Home-Based Care Alliance

At this conference, a number of myths are being circulated surrounding home based care and support and the role of grassroots women’s groups in linking to decentralizing health systems.

**MYTHS:**

1. Caregivers are not organized, and their contributions to the AIDS response are small-scale and fragmented.
2. Caregiving is labor performed by genderless volunteers, with multiple confusing titles, who are content to receive T-shirts, training and transport stipends for their work.
3. Anti-Retroviral (ARVs) treatment is making caregiving a lesser need.
4. The best way to compensate caregivers is to pay a subset as individuals.
5. There is a lack of evidence-based research to prove the value of caregivers’ contributions.

**REALITY CHECK:**

1. At AIDS2012, delegates from the grassroots women’s Home-Based Care Alliance (HBCA) represent 30,000+ organized caregivers in 11 African countries. These women, many of whom are themselves HIV-positive, widowed, or taking care of infected family and neighbors, have their own mutual self-help groups and community-based organizations, and were the first responders in the fight against the pandemic when it hit their communities more than 10 years ago. They have been actively providing direct care and support to those most in need ever since.

2. Caregivers are grassroots women whose work expands far beyond mere service provision, holistically reducing the impacts of HIV/AIDS as well as its effects, such as land and asset stripping, social stigma, food insecurity and gender-based violence. They are experts of their own local contexts, in poor rural areas and urban slums, and work tirelessly to address the needs of their communities. They are not seeking handouts or training in caregiving, but rather recognition for the work they’re already doing, direct support for organizing and leadership development, and inclusion in all levels of AIDS decision-making, programming, and implementation.

3. As a growing number of community members access ARVs and live longer lives, and as young people need support and education for prevention, the demand for caregivers is changing accordingly. Organized groups of Home-Based Care Alliances are more important than ever, acting as agents of community development and service delivery. The projected future of treatment and prevention depends on their skills and knowledge.

4. Caregivers are strong contributors to community development and should be awarded public grants in proportion to NGOs. They prioritize mutual self help and already are pioneering innovative collective income-generating activities (IGAs) and grants will scale up their efforts and reward grassroots cooperation and leadership.

5. A growing collection of documented, evidence-based research, conducted by independent analysts (Compensation for Contributions study carried out by independent analysts, a publication by the UK Consortium and a new report by the World Bank) confirm grassroots women’s groups’ capacity to foster relationships and collect data and information that enhances accountability and transparency with their governments.
At the 2012 International AIDS Conference, a top-down, business efficiency model seems to be taking women and communities most affected by the pandemic out of the picture—a potentially catastrophic ‘tide turning’.

Grassroots caregivers, organized into the multi-country Home Based Care Alliance, are championing a community-based approach to the AIDS response, linking people most in need with access to health services, and working efficiently and holistically to reduce the impacts of HIV/AIDS, curb poverty and marginalization and foster community ownership and government accountability.

Despite their significant contributions, documented through evidence-based research, grassroots women’s CBOS remain fragile and under-resourced, leaders are stretched too thin and susceptible to burnout, and their work is being displaced by NGOs who seek to replace or absorb them as service providers (not community developers).

In this context, the Home Based Care Alliance, representing more than 30,000 caregivers across 11 African countries, calls for:

1. **Formal Recognition of the Contributions of Women-led Home-based Caregiver Alliances (HBCA) to Care & Support in Africa, through:**

   - Priority access to governmental health services, medical, protective and food supplies (via certification and I.D. systems registering and recognizing women’s groups as partners) and national directories listing the location, work scope and contacts of women’s home-based caregiver alliance groups.

   - Earmarked budget targeting a % of municipal, AIDS Council, and poverty reduction monies (1-5%) for registered community based women’s organizations in the HBCA running care and support, women’s empowerment and poverty reduction activities locally.

   - Seats in planning and decision making bodies that design and fund community development and social service programs for poor affected/infected women and families (local to global)

2. **Public and Philanthropic Financing to Grow and Sustain Home-Based Caregiver Alliance activities, including the following elements:**

   - Grant awards to national or multi-state Home-Based Caregiver Alliances that enable women to undertake income-generating and fundraising activities (IGAs)

   - Health mutual and savings and credit initiatives

   - Direct funding for capacity building, organizing and leadership development

   - Public, transparent hearings and consultations on AIDS-related and health budgets that include strong representation of grassroots women’s caregiving groups.