses – including health care, food, transportation, and burial costs – and decreased income, as AIDS often claims men and women in their most economically productive years. The cumulative financial burden on these households is substantial. A study in South Africa found that two-thirds of such households reported a loss of income, and a third of the remaining income was spent on health care – leaving little for clothing, electricity, food, and other necessities.³

economically destitute – all factors that further increase their risk for HIV infection.

AIDS is severely stretching traditional coping mechanisms and extended family networks, often to their breaking point. As more working age women are living with HIV – struggling to provide for their families and often in need of care themselves – caregiving duties shift increasingly to older women and younger girls. In fact, older women are taking on caregiving on an unprecedented scale, assuming responsibility not only for their children and grandchildren, but for other children orphaned and made vulnerable by AIDS.⁵ In addition, AIDS frequently forces girls and young women to withdraw from school to fulfill caregiving duties and to help compensate for lost family income⁶ – heightening their risks of sexual exploitation and HIV infection.

In some countries, nongovernmental organizations (NGOs) and faith-based organizations (FBOs) have established home-based care projects using community volunteers, usually women in the community who receive minimal training and occasionally small stipends for transportation. Some of these programs are linked to formal care and support services, but most still need to be. The programs range from basic home visits to more comprehensive treatment and care programs. In many cases, home-based care starts with caring for a sick adult, but soon extends to helping others who are ill in the family, providing material

support for affected families, and services for orphans or other dependent children.⁷

- The UN Secretary-General's Task Force on Women and AIDS in Southern Africa found that two-thirds of caregivers in the households surveyed were female, and almost a quarter of them were over 60 years old.⁸
- In Viet Nam, women and girls make up 75% of caregivers for people living with HIV.⁹
- Households headed by older women in sub-Saharan Africa are twice as likely to include orphans as households headed by older men,^{10/11} and only 3% of all households caring for orphans (excluding Eastern Europe) receive any public support.¹²
- The number of children orphaned by AIDS has risen dramatically, from one million in 1990 to 15 million today; by 2010, the number could exceed 25 million.¹³ Studies show that in many countries, including Botswana, Namibia, Malawi, South Africa, Tanzania, and Zimbabwe, up to 60% of orphaned children, including those orphaned by AIDS, live in grandparent-headed households.¹⁴

Women caregivers need support and training

Home and community-based care for people living with HIV remains integral to the global AIDS response. Alongside dramatic expansions in access to antiretroviral treatment and HIV prevention, AIDS strategies must provide better and more coordinated support for caregivers, with particular attention to women and girls.

WHAT WORKS

Despite glaring gaps, innovative programs are working to support caregivers in AIDS-affected countries worldwide. These programs, often run by NGOs or FBOs, range from assisting older caregivers with the cost of providing medical expenses and support for orphans and vulnerable children, to improving access to HIV services for both caregivers and those they are caring for, to offering basic training in delivering home-based care.

- The India HIV/AIDS Alliance supports NGOs to provide community-based care for people living with HIV, as well as children affected by AIDS. The program provides psychosocial support, health care, voluntary counseling and testing, economic and food support, and skills training.¹⁶ In Delhi, Tamil Nadu, and Andhra Pradesh, the program is being implemented by 38 NGO partners. In Tamil Nadu, the program has supported 4,224 people living with HIV, 5,521 family members, and 4,692 children affected by AIDS.¹⁷ Most of the caregivers are women.
- Women Fighting AIDS in Kenya (WOFAK), an AIDS support organization of some 3,000 women, supports caregivers who are providing home-based care. The caregivers offer nursing care, nutritional support, counseling, and education for family members and communities. WOFAK is run largely by women living with HIV.¹⁸
- The Vietnam Women's Union (VWU) works with older women caregivers affected by AIDS. Through the

Caregivers need information on HIV prevention and care, access to basic supplies (blankets, aspirin, sleeping mats, etc.), training, and referrals for medical care, as well as social assistance to support vulnerable and orphaned children. Caregiving takes an enormous physical, psychological, and economic toll on its providers. Accordingly, caregivers need access to psychosocial support, counseling, and economic assistance to help them sustain this physically and emotionally draining, yet vitally important work.

Older women caregivers confront particular difficulties; they are less likely to remarry after being widowed and many face precarious economic situations, further exacerbated by discrimination in property inheritance and employment. In addition, older women are not traditionally targeted in HIV prevention programs, based on the sometimes mistaken assumption that they are no longer sexually active and therefore at low risk for HIV.¹⁵

Special attention must be paid to children and adolescents, especially girls, who become caregivers. In many countries, children as young as eight-years-old are assuming caregiving responsibilities to help their families survive. Many of these children are also coping with the death of their parents, relatives, or siblings due to AIDS – and struggle with HIV-related stigma and an increasingly uncertain future of their own.

establishment of "Empathy Clubs" – self-managed organizations that encourage and support older women caregivers in their communities – the VWU has already profoundly improved the lives of those providing care and their families.¹⁹

- In Mozambique, older people have established support groups, called older people's committees, to reduce the cost of care and increase their incomes. Money raised from small businesses is placed into a social fund run by the older people's committees. This fund pays for transport to testing centers and AIDS treatment clinics, and covers the cost of applying for a poverty certificate – a government benefit that exempts children from paying secondary school fees.²⁰
- The government of Swaziland, through a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria, pays a minimal stipend to 10,000 caregivers, largely women. This enables them to better survive and continue their work.²¹
- In Haiti, the HIV Equity Initiative has developed a low-cost way of providing in-home health services by training and paying community health workers, most of whom are women, to administer basic medications for AIDS and other diseases and to provide social support. Preliminary outcomes of the Initiative showed reduced mortality, hospitalizations, and opportunistic infections among those receiving such care.²²

WHAT'S NEEDED



Photo Credit: UNAIDS/Louise Gubb

Providing enhanced support to caregivers is a key to fulfilling global commitments on AIDS. In particular, the 2001 UN Declaration of Commitment on HIV/AIDS committed to review the social and economic impact of AIDS at all levels of society, especially on women and older people, and particularly in their role as caregivers. In signing the Declaration of Commitment – which was reaffirmed in June 2006 with the signing of the UN Political Declaration on HIV/AIDS – countries pledged to develop national policies and strategies that strengthen support for orphans and children affected by AIDS at the family, community, and national level. To meet these commitments, national governments and international partners should acknowledge the critical role of home- and community-based care, and especially of female caregivers in the AIDS response – and mobilize the financial and technical resources to support their work.

Actions for National Governments

- Ensure that home- and community-based AIDS care is an integral and budgeted element of all national AIDS strategies and programs, through direct assistance to AIDS-affected families and political and financial support to community mobilization efforts to increase access to HIV information and support services.
- Ensure that caregivers have information on HIV prevention, treatment, care, and support, as well as access to training and referral backup support, basic supplies, and resources to support children orphaned and made vulnerable by AIDS. These resources should be tailored to those most likely to provide care – with a strong focus on women, including older women and girls.
- Expand economic support to caregivers by increasing their access to affordable basic shelter, land to grow crops or raise animals, and other income-generating opportunities, including microcredit programs.
- Address the overall health and specific psychosocial needs of caregivers, in particular older women and young girls, through the provision of counseling and other assistance.
- Ensure that organizations and individuals working with caregivers are involved in the design, implementation, and monitoring of HIV prevention, treatment, care, and support programs at the national and community level.
- Encourage and support men and boys in sharing the responsibility of caring for those living with HIV.



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Actions for International Partners

- Ensure that bilateral and multilateral funding – from the Global Fund to Fight AIDS, Tuberculosis and Malaria, the U.S. President's Emergency Plan for AIDS Relief, the World Bank, and other donors – supports programs for caregivers, and that these programs are adapted and responsive to the needs of women and girls.
- Increase support for families and communities that are caring for children orphaned and made vulnerable by AIDS, including basic health care, psychological counseling, school fees, succession planning, and access to HIV information and services.
- Increase support for individual caregivers, especially women, through access to economic, technical, and psychosocial support to sustain their work and secure their future. This includes support for training on the effective provision of care, continuing education and employment opportunities for young women caregivers as well as counseling, particularly for older women facing stress, stigma, or depression.
- Support the collection and analysis of data on caregivers to better inform AIDS policies and programs.



Photo Credit: UNAIDS/K.Hesse

- ¹ UNAIDS/UNFPA/UNIFEM, "Women and HIV/AIDS: Confronting the Crisis," 2004.
- ² The Global Coalition on Women and AIDS is a worldwide alliance of civil society groups, networks of women living with HIV and AIDS, governments and UN organizations supporting AIDS strategies that work for women and girls. This brief is the fifth in a series that explores a range of key issues that particularly affect women and girls in the global fight against AIDS. All the briefings can be found at: <http://womenandaids.unaids.org>.
- ³ M. Steinberg, et al, "Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic," the Henry J. Kaiser Family Foundation, October 2002, <http://www.kff.org/southafrica/upload/Hitting-Home-How-Households-Cope-with-the-Impact-of-the-HIV-AIDS-Epidemic-Report.pdf>.
- ⁴ J. Ogden, S. Esim, and C. Gowen, "Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus," 2004, Washington DC, Population Council and International Center for Research on Women, p. 35. Available at <http://www.popcouncil.org/pdfs/horizons/xpndngcrcntnm.pdf>.
- ⁵ Losing one or both parents to AIDS is not the only way that children are affected by the epidemic; other children are made vulnerable when a parent or other close family member becomes sick, when other orphans are brought into an already poor household, or when they themselves become infected with HIV. See UNICEF, "Children on the Brink," 2004, http://www.unicef.org/publications/files/cob_layout6-013.pdf.
- ⁶ See UNICEF, "Girls, HIV/AIDS and Education," [http://www.unicef.org/publications/files/Girls_HIV_AIDS_and_Education_\(English\)_rev.pdf](http://www.unicef.org/publications/files/Girls_HIV_AIDS_and_Education_(English)_rev.pdf).
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- ⁸ Facing the Future Together: Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004, p. 38
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- ¹¹ UNICEF, "Africa's Orphaned Generation," http://www.unicef.org/publications/files/africas_orphans.pdf.
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- ¹³ Protection and support for orphans and families affected by HIV/AIDS, www.unicef.org/aids/index_orphans.html.
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- ¹⁵ HelpAge, "Facts and figures," <http://www.helpage.org/Researchandpolicy/HIVAIDS/Factsandfigures>.
- ¹⁶ India HIV/AIDS Alliance, "Integration: A Sustainable Approach, Experience from a community based HIV/AIDS care and support programme," 2004.
- ¹⁷ Email from Priya Mohanty, India HIV/AIDS Alliance, April 28, 2006.
- ¹⁸ J. Fleischman, "Strengthening AIDS Programs for Women: Lessons for U.S. Policy from Zambia and Kenya," CSIS Task Force on HIV/AIDS, May 2005, p. 16.
- ¹⁹ Older Women Leading the Way: Replicable model of community based HIV/AIDS response by Older Women Carers, (The Experience of the Vietnam Women's Union in Vietnam), December 2005.
- ²⁰ HelpAge International, "AIDS: the Frontline, Supporting Older Carers of People Living with HIV/AIDS and Orphaned Children in Mozambique, South Africa and Sudan," <http://www.helpage.org/News/Latestnews/@26777>.
- ²¹ T. Hultman, "Swaziland: Unpaid Caregivers Ease Swaziland's Grim Struggle Against HIV/AIDS," allafrica.com, May 7, 2004.
- ²² See Partners in Health, <http://www.pih.org/inthenews/030501EquityInitiative/index.htm>.



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