



Huairou Commission

Policy Brief

Home-Based Care:

Turning the AIDS Pandemic into an Opportunity for Development

HIV/AIDS has been declared a national emergency in countries throughout the world. The United Nations has declared that HIV/AIDS may be the largest single obstacle to meeting the Millennium Development Goals. Millions of dollars have been invested in HIV/AIDS responses and major donors, multilateral development agencies, civil society and governments meet regularly to debate and discuss effective uses of aid. And yet the burden of daily response stills lies on the shoulders of poor communities.

Through home-based care, grassroots women are creating a holistic, women-led, community-driven response to HIV/AIDS. Grassroots women coping with the AIDS pandemic on a daily basis are clear that HIV is not just a health issue. It is an issue encompassing all aspects of daily life—access to basic services including water, sanitation and transportation, livelihoods, food security and governance. Home-based caregivers provide palliative care, treatment for opportunistic infections and psychosocial counseling, they initiate locally appropriate and culturally sensitive stigma-reduction and awareness-raising campaigns, provide nutritional counseling and promote food security. They are also improving access to basic services by linking to the formal services that do exist—including clinics and hospitals, mortuaries, feeding programs and to resources such as bursary funds for orphans and other community development funds.

Yet rather than tying women into traditional roles as caregivers, home-based care groups are emerging as a key response strategy and as a platform for organizing, led by grassroots women. Caregivers have formed groups and in many cases networks of groups to provide mutual support and to build their own power. Through their groups, caregivers are engaging in peer learning, they are becoming trainers of trainers, and they are learning to negotiate with local government authorities and other decision makers to access funds and get themselves into decision making positions. Grassroots women have also begun using the pandemic to promote women's inheritance rights, and to make land and housing security for women real, through organizing Watch Dog Groups—local partnerships to prevent and mitigate land stripping (deeply related to HIV/AIDS). In short, caregivers are turning the HIV/AIDS Pandemic into an opportunity for development.

Caregivers within the networks of GROOTS International and in partnership with the Huairou Commission are now in the process of organizing the Home-Based Care Alliance to further increase their potential and capacity for advocacy. The idea for a federation of home-based caregivers arose out of the International Conference on AIDS and STIs in Africa in 2003 in Nairobi, Kenya,

when home-based caregivers were challenged by the Global Fund on AIDS, TB and Malaria to federate and organize themselves so that global donors could find them. Grassroots caregivers took up that challenge and, with support from the New Field Foundation, launched the Home-Based Care Alliance in Kenya in 2005 and in Uganda in 2007. Mobilization or pre-mobilization is also taking place in Uganda, Rwanda, Cameroon, Nigeria, Malawi, South Africa, Zambia and Zimbabwe. The overarching goal of the Alliance is to shift resources and decision-making to community responses to HIV/AIDS. The Alliance is meant to serve as a negotiating platform for caregivers, to build their capacity through peer learning and to ensure the livelihoods and sustainability through collective enterprise.

But without global support for caregivers to continue their organizing and to play these roles, they will continue to be marginalized locally, nationally and globally, and worse, they will burn out from their un-recognized contributions. The Huairou Commission is forging partnerships to bring the voices and priorities of caregivers to the center of the global AIDS response.

Recommendations for Action

Grassroots caregivers have come together during peer exchanges and at global events including ICASA, the YWCA International Women's Summit, the International AIDS Conference, the World Urban Forum and Africities to articulate their contributions and the challenges they face, and share ideas for support that would make a difference to them. Out of these exchanges they have developed the following call for actions by partners in funding and development agencies involved in the global response to HIV/AIDS:

- Recognize caregivers as valued stakeholders through giving them a formal place in decision-making bodies, local to global
- Earmark and monitor a fixed minimum percentage of money to go directly to support community-led responses to AIDS, particularly those being driven by women
- Support through funding grassroots women's organizing, to build constituencies and sustain long-term movement-building
- Support peer learning and networking among home-based caregivers as the most effective way to transfer knowledge, strategies, lessons learned and good practices

Opportunities to Function as Monitors and Decision-Makers

- Establish consultative mechanisms in funding and decision-making processes at the global, regional, national and local level to ensure participatory

processes and the inclusion of grassroots home-based caregivers, and an equitable distribution of resources

- Establish an official role for home-based caregivers as monitors and evaluators of national and international AIDS programs

Foster Collaborations for Accountability

- Commit to the de-politicization of AIDS-funding processes through establishing democratic, participatory processes for electing civil society representatives to local and national AIDS authorities, and to further promote networking among civil society after those representatives are chosen
- Support the many partnerships being forged between home-based caregivers and mayors, local authorities and other local-level government officials and administrators, which are effectively coordinating and monitoring community resources

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