Valuing and Compensating Caregivers for their Contributions to Community Health and Development in the Context of HIV and AIDS: An Agenda for Action

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Based on the results of the action research initiative Compensations for Contributions: Creating an Enabling Policy and Institutional Framework for Home-Based Care”, by the Huairou Commission with support from the UNDP-Japan Partnership Fund (WID/GAD).
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We dedicate this work to caregivers everywhere, who through their daily acts of love and commitment shape the world we want to live in.
BACKGROUND The Compensations for Contributions Initiative: Creating an Enabling Policy and Institutional Framework for Home-Based Care

Between August 2008 and March 2010, the Huairou Commission AIDS Campaign coordinated an action research initiative across Africa, with financial support from the UNDP-Japan Partnership Fund. Home-based caregivers in 13 countries across Africa were consulted through 1366 structured interviews in 6 countries, approximately 40 focus groups, a 60-person Grassroots Women’s International Academy, local dialogues, national advocacy campaigns, and participation in global decision-making spaces including the International AIDS Conference and UN Commission on the Status of Women.1

This action research initiative sought to capture the realities of tens of thousands of grassroots women who struggle every day to provide care and support to people living with HIV and AIDS, orphans, the elderly and chronically ill. We at the Huairou Commission knew anecdotally from our ongoing work with these women about the leadership and the holistic, developmental initiatives they conduct in their communities that incorporate caregiving activities. We also recognized that very few global institutions working on HIV and AIDS at the international level were aware of, or acknowledging, this work in any meaningful way. To bridge these gaps – between what was really happening in communities and what was being addressed at the global level – the UNDP-Japan Partnership Fund supported the Huairou Commission to conduct rigorous research on the wide range of contributions being made by home-based caregivers, and the costs they were paying – in labor hours and out of pocket expenditures – to make those contributions. Based on the results of this research four key areas of support for home-based caregivers have emerged:

1. Organizing
2. Recognition
3. Resources
4. Remuneration

The Huairou Commission believes that supporting home-based caregivers in these ways is an absolutely necessary step in establishing an effective and sustainable continuum of care. Building on the leadership and initiative that home-based caregivers are already taking in their communities is a critical component of supporting effective health systems, ensuring universal access to treatment, care and support, establishing accountability for AIDS funding, mitigating the economic and development drain of HIV and AIDS on families and communities and, ultimately, halting and reversing the spread of HIV.

This report summarizes the Initiative’s research findings (which can be found in their entirety in a separate report2), and provides recommendations for action that are meant to be a starting point for government, civil society and donors to dialogue with home-based caregivers to craft effective policies and mechanisms to support home-based caregivers and effectively address health and development challenges based on the work that caregivers across Africa are already doing in their communities. Within the recommendations the reader can find examples of caregivers’ leadership, capacity and talents, which form a starting point for policies, programs and implementation mechanisms.

1 See Annex 1 for profiles and contact information of all groups who participated in the research and are featured in this report
BASELINE ASSUMPTIONS

Grassroots women’s initiatives are the foundation of a sustainable response to HIV and AIDS that does not just stem the tide of the pandemic, but begins to reverse the root causes of HIV and AIDS. These causes – women’s inequality and marginalization; poverty; under-resourced health systems; food insecurity; lack of clean water, adequate sanitation, accessible transportation, and communications; poor governance; and women’s limited control over land – contribute to extreme vulnerability to HIV. Likewise, the contexts in which home-based caregivers work face serious shortages of health workers, clinics and hospitals.

In response, women’s initiatives aim to bridge gaps between effective community-level initiatives, and the systems for funding and decision-making established by governments. By bringing together these streams of action, the global community could stop HIV, establish effective, comprehensive treatment, care and support for those infected and affected and at the same time respond to the development challenges that make people vulnerable to HIV in the first place.

This is a good point in time to focus in on these issues. Long-dominant modes of financing are being reexamined, and “health systems strengthening” and “task shifting” are emerging as newly popular strategies for AIDS funding. Likewise, exploring public funding modalities for women’s unpaid care work is increasingly relevant.
KEY FINDINGS from the Compensations for Contributions research on Caregivers’ Contributions

Home-based care is often thought of as a non- or para-professional health service, in which people with basic training in primary health care, sanitation and counseling for people living with HIV and other chronic illnesses provide services in the sick person’s home, supplementing the work of the formal health system. But most home-based caregivers engage in a much broader range of work than this. In fact they can more accurately be characterized as community development agents rather than low-level health workers. As part of this re-definition, it is important to note that the caregivers in the Huairou Commission’s network typically refer to the individuals they serve as their “friends” or “neighbors” (rather than clients or patients) in order to avoid establishing barriers or hierarchies.

Caregivers serve at the forefront of the response to AIDS and, out of necessity, regularly shift their strategies and focus as the pandemic changes and evolves. For example, with increasing access to anti-retroviral treatment, the work of caregivers has shifted from caring for the bedridden to ensuring treatment adherence through linking to clinical services, regular check-ins and providing nutritional support.

The action research resulted in this list of the various work caregivers are leading:

- Provide home-based care for friends
- Provide treatment adherence support for anti-retrovirals and TB treatment
- Link friends with social services provided by NGOs, government, churches, etc
- Provide ongoing psychosocial counseling and support to people living with HIV
- Convene and facilitate support groups for people living with HIV
- Conduct education and awareness-raising on HIV and AIDS prevention, services for treatment, care and support, and campaigns against stigma through community mobilization, mass media, door to door visits and other similar strategies
- Conduct information campaigns on the importance of being tested
- Encourage those living with HIV to engage in community life
- Lobby and advocate for better and more services and funding for HIV and AIDS
- Mobilize and involve youth in their efforts, especially around awareness raising
- Counsel and work with survivors of violence
- Engage in livelihood and income-generating activities to raise resources for their efforts and to support other needy people
- Build partnerships to increase coordination in the community with church groups, government, farming groups, social welfare, health professionals, hospitals and clinics, social workers, traditional leaders, NGOs, religious leaders, caretakers, traditional healers and birth attendants
- Increase food security through gardening, farming and feeding programs
- Leverage and distribute resources such as food, clothes and school fees to those in need

3 In keeping with the vocabulary used by the caregivers within our network, this report calls the people caregivers assist “friends”.

4 Common activities include soap making, gardening and raising livestock
• Offer skills training programs for orphans and other children
• Ensure friends and orphans have proper documentation (such as birth certificates, wills and medical records) to receive government benefits
• Facilitate community dialogues solutions to cultural practices (like wife inheritance and land grabbing, which both are triggered by, and leave people more vulnerable to, HIV and AIDS)
• Conduct outreach to sex workers and drug users to counsel them and link them into groups and programs
• Collect statistics for the government and NGOs

The research revealed some demographics of caregivers:
• Women were prominent among interviewed volunteers: across all countries more than two-thirds of volunteers were women.
• More than two-thirds of volunteers surveyed were between 30 and 49 years old, ages when a woman usually has significant responsibilities in terms of her children and family.
• More than half (55%) of both male and female volunteers also did income-earning work.

The research also demonstrated a wide breadth of experience and responsibilities among volunteer caregivers:
• Almost all (96%) volunteers reported that they undertook home visits, 82% did monitoring of anti-retrovirals and 74% visited friends in the clinic or hospital.
• Volunteers also did a wide range of other tasks, including: engaging in advocacy in public forums, training household caregivers outside their homes, organizing and mentoring orphans who are not family members, and following up on school performance of orphans.
• One third of the volunteers had not received any special training related to the volunteer work. Of those who had received training, more than half (52%) received only one-off initial training before they started doing volunteer work.

The research illustrated caregivers’ connections to health systems, resources and critical supplies:
• Strong linkages exist between the volunteers and the countries’ health systems: the overwhelming majority (93%) of volunteers reported referring friends to health professionals. Further, more than sixty percent of the volunteers surveyed received friends referred by health professionals and were supervised by health professionals.
• Gloves were the item for which volunteers were most likely to report receiving money to help with costs, but only 41% of volunteers received this assistance. And some who received gloves also reported having to spend their own money on gloves.
• Care kits and cleaning materials are essential tools for volunteers. However, only 35% and 26% respectively of volunteers reported receiving these tools.
• A large majority (87%) of volunteers reported incurring transport costs that were not covered by the organization or group with which they worked.

Time spent volunteering
Volunteers were asked in two ways about the number of hours spent volunteering per day. Firstly, they were asked the question: “Over the last seven days, how many hours did you spend per day on average on volunteer work on the days you did this work?” Secondly, they were asked to detail all the activities that they did on the last day that they did volunteer work, including both volunteering-related activities and other activities, and the time spent on volunteering was calculated from this “diary”. The simple question method gave an average of 5.8 hours per day across all countries, while the diary method gave an average of 4.6 hours. Other international research efforts have found that the diary method usually gives a more accurate, lower, estimate.

Volunteers were also asked how many days on average they volunteered per week. Overall, volunteers reported an average of 69 hours of volunteer work per month. The average ranged from 36 hours per month in Malawi to 106 hours in Kenya. Even in Malawi, the number of hours is close to a full week’s work in many paid jobs in the formal sector. Yet most of these efforts were work for no pay, while the volunteers often incur costs in doing the work.

5 Care kits typically include items such as basic medicines like aspirin and anti-diarrheal pills, protective items including gloves, anti-septics, plastic aprons and hand towels, soaps, salves, wound dressings, lotions, gauze and bandages, in addition to pens and paper for record keeping and referral cards to the hospital.
The findings from this research point to four key areas in which support for home-based caregivers could make a significant impact in backing and expanding their work: Organizing; Recognition; Resources; and, Remuneration. These recommendations, which emerge from constituencies of grassroots home-based caregivers and their partners in our network, are detailed below. The recommendations point directly to achievable actions, because they are built on work that is already ongoing. In many communities in Africa, home-based caregivers expressed that they feel they are providing services without support or acknowledgement from the government, while funding for HIV and AIDS meant to reach communities through the government is simply not getting to the ground. Building on the existing leadership and initiative taken by home-based caregivers will allow new investments to address AIDS in poor countries to amplify the impact of ongoing work.

The action research initiative pushed us to envision what it would really look like if home-based caregivers were recognized and fully resourced to play the critical roles they have taken on in the past 30 years of the AIDS epidemic. What would a well-supported, vibrant, holistic, community-driven response to HIV and AIDS actually look like?

These recommendations are offered as a starting point for continued dialogue among government, civil society, donors and home-based caregivers to craft and implement effective policies and mechanisms to support home-based caregivers. They are based on the work that caregivers across Africa are already doing in their communities, as well as the work they aspire to do.

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**Organizing**

- Support and provide sustainable funding for organizing for caregivers, locally, nationally and across borders
- Support community-based strategies led by home-based caregivers to stop asset stripping and land grabbing

**Recognition**

- Develop structures for on-going, formal and meaningful inclusion in decision-making by governments and NGOs (rather than on an ad hoc basis)
- Facilitate comprehensive and efficient integration of caregivers into health systems to ensure continuity of care in the community, including referral systems and on-going trainings and updating on health information for caregivers
- Establish formal accreditation processes for caregivers driven by caregivers themselves and recognized by governments and development agencies
- Select caregivers already working in communities for paid positions, government health committees and for professional training programs (eg. nursing) that become available
- Establish grassroots women as monitors and evaluators of health and AIDS programs and funding

**Resources**

- Allocate budgets and establish effective funding modalities for:
  - Adequate provision of health care supplies
  - Physical space for home-based care groups, either offices or integrated health centers
  - Support to initiate or scale up health mutual funds and other community health insurance schemes
  - Transport stipends or other transport support (eg. bicycles or cars for all caregiving groups)
  - Support to maintain and scale-up food security initiatives such as collective farming and gardening and establishment of kitchen gardens
  - Provide matching grants for savings and credit groups

**Remuneration**

- Make immediate investments in the formal recognition of home-based caregivers through direct payment or via alternative models of financial remuneration including:
  - Income-generation and sustainable livelihoods support
  - Investment in savings and credit groups
  - Establish development funds that are controlled by home-based caregivers

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We invite you to join with us in our Campaign, to help to strengthen these recommendations and work with us to pilot actions to make tangible changes in communities coping with HIV and AIDS around the world.
DETAILED RECOMMENDATIONS

1. Recommendation for Organizing

   a. Support and provide sustainable funding for organizing for caregivers locally, nationally and across borders

   b. Support community-based strategies led by home-based caregivers to stop asset stripping and land grabbing

a. Support and provide sustainable funding for organizing caregivers, locally, nationally and across borders

Home-based caregivers must be organized to meaningfully make their voices heard in decision-making, to generate recognition of the contributions they make to fighting HIV and AIDS, to negotiate effectively with health officials, local AIDS authorities and decision-makers, and to make the needs of their community known. Organized into their own groups, networks and federations, caregivers are able to withstand shifting political and donor trends and are able to bring together constituencies, plan activities and interventions specific to their communities, and to ensure that they are representing the voices of many when they get access to decision-making spaces. Likewise, when caregivers organize across borders, they share experiences, challenges, and best practices, build solidarity and gain strength from knowing that they are not alone in their struggles. However, when investments in development are made without funding to support community organizing, communities are only targets, beneficiaries or participants in programs; without a focus on empowerment, they will never lead and drive development or make their voices heard on an equal level with those who bring in financial resources. Many home-based caregivers understand this, and have for many years built their own groups, networks and federations. The Home-Based Care Alliance is one organizing initiative that has emerged through the work of GROOTS Kenya, GROOTS International and the Huairou Commission, and has proven to be an effective model for home-based caregivers to build a platform for self-coordination, strengthening their work, and for advocating for recognition and participation in decision-making at the local and national levels. The Alliance has been actively growing in Kenya and Uganda in the past 4 years.

We recommend that donors support caregivers’ networks to continue to build and strengthen organizing at the community level, nationally, and across borders. This includes support for forming and strengthening their groups and networks, and support for their own community-mobilization efforts, such as mapping, peer exchanges, community conversations and dialogues and advocacy/activism.

There are clear practical and strategic benefits to organizing. Practically, caregivers have been able to better organize their work in communities, to clear up duplication of work and of data. In Kenya, prior to organizing the Alliance, caregivers often traveled long distances to reach friends in far-off locations, creating a lot of unnecessary travel and expenditure of resources for the caregivers. Meeting all of the caregivers in the region and tracking who their patients were and where duplication could be eliminated was an immediate gain for the caregivers. Strategically, the Alliance members have been able to come together, convene the larger community in dialogues with decision-makers, gain recognition for their work, get active caregivers onto decision-making bodies, and ensure AIDS and health funding is better used. In both Kenya and Uganda home-based caregivers have gained positions in government bodies through the efforts of the Alliance.

Because caregivers organized on their own (including documenting their work, understanding their contributions and consulting with the community about its needs) they have been able to approach the local government, hospitals, NGOs and other stakeholders from a position of power to create partnerships to address the AIDS-related health and development problems facing their communities. They have not had to wait for government, NGOs or donors to come to their area, but
rather have been able to call on these bodies for action on the most pressing issues. Through organizing, home-based caregivers are being repositioned from being seen as victims, service providers or program beneficiaries, to being seen as leaders, experts and agents of change.

The Alliance is now being built from the bottom up in: Benin, Cameroon, Ethiopia, Ghana, Kenya, Malawi, Nigeria, Rwanda, South Africa, Uganda, Zambia and Zimbabwe.

b. Support community-based strategies led by home-based caregivers to stop asset stripping and land grabbing

38% of respondents in the Compensations for Contributions research are following up on grabbed land as part of their work as home-based caregivers. Asset stripping from widows and orphans after the death of their husbands and parents is a major issue that has come to light thanks to the crisis of HIV and AIDS. Home-based caregivers in many countries have begun to mobilize against this destructive practice in their communities, building partnerships with local government authorities and opinion leaders, raising awareness in the community, ensuring widows and orphans have birth and death certificates so that they can claim their land, and being trained as community paralegals to make links with the formal court system. Even when strong policies protecting women’s land and property rights exist, they are often not enforced at the community level unless a group of people is organized to enforce them.

→ We urge governments to recognize and formally involve community-based organizations actively working to protect women’s land, property and inheritance rights in the enforcement of laws and policies, and for activists and donors to fund these CBO’s and work with them on practical strategies for protecting women’s land, property and inheritance rights, rather than only working to develop national laws and policies.

Rwanda Women’s Network, working with a large number of genocide and sexual violence survivors, has established and strengthened their community paralegal program as an important education, advocacy and prevention tool. This has helped to support and promote good practices in the prevention of evictions and advocacy around it. As of 2008, RWN had trained 213 community paralegals, who act as resource persons in communities, solving local cases of disinheriting and other disputes, and have advocated at national, regional and international levels for women’s rights to own and control land and property.

Peer exchange demonstrates the power of organizing

Home-based caregivers are also building power by organizing global constituencies through exchanges across borders. Organizing and sharing experiences across borders provides a unique and striking opportunity for communities to learn how to organize themselves to face the epidemic directly. Peer exchanges give caregivers an opportunity to share effective practices and build solidarity and a collective voice to make impact at higher levels of influence.

“Learning from the Experiences of Africa”

From July 28-31, 2009, an historic peer exchange brought together 26 women from Guatemala, Honduras, Belize, Kenya and Uganda. Held in Livingston on the coast of Guatemala, the exchange was organized by the Huairou Commission. Although they came from diverse countries, the participating women identified shared issues that leave women in their home communities in vulnerable positions, such as lack of land ownership, insufficient health institutions, domestic violence, migration of men for labor and the subservient position of married women. The lack of power and access to support created by these problems puts women at risk for contracting HIV. The African women, some of whom have been responding to AIDS for over 20 years, offered their experience to the Latin Americans, whose communities currently have lower HIV prevalence rates. The Africans’ experiences helped the Latin Americans understand their vulnerabilities, how those translate into greater risk of HIV infection, and the importance of addressing those issues before HIV prevalence turns into a pandemic.

The African women also shared their achievements in mitigating the effects of AIDS, breaking the silence, preventing property grabbing, raising awareness of women’s contributions, and empowering women through collective organizing. Learning about their successes and struggles has inspired the women in Guatemala to begin their own community organization to respond to HIV and AIDS.

“We don’t have to wait until we have a pandemic to do something. We do not have to wait for the government to do something. We [neighborhood women] can raise the consciousness among the community of Livingston”. — Guatemalan participant
2. Recommendations for Recognition

a. Meaningful, on-going, formal inclusion in decision-making by governments, development agencies and NGOs

b. Comprehensive and efficient integration of caregivers into health systems

c. Select caregivers already working in community for paid positions, government health committees and for professional training programs (eg. nursing) that become available

d. Support caregivers to establish and implement formal accreditation processes

e. Establish grassroots women as monitors and evaluators of health and AIDS programs and funding

a. Meaningful, on-going, formal inclusion in decision-making by governments, development agencies and NGOs

Many governments have developed decentralized responses to HIV and AIDS that are guided, but not implemented, by national AIDS authorities, ministries of health, etc. Decentralizing the responses creates opportunities for government and civil society to forge responses to HIV and AIDS that are responsive to community needs and build on the existing capacities in the community.

Unfortunately, however, decentralized structures are often misused—for political patronage and to channel funding to pet projects—or simply ineffective due to limited capacity among its members and constituents. Women in particular have often been excluded from these structures due to long-standing patriarchal practices.

Another major mode of funding anti-AIDS initiatives is directly through civil society; national and international NGOs are often able to access funding to provide services in communities. However, NGOs’ professional staff, who come from outside of communities, are rarely able to correctly identify or reach the people that are most in need in communities. Many NGOs are unaware of, or unwilling to link to, existing CBOs. Some percentage of their funding necessarily goes to staff outside of those communities; thus funding often does not reach the neediest people in communities. Further, existing AIDS responses remain hampered by limited resources, scattered and marginalized.

We recommend that the great capacity, expertise and commitment among grassroots women — and particularly the leadership being taken by home-based caregivers responding to AIDS — are systematically involved in local decision-making structures, decentralized funding bodies and NGO initiatives. This will result in more effective responses to HIV and AIDS which are accountable to community needs and priorities, and support sustainable local initiatives. They can also more effectively reverse the marginalization of poor women by involving them in decision-making from the beginning.
Experiences documented by the Huairou Commission show that when grassroots women leaders are involved in decision-making in on-going and formal ways, development initiatives are more successful, resources are used more effectively, and services are more accessible to the people who need them the most. Home-based caregivers began to respond to HIV and AIDS without any outside entity asking them to. They have innovated effective solutions to development and health-related problems facing their communities, directly delivering or linking to services and education in the community. And yet when it is time for decisions to be made by the government, for NGOs to plan programs and interventions, or for public funding to be allocated, grassroots home-based caregivers are consulted, at best, in the final stages; they are also routinely used to promote programs they did not design or ask for, are used to deliver services with little or no compensation, or are merely treated as beneficiaries.

In Kenya, for example, 207 grassroots women who are members of the Home-Based Care Alliance and GROOTS Kenya now sit on devolved decision-making structures, such as Constituency AIDS Control Councils, district health committees, bursary funds, Constituency Development Funds, land boards, and others. These seats have been acquired through active organizing and partnership building by home-based caregivers, supported by GROOTS Kenya.

The presence of these women on local structures has had immediate benefits for both the community and decision-makers. In the Western region of Kenya, the Shibuye Community Health Workers conducted Local-to-Local Dialogues, a platform for public dialogues between grassroots caregivers and local leaders to share caregivers’ perspectives, to discuss challenges within the community and develop collaborative solutions. Before these dialogues, the Alliance consulted the community to identify major issues faced by them and also educate them on the National AIDS Control Council (NACC) Strategic Plan. For the community, the main issue was that the CACC was an inaccessible, non-transparent entity whose programs were not sustainable. To change this, the group invited CACC officers, the Provincial Administrators, Kakamega district officers and local chiefs. In the meeting, the community demonstrated their knowledge of the NACC Strategic Plan. They expressed their willingness to track resources, identify existing groups in the area, and support existing coordinating structures of the CACC. After the meeting, the Kakamega District Home-Based Care Alliance was formally recognized as integral to the process of information dissemination and planning.

The relationship between organized home-based caregivers and the government is now collaborative rather than autonomous and in parallel. Through the Shibuye community leadership, the Kakamega District Home-Based Care Alliance now has official partnership status with the Shinyalu Division CACC Office. The formal partnership between the Alliance and Kakamega District office gives the group authority to intervene officially on issues such as domestic violence, and land and property disputes. The District Officer has stated that this is a strategic partnership that simplifies the government’s work and enables chiefs and sub-chiefs to work hand-in-hand with local communities to address community problems. For the Alliance, this partnership ensures them a voice within the District decision-making structures which enables them to access resources and protect their rights.

Similar processes have happened across Kenya. In Gatundu District in Central Province, caregivers have influenced staffing levels and stocking of medicines at local dispensaries. They have improved access to local officials by facilitating forums where district agriculture extension offices and government officials in other departments educate the public on government policies and resources. In Kitui, home-based caregivers effectively advocated to an NGO active in the area to establish regular visits from a mobile clinic to occur at times and locations that make sense for the community. By raising the awareness of local decision-makers about the commitment, knowledge and capacity and building partnership of caregivers, self-organized groups of volunteer caregivers have been able to bridge gaps between established administrative structures and the communities. This has increased transparency, accountability and the flow of information between communities and officials. These communities are now empowered to take issues affecting them to the relevant government officers without fear of reprisal.
b. Comprehensive and efficient integration of caregivers into health systems

In much of the developing world, and particularly in sub-Saharan Africa, health systems are too limited and weak to meet the extent of people's needs; this is particularly true in rural and remote communities, where hospitals and clinics are few and far between. Even in urban areas, hospitals may exist, but are often under-funded or under-staffed, suffer from frequent shortages of medicines and supplies, and are in many cases located in areas that are inaccessible to the poorest people living in informal settlements. Because hospitals and clinics are generally located in towns and cities, and transportation is too expensive for most families to afford unless there is an emergency, caregivers and community health workers are the first people citizens turn to when they fall sick. Home-based caregivers fill in these huge gaps; in many places they are the sole face of the “health system.”

At the same time, government and donors are searching for new ways to fund “health systems strengthening” and “human resources for health.” The current positions of home-based caregivers and community health workers offer opportunities to build upon to achieve strengthened health systems.

We recommend that government and private health care providers actively seek out and link volunteer home-based caregivers up with hospitals, including keeping them up-to-date with training and information. Caregivers can be trained and supported to raise awareness and provide information about common illnesses and diseases; know when to refer sick people to the hospital; and, check up on patients who are released from the hospital. Because caregivers live in, and are in regular contact with people across their communities, they can also raise concerns at the hospital or with health authorities about common health issues, and make recommendations for interventions to treat those issues, such as well-timed and located mobile clinics or VCTs.

Health centers and home-based care programs established by NGOs and particularly faith-based organizations have piloted model programs integrating home-based caregivers into their health systems; these can be learned from, built upon and expanded to public health systems as well. For example, St. Joseph’s Care and Support Trust at Sizanani Village is a non-governmental organization operating in Gauteng Province, South Africa, that was initiated by a Catholic nun in the late 1990s to mitigate the effects of HIV and AIDS. They now operate a VCT center, provide anti-retroviral therapy, palliative care, counseling and home-based care for 6000 people in the surrounding district who are HIV-positive.

Home-based caregivers with St. Joseph's play a key role in ensuring people from the community know about and are able to access St. Joseph's services, continually monitoring their treatment and progress and providing basic care in the home. The caregivers are provided with initial and on-going training to keep them up to date with the latest information. The caregivers are supervised by nurses who provide them with advice and assist them in record-keeping and monitoring of patients. St. Joseph's has also raised money to support local community-based organizations that have begun their own caregiving initiatives and feeding programs for orphans and other children, and in some cases has built feeding and outreach centers for them in their communities. St. Joseph’s-affiliated caregivers are recognized and supported as key outreach agents between the community and the health center, sharing information about the clinic with people in the community who might not know it is there or be wary to visit, referring patients in need to the clinic, and providing input to the clinic.
c. Select caregivers already working in community for paid positions, government health committees and for professional training programs (eg. nursing) that become available

As “human resources for health” gains attention and funding and as AIDS responses shift their focus and strategies, new committees, structures, boards and positions are forged by government. Likewise, NGOs get funding for programs in certain communities but have limited commitment when funding runs out. Massive resources are often spent in establishing these structures but little is done to ensure long-term sustainability. Meanwhile, home-based caregivers, who continue to lead local health responses, struggle to get recognition by these emerging bodies—and once those committees, boards, and NGOs have run their course the caregivers are left to continue providing care for people with HIV, finding food and school fees for orphans and ensuring the hungry have enough to eat.

✔️ We recommend that new initiatives build upon the work already going on in communities, and that resources go to strengthening those responses rather than creating entirely new structures. This may include providing financial support to grassroots organizations or offering caregivers chances to serve in paid NGO positions and on government leadership structures.

In Uganda the government has recently decided to establish government-supported Village Health Teams. Resources are now being spent to establish the committees, recruit and build the capacity of members. Uganda Community Based Association for Child Welfare and the Uganda Home-based Care Alliance are advocating that those resources go to support home-based caregivers and community health workers who have, on their own initiative, been doing the type of work the Committees are now charged with. They are working with the government to ensure that home-based caregivers are funded to establish these committees in partnership with local ministry of health and other governmental authorities.

d. Support caregivers to establish and implement formal accreditation processes

Meaningful recognition of skilled and committed home-based caregivers involves formalizing and accrediting their work. It is unfortunate but true that some people have used the HIV and AIDS pandemic as an opportunity for personal gain, to the detriment of communities and the reputation of those working in good faith to alleviate the suffering created by HIV and AIDS. Too often, training or paid positions have gone to those who are politically well-connected, rather than those who are actually doing caregiving work in communities. Caregivers everywhere have piloted accreditation systems, developing identification cards recognized by community members, hospitals, clinics and decision-makers that signal caregivers’ special roles and skills. Formal accreditation systems in the hands of caregivers will create bottom-up demand to ensure that caregivers have access to a comparable standard of training and access to the supplies they need.

✔️ We recommend assisting caregivers to establish formal accreditation processes that are recognized by governments and development agencies. This would serve to counteract abuses of systems intended to support grassroots caregivers by those only interested in financial gain by vetting and validating the work of those who are committed to caregiving work, have the best interest of their community at heart and have been trained in key caregiving skills.
Home-based caregivers are interested in working with nurses and health professionals to establish comprehensive guidelines and criteria for accreditation of caregivers, and to work also with their friends and others in the community to monitor these standards. They should be included on committees and public health boards working to establish and enforce criteria. Caregivers also request support not just for one-off trainings, but for training-of-trainer programs that would comprise a part of accreditation to hold themselves accountable to standards and train each other in skills needed to effectively do their work.

**e. Establish grassroots women as monitors and evaluators of health and AIDS programs and funding**

Caregivers know the neediest people in their communities, they are aware of where health clinics would be most useful, of what materials and medicines are most needed in their communities. It is a huge missed opportunity to not utilize this knowledge through involving caregivers in on-going monitoring and evaluation of AIDS and health systems.

＞We recommend that caregivers are granted mandates from governments, donors and NGOs to form citizen monitoring and evaluation committees that, working with people living with HIV and other HIV-affected people, track public expenditures for HIV and AIDS and health in their communities, and ensure that those funds are reaching sustainable, needed programs, and benefiting those most in need. Without a formal mandate, many citizens may fear to speak out about general problems in their community, and in particular abuse of power or misuse of funding. Mandates are critical to ensure this kind of citizen participation and ensure a cooperative partnership between government and civil society. We further request for donors to fund pilot projects to demonstrate caregivers’ capacity to play this role and demonstrate the positive benefits for governments and communities when public funds are better used.

7. Interview with Jane Nyokabi Gitau, GROOTS Kenya, November 2009

**The Home-Based Care Alliance.** Kenya has undertaken this type of accreditation in some areas. An example of how this has benefited communities was shared by a caregiver from Kenya. “Most people now have access to ARVs, and very few HIV-positive people are bedridden. Yet when ART was rolled out, and the government hospitals trained caregivers on caring for people on treatment, they often plucked people from the community, rather than training those people who were really doing caregiving. This was another challenge the Alliance was meant to address – to ensure that those committed caregivers in communities were receiving the trainings and materials that were meant for them, so that they really benefitted the communities rather than just a few individuals who were not organized, who couldn’t share their knowledge with other caregivers through their organizations and who weren’t caring for the most needy.”7
3. Recommendations for Resources

a. Make physical spaces accessible to home-based care groups

b. Support health mutual funds and other community health insurance schemes to ensure social protection of caregivers and their families

c. Support for food security initiatives

d. Ensure adequate health care supplies

e. Transport stipends or other transport support

a. Make physical spaces accessible to home-based care groups

Claiming space is a critical organizing strategy among women’s groups throughout the world. Access and control over public space reflects and enables the accomplishments of grassroots women’s groups and provides a base for their community building activities. Women-controlled spaces help women meet to organize around their practical needs, access resources, and gain and maintain institutional recognition. During times of crisis, women-owned centers (such as communal living rooms and mothers’ centers) provide shelter, help plant the seeds of social cohesion and inclusion in the community, and place women at the center of rebuilding their communities.⁸

When home-based caregivers have physical spaces in which to meet and store their supplies, their work is better coordinated and more visible and accessible to the community. Caregivers’ organizations that have their own spaces gain legitimacy and formality in the eyes of government, NGOs and other stakeholders, and their responses and organizations become more sustainable.

We recommend that donors and communities support caregivers to control their own physical spaces.

In Trujillo, Honduras, Nuevo Amanecer (New Hope) has successfully advocated to run an integrated community health center on the grounds of the local hospital. Their space has raised awareness of their work, encouraging more people living with HIV to access home-based care and information about HIV and AIDS (in an area where HIV and AIDS are highly stigmatized), has improved their links with the formal health system (and thereby increasing their friends’ access to ARVs and health services), and has allowed the group to offer housing and care for people living with HIV who travel long distances to the hospital.

b. Support health mutual funds and other community health insurance schemes to ensure social protection of caregivers and their families

Many caregivers participating in this research reported that since they do so much to provide for the health and well-being of the community, their own family’s health care ought to be subsidized or ensured in some way.

➔ We recommend that effective, community-led health insurance initiatives that could benefit caregivers and entire communities should be transferred and scaled up in areas that lack coverage.

Swayam Shikshan Prayog (SSP) in India has piloted an innovative and effective Health Mutual Fund (HMF) which, through Huairou Commission-supported peer learning, is being transferred to several countries in Africa. The HMF is a community-owned health insurance service currently active in rural areas of Maharashtra state. The HMF, through which members are reimbursed up to 80% of their hospitalization costs, is managed by SSP federation members and promoted by community health workers at self-help group meetings, village-government meetings and through informal gatherings and village events. Membership in the fund, affordable at only 100 rupees ($2) per year, guarantees discounted outpatient services, partial-claim reimbursement for emergency hospitalization, free or discounted access to preventative health camps and a community-run health referral system. HMF also established partnerships with various government and private health service providers through creation of a service providers’ network, which is maintained and managed by the federation and community health workers.9

c. Support for food security initiatives

Good nutrition is crucial to general immunity to disease and in particular to staying healthy when one is HIV-positive. Further, when a person is taking ARVs, his or her nutritional requirements increase as ARVs can be toxic to malnourished people or when they are taken without food. Across Africa, home-based caregivers have begun locally based, sustainable food security initiatives to support the health of their friends and the children they care for. Some of these initiatives include collective farms and gardens (which also serve as sources of livelihoods for caregivers), and sharing skills so that people living with HIV, families and orphans with little or no income can begin kitchen gardens. In urban areas, many people have begun sack gardens to ensure that they can access fresh produce. Many such small-scale initiatives exist across Africa. Many, however, fail to thrive because they lack capital for start up, to purchase seeds, fertilizers or irrigation systems, lack experience in gardening, or have not established effective models for sharing the work. Addressing these challenges are not difficult – they will only take small investments from development partners, and will have big pay off in terms of increasing the health and well-being of HIV-affected communities.

➔ We recommend expanding support to caregivers’ food security initiatives such as collective farming and gardening and establishment of household kitchen gardens. Food aid and subsidies should be distributed through and monitored by community-based organizations to ensure it reaches the most needed.

In Kabwe district, north of Lusaka, Zambia, Chisomo Home-based Care has leveraged a piece of land at their local church which they use to grow food for their friends who are at home and in the hospice. When there is a surplus, the caregivers take the produce for their own use, or sell to boost their income.

The Ntankah Village Women Common Initiative Group is a community-based organization which began in 1996 as a collective farming group that shared a revolving loan fund known locally as 'Njangi'. Members of Ntankah have developed a 'Grassroots Women Environmental Protection and Poverty Alleviation Project', involving over 300 women. Its rationale was that land and ecosystem degradation have serious consequences for marginal agricultural areas; such degradation threatens food security and the livelihoods of rural dwellers as well as environmental stability. Rural households affected by HIV and AIDS, with their limited capacity for income-generation and need for increased food, are particularly vulnerable and especially benefit from improved agricultural techniques in the community. About 150 women have been taught sustainable agricultural practices and soil fertility management techniques, such as proper land preparation, seed selection, and the importance of agro-forestry. In line with the promotion of organic agriculture, the Ntankah group has concentrated on the production of compost using household waste and agricultural waste from farmland. The group has also constructed a modern piggery with the capacity of housing twenty sows. The manure from the piggery will be used on the group farm, as well as distributed among group and community members to improve soil fertility, increasing yields and ultimately the incomes of farmers.

### d. Ensure adequate health care supplies

Caregivers provide the first line of response to HIV and AIDS, caring for people with a range of AIDS-related illnesses in their homes when no one else can, and are doing it without even the most basic supplies. The Compensations for Contributions research demonstrates conclusively that, across the board, home-based caregivers are working with severely inadequate supplies. In some places, caregivers described that although some local clinics were willing to provide supplies, the clinics themselves were often unable to because of regular stock-outs.

Over and over, home-based caregivers have complained of having to use (or even re-use) plastic bags in place of gloves when treating sores, bathing patients and even delivering babies, leaving both the sick person and the caregiver vulnerable to infections. Most caregivers cannot afford to purchase medicines, soap, bandages, gauze, or other basic medical supplies. Other supplies caregivers need to do their work include bicycles for transport, boots, umbrellas and ponchos to cope with inclement weather (especially in areas with dirt roads), hats or umbrellas to shield them as they walk to their friends' homes and sturdy bags for carrying supplies.

> We recommend that public health systems budget to provide these supplies and establish regular distribution systems to deliver these supplies to home-based caregivers.

### e. Transport stipends or other transport support

The most common lament of home-based caregivers consulted for this research is the large amount of time and personal funds they spend on transport to reach their friends and accompany people to hospitals and clinics. In rural areas without public transport, where few cars or taxis runs and with no good roads, caregivers often spend hours walking door-to-door to visit people who need their care.

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10. This was developed by Ntankah C.I.G. in association with the Global Environment Facility (GEF) small grant program of the local UNDP, within the framework of an MOU called ‘Women Empowerment and the Global Environment’, signed between the Huairou Commission and UNDP.
11. Women-led development for disaster risk reduction: Examples of grassroots women’s innovations, capacities and priorities to increase the effectiveness of recovery and resilience programs. GROOTSInternational. Edited by Maureen Fordham, Supriya Akerkar and Manuela Scharf, Northumbria University School of Applied Sciences, Gender and Disaster Group. 2010.
In Moutse, South Africa, in the disputed Limpopo-Mpumalanga border region, home-based caregivers with Women Together in Development, (a CBO that is part of the Land Access Movement of South Africa), reported having to travel one hour to the nearest hospital, with no clinic in between and no mobile clinic services available. This district hospital often faces stock outs, which means that caregivers accompanying their friends to receive ART then commonly travel an additional four or five hours to the next nearest hospital -- they must cover those expenses out of their own pockets. Likewise, in Mbulawane and Ndwendwe, outlying areas of KwaZulu Natal, members of the Rural Women’s Movement spend 36 Rand ($5) each way for a taxi to the nearest hospital. Most of these caregivers do not have paid employment and struggle to make ends meet for their own families, and so these transport costs threaten their own security and resilience.

We recommend that caregivers are supported to gain control of means of transportation, such as bicycles, cars, vans or ambulances. Alternatively, donors and governments should support stipends for caregivers’ transport, perhaps through the formal health system, or as a part of comprehensive treatment adherence planning.

We also echo the recommendation from caregivers to build up the health system to make it more accessible. Women in South Africa are advocating for a health clinic to be built every 10 kilometers. Mobile clinics are another innovative solution to this issue, immediately multiplying the number of people who can reach health services greatly without making big investments in infrastructure.
4. Recommendations on Renumeration: Make immediate investments in the formal recognition of home-based caregivers through direct payment or via alternative models of financial remuneration including:

- Income-generation and sustainable livelihoods support
- Investment in savings and credit groups
- Establish development funds that are controlled by home-based caregivers

Perhaps the most contentious issue among people working in the field of home-based care is whether and how to pay home-based caregivers. On the one hand, caregivers provide critical and invaluable services to their communities; home-based care often places great burdens on caregivers who decrease or abandon gainful employment or income-generating activities because of the time they dedicate to caregiving. In a developed country, non-family members are never asked to do this work without compensation. A number of NGOs across Africa, with donor support, do provide stipends or salaries for the caregivers who work for them. Likewise in South Africa, the government provides a small stipend for some caregivers who are part of legally registered NGOs.

Yet the vast majority of caregivers work with no stipends or salaries. Indeed, many caregivers have not asked for stipends and have even expressed concern that provision of stipends would attract people to caregiving who are not motivated “from their hearts.” In particular, they fear that stipends would be used for political patronage rather than to compensate true caregiving work conducted with compassion and a sense of duty. Many organized groups of caregivers, who are claiming their identity as community development workers, recommend exploring alternative forms of funding for home-based caregivers. Rather than receiving stipends or salaries as low-level para-health professionals, we recommend approaching remuneration in the community-based spirit and organizing form in which home-based caregivers are working. Our recommendations range from initiatives to prevent caregivers from impoverishing themselves in the short-term, long-term initiatives that decrease caregivers’ poverty and increase their resilience, and the ultimate aim of allocating public resources so that caregivers can have access to and control over development funding.

We strongly call for immediate investments in the formal recognition of home-based caregivers through direct payment or via alternative models of financial remuneration. The alternatives described below, and other possible models, use public budgets or other modalities to reward the work of people who are motivated to be home-based caregivers, play these development roles.
• **Income-generation and sustainable livelihoods support**

Many caregivers have established self-help initiatives which have demonstrated varying degrees of success. Caregivers surveyed for this research reported involvement in small livestock rearing, collective farming, retail shops, sewing and tailoring projects, making handicrafts, and many more. Successful businesses give home-based care groups an autonomous source of income so that they are not dependent upon donor funds; they also build caregivers’ capacity and confidence, and provide services needed in the community.

⇒ **We recommend increasing investments in start-up capital and capacity building for caregivers to plan and run businesses.**

In Lilongwe, Malawi, **Paradiso House Home-Based Care** has established a successful bakery in the community, making breads, rolls and scones which they sell to their neighbors at a reasonable rate. The profits go to pay school fees for orphans in the community. Caregivers have also reported great benefits from learning to bake and run a small business. When one caregiver at Paradiso was asked how her life has changed since she began caring for people, she responded, “I’ve learned a lot. Now I’m a full time baker. I’ve been strengthened. I didn’t think I had any leadership skills, but now I’m a team leader here.”

In Kwara State, Nigeria, **International Women’s Communication Center** has devised an innovative vocational training/job placement program through its Yearly Women’s Institute. The institute provides vocational training—including sewing, design, computer literacy and office skills—to the most disadvantaged girls from throughout Kwara. The success of this program has rested on the partnerships IWCC has formed with local authorities throughout the state, who refer girls who are very poor, orphans or HIV positive to the Institute. At the end of a year of training, the local authorities then facilitate job placement for the girls in their communities. One can find a number of the Institute’s graduates now holding down jobs at government offices around the state. The Yearly Women’s Institute also includes courses in reading, writing and speaking English. Girls and women are economically empowered through seed grants for small business and a micro-credit program. In these ways, the Institute has effectively reduced poverty levels among the most disadvantaged girls in Kwara since its inception.

• **Investment in savings and credit groups**

Grassroots women around the world have a long history of mutual support and self-help through simple revolving funds (often called “merry-go-rounds”). Home-based care groups already use these schemes to support their individual needs for income and scale up small businesses.
Establish development funds that are controlled by home-based caregivers

Through decentralization, community development funds have been established in communities across Africa, often under the patronage of the Member of Parliament or another local elected official. As noted earlier, however, locally controlled funds are susceptible to misuse for political patronage or to support pet projects. Rarely do they reach legitimate, effective community-based organizations or meet the needs of communities. Declared percentages of development aid should be dedicated to caregiving at the community level.

We recommend maintaining and actively improving mechanisms for channeling money from the government through these decentralized bodies; we also recommend establishing challenge grants that can be controlled directly by caregivers themselves, or community teams brought together by caregivers with clear monitoring and accountability mechanisms. These grants can be used to meet immediate community needs, and can serve as an alternate model to show what is possible when funds reach community organizations.

We recommend increasing support for caregivers to share their successful livelihoods support and asset-strengthening methodologies with each other, and funds to increase available funds.

Savings and Credit Groups (SCGs) are groups of individuals who make regular contributions to a central pool. The savings pool is then available for women in the group to give and take loans. SCGs provide their members opportunities to manage and develop savings while being involved socially with other members of the community. Members are able to take loans from SCGs and break free of the downward spiral of debt caused by taking loans from local money lenders that charge high interest rates. In places where there are no money lenders and banks will not make such small loans to women, the savings and credit group is often the only means a woman has to start or improve her small business.

Collective saving and offering loans to group members helps to defray the financial burdens of caregiving. Many successful savings and credit schemes exist. In Zambia, the Homeless and Poor People’s Federation and People’s Process for Housing and Poverty in Zambia (which is currently organizing a Home-Based Care Alliance and is already a member of Slum and Shack Dwellers International) has founded a large federation through organizing daily savings for members. Based on the principle of self-reliance, the savings concept rests on the fundamental belief that poor people themselves need to be at the center of any effort to improve their lives. By doing savings, the poor move from being beneficiaries or recipients to key stakeholders in development. In Zambia, the federation is active in 19 regions, with 30 savings schemes in Lusaka alone. The savings scheme began through having a core set of members – the collectors – go door to door in their neighborhood each day to collect about 5 cents a day. As the group savings grows, members can begin to take out loans to support their own income-generation. Savings takes place at the community level through the savings scheme. Those schemes then contribute to a regional group account to respond to needs across the Federation. The ultimate aim of the Federation is to save towards the purchase of land and building of homes for and by the poor, and the money the groups save serves as collateral for taking larger loans, and also demonstrates the group’s own commitment to advancing its development aim, building the confidence of would-be donors. However the savings scheme along the way becomes a means of social and livelihoods support, and a platform to addressing many other community issues such as health or hunger. The economic underpinnings of the federation give members a direct means to address those issues, by allowing them to purchase land for a farm, or divert a portion of their savings towards a special fund for health.

In a merry-go-round, members of a group make a set donation at regularly scheduled interviews. One member each time takes the entire fund of donations either via lottery or a scheduled rotation.
CONCLUSION: A PLAN OF ACTION

It is time for policymakers, donors, governments and NGOs to look to communities for effective solutions to the many challenges facing HIV and AIDS-affected communities. We hope that this research and report has demonstrated the capacities that exist at the grassroots level and can serve as a basis for action to effectively address the complex challenges facing communities coping with HIV and AIDS, poverty and inadequate health systems.

During the Grassroots Women's International Academy on Home-Based Care, the following action plans were made. We invite the partnership of local and national government, regional and global policy makers, academics, activists, NGOs and donors in advancing these plans to forge practical solutions to the challenges facing grassroots home-based caregivers, and to institute formal and meaningful recognition, including compensation, for grassroots home-based caregivers who are bearing a huge burden of response to HIV and AIDS and who, person by person, home by home, community by community, are advancing health, development, resilience and good governance in a spirit of love and compassion.

60 grassroots home-based caregivers and NGO partners from 21 organizations in 13 countries across Africa, gathered in Johannesburg for a 5-day Grassroots Women's International Academy on Home-based care, all members of the global coalition of the Huairou Commission, commit themselves to the following actions:

- To form a regional home-based care Alliance to counter the fragmentation of community efforts, and through which home-based caregivers can advocate on their own behalf for recognition and resources
- To use the results of the Compensations for Contributions research initiative to advocate for compensation for groups of caregivers, beginning with pilot projects demonstrating how this might work in light of various national and local contexts
- To create teams and organize for impact at national, regional and global policy dialogues on HIV and AIDS
- To monitor funds for HIV and AIDS coming into our countries and communities
- To undertake peer exchanges to share skills and build relationships
- To create partnerships with NGOs for capacity-building
- To raise awareness of caregivers' issues and contributions through the media
ANNEX:
ORGANIZATIONAL PROFILES AND CONTACT INFORMATION

Ntankah Village Women Common Initiative Group (NVWCIG) was formed in the rural areas of Cameroon’s Northwest Province as a women’s farming group. Many of their activities still center on joint farming, as they assist each other to do farm preparation, planting, weeding and harvesting. They do joint input harvesting to reduce costs. At the social level, they render moral, financial and physical assistance to members when they are sick, when they lose family members and on occasions of births, deaths and marriage celebrations. They have also traditionally carried out thrift and loan in a revolving scheme known as ‘Njangi. The group actively encourages women in general and members in particular to carry out their civic responsibilities like registering and voting, obtaining birth certificates for their children and also ensuring that members follow the vaccination program for newborn babies and infants. The group has carried out joint execution of group projects like group piggery and poultry. The group assists in local community development projects like construction of the local health post, bridges, water supply, road digging and community cleanup campaign and hygiene and sanitation.

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Grassroots Sisterhood Foundation in Ghana began in 2000 as a pressure and support group for victims of domestic violence, who were often blamed for the actions of violence against them. They felt stigmatized, and as a result many women and girls stopped pursuing cases they were seeking justice for. Women and girls are the main beneficiaries. Traditional, religious and local authority, men, women and youth and women groups are the targets of GSF’s activities. GSF focuses on the promotion and protection of women’s rights. Their activities surround issues of domestic violence, early and forced marriages, land, property and inheritance rights, and they have recently included HIV/AIDS and home based care.

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GROOTS Kenya is a network of women self-help groups and community organizations in Kenya. It formed as a response to inadequate visibility of grassroots women in development and decision-making forums that directly impact them and their communities. GROOTS Kenya bridges this gap through initiatives that are community-centered and women-led. The network’s objective is to “ensure that grassroots women are masters of their own destiny through their direct participation in decision making processes.” Thus GROOTS Kenya’s goal is to strengthen the role of grassroots women in community development by serving as a platform for grassroots women’s groups and individuals to: come together, to share their ideas/experiences, to network and to find avenues to directly participate in decision making, planning, and implementation of issues that affect them.

Although GROOTS Kenya’s work is centered around the lives and needs of Grassroots Women and therefore largely non-thematic, it accomplishes its goals through four main program areas:

- Community Responses to HIV/AIDS
- Women and Property
- Women’s Leadership and Governance
- Community Resources and Livelihoods

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The International Women's Communication Center (IWCC), based in Ilorin, Nigeria, was created in 1993 by a group of women human rights activists with the aim of disseminating information about the international women’s struggle to women at the grassroots level and initiating women’s rights projects at the community level. IWCC is engaged in women’s empowerment and anti-AIDS initiatives throughout Kwara State. IWCC actively engages and empowers women from both Muslim and Christian communities in Kwara, IWCC’s programs are community-based. IWCC’s HIV/AIDS programs are based on groups of volunteer Home-Based Caregivers, coordinated by IWCC’s Community Volunteers. Caregivers provide palliative and nursing care, treat opportunistic infections and counsel and support infected people and their affected families.

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Rwanda Women’s Network (RWN) is a national humanitarian Non-Governmental Organization dedicated to the promotion and improvement of the socio-economic welfare of women in Rwanda through enhancing their efforts to meet their basic needs. The Network came into being in 1997 taking over from its parent organization, the US-based Church World Service (CWS), which had initiated a two-year program (from 1994 to 1996) in the country following the 1994 genocide. Todate, RWN caters to survivors of sexual and gender-based violence across the country in the recognition that women and children bore the brunt of the genocide, and remain the most vulnerable and marginalized groups within Rwanda civil society. The Rwanda Women’s Network implements four core programs.

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Rural Women’s Movement (RWM) in South Africa is made up of 500 indigenous women’s organizations that are implementing and managing different projects including small-scale farming, catering, block making, hand crafts, and arts and culture. The majority of members are widows, single mothers, young women, married women, deserted women and the youth whose ages range from 16-84. RWM made up of marginalized groups who are suffering and confronted by issues of poverty and oppression. The majority are living on privately owned farms, traditional authority and freehold areas. On top of projects focusing on increasing women’s rights with regards to land, economic status and governance, RWM is also working with 2000 orphaned children throughout the province of KwaZulu Natal trying to make sure children do not drop out of school after losing their parents.

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St. Joseph’s Care and Support Trust operates in the Metsweding Municipality, South Africa and is a faith based NGO that seeks to mitigate the impact of HIV/AIDS in the district. It is the only organization that offers integrated HIV/AIDS programs which include health care, spiritual psycho-social support services and community-based initiatives in the Metsweding District. Following an assessment conducted by the Council for Health Service Accreditation of Southern Africa (Cohsasa) in May 2005 targeting Management, Human Resources and Health Care, St. Joseph’s received an overall aggregate score of 87.3%. This is one of the highest forms of accreditation which had been achieved by any hospice institution.

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African Solutions to African Problems (ASAP) in South Africa supports community-based organizations of women caring for orphans and vulnerable children affected by HIV/AIDS. They are currently working with 6 pioneer community-based organizations made of up 585 women supporting 8500 orphans and vulnerable children in more than 112 community Drop-In and Daycare centers in impoverished communities in South Africa. A key aspect of ASAP support is to provide capacity-building interventions that help the groups to develop their organizations, improve their services and attain their own development goals.

ASAP has demonstrated that grassroots organizations and their social networks of women are capable of scaling up and replicating effective models of care for orphans and vulnerable children. Based on practical experience, ASAP has developed a unique 7-year Model of community-based intervention that builds the capacity of emerging groups to develop into mature organizations with a community network to care for the majority of orphans and vulnerable in their community. ASAP is expanding our model to a further 6 community-based organizations.

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Uganda Community Based Association for Child Welfare (UCOBAC) was formed in 1990 in response to estimates of 1 million orphans in Uganda caused by the effects of the war, AIDS and other related factors. UCOBAC activities include: Promotion of information exchange in order to increase awareness of the public, NGOs, communities, and individuals about the plight, needs and rights of vulnerable children and women, through advocacy materials and networking; Influencing attitudes of communities in favor of children’s and women’s welfare; trainings for local NGOs, CBOs, district affiliates leaders and community leaders, in the areas of rights, needs, and development.

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Action for Women and Awakening in Rural Environment (AWARE), Uganda: AWARE was established in 1998, in the Kaabong district in the North-East of Uganda, originally Kaabong Women’s Group Organization in 1998. AWARE works with its paralegal volunteers and home-based care workers to reduce HIV-related stigma and to secure women’s land rights. They employ several strategies, including Local-to-Local dialogues, rotating loans, civil literacy courses and a women’s center.

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Seke Rural Home-Based Care, based in Harare Zimbabwe, Seke Rural Hospice was founded in 2001 to improve the quality of life for those affected by HIV/AIDS, the terminally and chronically ill, and orphans and vulnerable children living in the rural areas around Harare. It has a catchment area of approximately 80,000 people and provides home-based services to 5,000 patients. Its 19 full-staff members include a home-based care coordinator, palliative care nurse, social workers, and agricultural and sanitation officers. There are 460 secondary caregivers who volunteer for the hospice.

In addition to providing home-based care to the terminally and chronically ill patients, Seke Rural Hospice also provides psychosocial and material support, counseling and bereavement services, and strengthens existing support groups for people living with HIV/AIDS.

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Organization for Social Services for AIDS (OSSA) is an Ethiopian indigenous humanitarian organization working in communities to reduce the spread of HIV/AIDS in Ethiopia. OSSA was founded in 1989 by a group of religious ministers from the various faiths in Ethiopia (Orthodox Christian, Catholic, Muslim and Evangelical) in conjunction with the Ministry of Health. The founding of OSSA was a response to the growing incidence of HIV/AIDS in Ethiopia. OSSA now operates through nine main branches in major towns and cities where the prevalence of HIV/AIDS is highest. The Mekelle main branch was established in October 1994, with a paid coordinator and a number of voluntary staff. The voluntary staff became paid staff in 2003, after 7 years of voluntary service, and the office now has 10 full-time professional staff. OSSA is working at the community level to reduce the spread of HIV. Many of its activities take place for and with youth - as it is essential that the younger generation understands the ways in which HIV is spread and how to prevent it.

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Catholic AIDS Action (CAA), Namibia was founded in 1998 by Dr Lucy Steinitz and Sister Dr Raphaela Händler, through the Namibian Catholic Bishop’s Conference as Namibia’s first church-based response to the country’s HIV/AIDS crisis, which had already reached pandemic proportions. It has since grown to be the largest NGO responding to AIDS in Namibia, currently operating 14 offices in 9 of the 13 regions. Working closely with local parishes and faith communities, the work and mission of Catholic AIDS Action has four principal focuses: home-based family care and counseling, youth education and prevention, care and support to orphans and vulnerable children, and voluntary counseling and testing. Services are available to all, irrespective of religion, race or background with a preferential option for the very poorest affected by this pandemic.

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Lambassa ICA has worked to help rural people in Benin contribute to their own development independent of external assistance since 2003. It is affiliated with the Institute of Cultural Affairs based Montreal. It has helped communities in Benin’s northern frontier fight desertification, deforestation, soil degradation and drought by planting 2.5 million trees in support of the United Nations Environment Program’s Plant for the Planet Campaign. It is also running programs on HIV/AIDS prevention and awareness, community health, water conservation, legal empowerment, and participation training.

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Land Access Movement of South Africa (LAMOSA) is a federation of community-based organizations advocating for land rights, formed by people claiming land who were dispossessed. In their land rights program, they address gender, livelihoods and HIV/AIDS. They began working on home-based care as, through their mobilizing around land, they found that communities were dealing with high levels of HIV and orphans. The caregivers that belong to the LAMOSA federation provide care, organize to pay school fees and uniforms, spiritual support and hospital visits, and they hold dialogues with local leaders and authorities.

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Zambia Homeless and Poor People’s Federation and People’s Process on Housing and Poverty was formed 2001, when they started a savings scheme in Lusaka to alleviate poverty. With the AIDS epidemic, they saw a need to start a health savings account, and they opened a regional account. Every time they have a meeting, each Savings Scheme contributes to a regional account to support bereaved families or members in the hospital, as well as prescription support. Their general savings account goes to procure land and build housing for the poorest of the poor in their community, and to ensure or upgrade access to water and sanitation. The Federation lobbies for land through the government, they use the media, and they approach the traditional chiefs. Since beginning to work directly on HIV/AIDS, 5 federations are building foundations for care centers.

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The Ranchhod Hospice in Zambia was a pioneer organization on HIV/AIDS established in 1991 with a mandate of providing integrated human development to vulnerable members of society. They provide counseling and testing and care for caregivers. They have also been able to take advantage of a government policy of expanding access to Voluntary Counseling and Testing by securing government resources to train home-based caregivers to provide VCT in people’s homes using rapid finger prick testing. The process has empowered the caregivers to be counselors, it has reduced stigma as the tests are discretely performed in homes, and has expanded outreach because caregivers who live very far from established clinics or VCT centers can bring the testing and counseling directly to community members.

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Mary Joy Aid for Development of Ethiopia was established in 1994 by a nurse in order to address the health issues of a few target areas. The organizational vision is to try to see a healthy, poverty-free and empowered society. They provide comprehensive AIDS prevention, care and support, livelihoods support, private community coordination and capacity building programs for community and organizational staff. They strongly work to fight stigma and discrimination including by providing homes for the homeless, for those who are kicked out because they are HIV+. Mary Joy was established its home-based care program using existing community based organizations that provide funeral services for community members. The leaders of these CBOs were sensitized about the importance of home-based care to increase outreach and education on AIDS, which the CBOs were aware of as they saw increasing numbers of deaths. They now have 508 trained home-based care providers who are volunteers. These caregivers are assisted by 134 peer mother groups, who have been organized to provide care and support to those in need and to ease the burden on the caregivers.

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The Coalition of Women Living with AIDS in Malawi began with 46 members from a variety of mixed-sex networks of people living with HIV. They took advantage of the wide mobilization of women into support groups in their respective districts to meet and recruit new members and to build a major organizing and constituency base to ensure that women’s needs, from the bottom up, were having an impact on policies and programs that affect people living with HIV. To date, the Coalition has 100,000 members. One of the organizing successes the Coalition has achieved is to ensure that fertilizer subsidies benefit women living with HIV across Malawi, so that they are able to grow food to stay healthy and so that they are able to adhere to their anti-retroviral treatment regimen.

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