



Grassroots home-based caregivers frame an agenda for immediate action at the International AIDS Conference, Vienna, Austria

Grassroots women home-based caregivers and their partners and allies anchored a program at the 18th International AIDS Conference in Vienna, Austria, clearly demonstrating their central role in creating comprehensive responses to HIV and AIDS at the community level, and calling for immediate action and investments in their organizations and initiatives.

In Vienna, caregivers clearly stated: that they are major actors in the fight against HIV and AIDS; that they are creating holistic and effective community health systems and ensuring access to treatment and prevention; and that they must be recognized and resourced for their efforts if the global community is serious about ending the crises of HIV and AIDS and creating more resilient communities.



For this Conference, the Huairou Commission leveraged partnerships to open spaces for grassroots women to gain visibility for their contributions to fighting AIDS, to share their strategies and good practices, and to make their voices heard in strategic dialogues with institutional allies. Speaking from the expertise gained as on the ground practitioners and the insights of their daily experiences, grassroots caregivers joined with partners to advance a call for recognition and support through the following activities and organizing spaces described in this report.

Home-based caregivers made substantive contributions to a variety of policy and operational dialogues in Vienna, including civil society consultations on WHO's new HIV strategy and a bridging session on social protection organized by UNICEF and UNAIDS. Caregivers and their partners used their daily realities and successful





practices to meaningfully participate in rich policy and program debates and dialogues on health systems and community systems strengthening, social protection, treatment access and adherence and gender equality (including through women's land, housing and inheritance rights). In these discussions, caregivers demonstrated that while professionals and institutions working at the policy level may define their work in limited sectors and themes, grassroots women respond to AIDS and related development and rights issues as a matter of their daily lives. In this way they contribute to policy dialogues with a unique and grounded perspective, which can liberate policymakers, institutional and NGO staff from endless rhetorical debates and turf battles that wind up slowing progress towards making real change.

Major dialogues in the Conference focused on "Treatment 2.0" (which refers to radically simplified treatment regimens and treatment as prevention), new advancements in microbicides, human rights of those considered most at risk, and global funding commitments for AIDS. In this context, home-based caregivers demanded meaningful inclusion in dialogues and decision-making, insisting:

- that treatment and prevention could not be rolled out if they were not in communities linking people living with HIV to health clinics, sharing information on available services, and ensuring food and nutrition security;
- that funding would not reach those who need it most if they were not in communities watching where funding went, and ensuring it reaches the most poor and vulnerable households;
- that many people, including sex workers and drug users, and especially at the grassroots level, would not know or be able to claim their rights if organized groups of caregivers were not joining them to raise awareness on and in some cases actively protecting those rights.

Participation in the Caregivers Action Network

The majority of our program and advocacy in Vienna took place as part of the Caregivers Action Network (CAN), which organized for months leading into the AIDS Conference to ensure that caregivers and the issue of care and support gained unprecedented attention, and that care and support practitioners could come together to network, share skills





and experiences, and form a united voice for advocacy.

CAN organized a large and active Networking Zone, which featured presentations on research, skills sharing, and dialogues on key issues such as reducing the burden of care, involving men in caregiving, and bridging the divide between community care and support and palliative care advocates. The Networking Zone regularly attracted a sizeable crowd of engaged participants. A daily caucus drew in allies from UNAIDS and WHO, and also featured high level advocate Stephen Lewis, all of who gave the CAN team insightful political advice on making impact through advocacy.

“The recognition of home-based care and care and support is long overdue in discussions of universal access” –Hedia Belhadj, Partnerships Director, UNAIDS

On Monday night, CAN co-organized [From Universal Access to the MDGs: Why Home-Based Care Matters](#), a panel session in the Global Village. This panel session in the Global Village brought together caregivers, faith-based organizations, supportive NGOs, and high level allies from UNAIDS and donor institutions to describe the ways



caregivers are contributing to achievement of the MDGs and universal access targets, demonstrate how and why NGOs and donors are supporting these efforts, and push forward an agenda for action.

Nearly 100 people came together Monday night for this panel, which included primary carer, a secondary carer, representatives of faith-based organization, NGO and a donor institution. Panelists shared from their experiences clearly how home-based caregivers are not only contributing to, but are central to efforts to achieve Universal Access to Treatment, Prevention, Care and Support. Speaking from the community perspective, particularly from poor communities in sub-Saharan Africa, the speakers demonstrated the ways that caregivers in the home and community, working in community-based organizations or with churches, have been providing the major response to HIV and AIDS since long before global health and policy institutions took AIDS up as an issue.

The panelists ended with recommendations:

- To develop strong guidelines and policies on home-based care and palliative care in every country before 2015





- To bring caregivers centrally into decision making at the local, national and global levels
- To revisit funding channels so that money actually reaches the intended beneficiaries

Agnes Atim of NACWOLA, and the recipient of the Cordaid/CAN award on home-based care in 2009, ended the session with a strong call for everyone who is working on care and support to link together through CAN, "to link up, join hands, give voice to the voiceless and ensure that this work of care and support is recognized."

CAN also was invited by UNAIDS to have a representative at a Bridging session on Social Protection. UNAIDS and other institutions are increasingly exploring social protection mechanisms for their role in reducing vulnerability to and mitigating the impact of HIV and AIDS. Within UNAIDS home-based care actually falls within social protection, so this was a key venue in which to be represented. In this high level panel, Agnes Atim of NACWOLA represented the Caregivers Action Network, and called strongly for community-led initiatives to be recognized and supported within social protection frameworks, and for caregivers to be placed centrally in the design, implementation and monitoring and evaluation of social protection programs to ensure that they reach their intended beneficiaries.

The Compensations for Contributions research

Vienna was a major venue for dissemination of the results of the Compensations for Contributions research reports. The results were formally presented in a session in the Caregivers Action Networking Zone, "Home-based caregivers role in creating comprehensive treatment, care and support systems". The research outcomes starkly demonstrates the time and resource contributions being made by home-based caregivers. Those sampled, over 80% of whom were women, contribute out of their own pockets for supplies, transport, food and clothing; are rarely given stipends or any other support; and work on average 65 hours per month, labor costs when





aggregated worth millions of dollars each year. Caregivers are using this solid evidence to advocate for recognition, resources and remuneration from the local to global levels.

The intersection of HIV and women's land, housing and inheritance rights

Esther Mwaura-Muiru of GROOTS Kenya and the Huirou Commission, and Tamar Ezer of Open Society Institute featured two aspects of work that the Huirou Commission is involved in during two sessions in Vienna. The two sessions:

“Women, HIV and Human Rights: Addressing Property and Inheritance”, in the Human Rights Networking Zone and the “International AIDS Housing Roundtable”, a formal satellite session, brought together land and housing activists working to



increase secure tenure, housing access for people living with HIV, and to demonstrate the vital linkages between land and housing, HIV prevention, treatment, care and support. In both sessions, Esther focused on grassroots strategies including Watch Dog Groups through which grassroots women leaders (many home-based caregivers) are actively enabling women to claim and maintain their land and housing in places where women have often been victims of disinheritance, particularly since the beginning of the HIV/AIDS pandemic. Tamar shared an upcoming publication of OSI, Huirou Commission, UNDP and COHRE: “Tools for Change” – designed to be a manual to make human rights instruments accessible to human rights advocates working at the local and national level.

Sharing grassroots-led tools and methodologies

The CAN Networking Zone was a venue for grassroots caregivers in the Huirou Commission to showcase the successful strategies they are using in their communities to gain recognition and resources.

-Community caregivers organize for impact: The Home-Based Care Alliance. In this session in the Caregivers Action Networking Zone home-based caregivers who have organized bottom-up Alliances of grassroots caregivers in their communities and countries shared the process of organizing and the strong impacts they have made. The Home-Based Caregivers Alliance, a grassroots monitoring and accountability initiative organized and led by caregivers themselves, has greatly increased the amount of funding reaching community-led AIDS responses, particularly those led





by caregivers, has led to an increase in grassroots caregivers sitting on local decision making and decentralized funding councils and committees, and reduced duplication of services by NGOs, CBOs and government.

-Step-by-Step Advocacy training session for home-based caregivers and their partners: The Local to Local Dialogue. In this session, Shannon Hayes of the Huirou Commission and network members Mercy Likalaba Ilusa of GROOTS Kenya and Limota Goroso-Giwa provided networking zone participants with a step by step guide for conducting successful advocacy in their communities using the Huirou Commission's Local to Local Dialogue methodology. The Local to Local Dialogue process is a series of community-initiated, locally customised strategies whereby grassroots groups, most often women-led, initiate and engage in ongoing dialogues with local leaders and authorities to negotiate on a range of development issues and priorities, plans and programmes in ways that enhance community participation and address women's priorities. Shannon laid out the steps of the methodology while Mercy provided concrete examples of how she and other leaders in her grassroots organizations in Western Kenya used the methodology in their community to successfully address the fact that many women and orphans were being thrown off of their land upon the deaths of their husbands or parents. Limota then shared some of the successes IWCC has had through the Local to Local dialogue in Kwara State, Nigeria, in gaining acceptance in the Muslim community for girls to go to school.



Women ARISE

Women's organizations from around the world organized for this AIDS Conference with new coordination through Women ARISE. They advanced a strong, unified agenda and ensured that issues of sexual and reproductive rights, the rights and issues of sex workers and women drug users, to name just a few, were visible throughout the Conference program. They also made strategic interventions and called for concrete actions through sessions on funding and actions for achieving women's equality within the response to HIV. The Huirou Commission participated in Women ARISE and made clear that while they and their issues of poverty, access to food and basic services, may not be fully included in the women's agenda, that home-based care and support are some of the most urgent and





pressing women's issues, especially in poor communities where women are shouldering the major work of providing care for people infected and affected by HIV and AIDS. The Huirou Commission will continue to participate in Women ARISE to seek allies in the women's movement to join with them in advancing grassroots women's urgent agenda.

Next Steps

The Huirou Commission will continue to work with GROOTS International to build Home-Based Care Alliances at the local and national level across Africa to ensure that grassroots caregivers have their own platforms for networking, peer exchange and advocating for resources and recognition from the local to global levels. We will also continue to work with the Caregivers Action Network to bring forward the



priorities of grassroots caregivers and ensure their voices are central in advocacy and policy and decision-making at the national, regional and global levels.

Working with CAN, caregivers and their partners will push forward a strong call to action from now to the next AIDS Conference in 2012, which has

been signed by hundreds of allies throughout the Conference. Following up on the Conference, it will be sent to the heads of UNAIDS, the Global Fund, PEPFAR and other major institutions in order to request dialogues towards immediate and long term actions that can be taken to recognize and resource quality palliative home-based care and support and caregivers as central pillars of a comprehensive response to HIV and AIDS.

To sign onto the Call to Action, write: all_caregivers@yahoo.com

A Call to Action: Recognize and resource quality palliative home-based care and support and caregivers as central pillars of a comprehensive response to HIV and AIDS

We, the undersigned, call for an immediate and urgent increase in focus and investment in quality palliative care and support for all people living with and affected by HIV and AIDS around the world, particularly through action to support family and community based caregivers.





Even though care and support is one of the three pillars of universal access and is central to achieving prevention and treatment commitments, it remains neglected in the AIDS response and does not receive the attention or funding it merits. Family and community caregivers are anchoring a major response to HIV and AIDS by providing the majority of HIV care and support, yet neither caregivers nor their concerns have been adequately recognized or represented in HIV policy, programming or funding dialogues and commitments.

The AIDS pandemic has changed the fabric of communities around the world and created a particular burden in the lives of many people. For decades overburdened and under-resourced public health systems have displaced care and support into the household and community. This has meant that family and community caregivers, the majority of whom are women and girls, have been left with little choice but to devote their time, energy, skills and the little resources they have to provide community health services. These carers receive very little if any recognition, psychological and financial support, equipment or training. Older women and young girls are often particularly severely affected, with older women looking after their adult children and grandchildren without access to income generation or emotional support, and many girl carers missing out on school and other opportunities.



Now, thanks to the wide roll-out of ARVs, people are living longer with HIV. However, it is often forgotten that this means that increasing numbers of positive people are in need of a wider range of care and support services over longer periods of time. Caregivers' workload is increasing yet they continue to be ignored, undervalued, under-resourced and under supported. This must change. To ensure a comprehensive and effective response to HIV and AIDS that incorporates care and support and the contributions of caregivers, we recommend the following actions:

- Ensure that quality palliative home-based care and support and carers are recognized for their critical role in the continuum of care, particularly primary health care and the provision of social protection to the poorest and most vulnerable. As such, national plans and funding for community and public health systems and social protection mechanisms must include and directly support quality palliative home-based care and caregivers.





- Design, implement and fully fund comprehensive national policies on HIV care and support that increase access to quality palliative home-based care and support and effectively coordinates the government and civil society HIV responses. Ensure that a minimum percentage of direct funding support is earmarked for community-led responses to AIDS, particularly those driven by women.
- Include caregivers as decision-makers in the design, implementation, monitoring and evaluation of resources and programs. National governments and global donors must be held accountable to the needs and priorities of communities by key stakeholders living with and affected by HIV, including home-based caregivers
- Recognize, affirm and support community caregivers by providing adequate equipment, psychosocial support, compensation and supervisory support from health professionals. Provide caregivers with sufficient and regular training on quality palliative home-based care and support. The training should enable them to recognize and support the health needs of the people they are caring for and administer medication or refer as necessary so that people living with HIV have access to the medications that they need, including opioids.
- Recognize the unique requirements of caring and protecting children affected by HIV and AIDS, especially child-headed households, related to: exploitation, trafficking, child labor, violence, sexual abuse, child marriage birth registration, stigma and challenges posed by institutional care
- Reduce household poverty and the cost of care through provision of basic services and the cost of care through government provision of basic services and social protection measures (including universal pension coverage, cash transfers, access to water, sanitation, food security, women's land and inheritance rights, etc) and through building the capacity of community-based organizations to be involved in provision of these services and to develop livelihoods initiatives for care providers. Reduce the burden of care specifically on women and girls through strategies and programs to engage and support men as caregivers while also promoting women in leadership and decision-making roles in care provision.

Press and Publicity

<http://www.ips.org/mdg3/women-vital-in-global-fight-against-aids/>

<http://healthdev.net/site/post.php?s=7127>

<http://unaids.org/?p=444>





<http://www.housingworks.org/blogs/detail/iac-satellite-meeting-shows-global-power-of-aids-housing-advocacy/>

The Huirou Commission's delegation at the International AIDS Conference was:

- Limota Goroso-Giwa, International Women's Communication Center, Nigeria
- Shannon Hayes, Huirou Commission Secretariat
- Merceline Likalaba Ilusa, GROOTS Kenya
- Esther Mwaura-Muiru, GROOTS Kenya
- Masitulah Nakisozi, Uganda Community Based Association for Child Welfare (UCOBAC)
- Emily Tjale, Land Access Movement of South Africa

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