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The Home-Based Care Alliance Newsletter



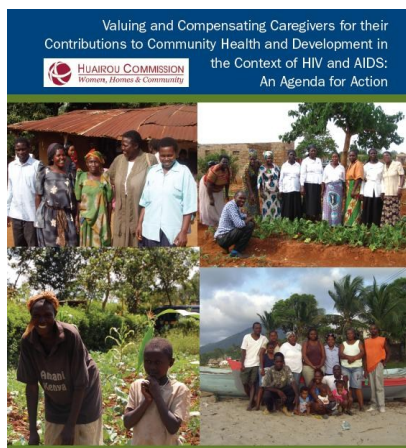
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On World AIDS Day, Caregivers Celebrate Significant Gains Made Through Research

One of the original aims for this research process was to contribute to a body of knowledge and build a platform of actors to gain concrete recognition for home-based caregivers. The research began with the base of established constituencies of home-based caregivers and their NGO partners. The participating organizations were able to leverage their combined strength and the new knowledge and contacts generated through this research to take advantage of new and on-going policy and program developments, such as AIDS strategic planning and the reformulation of primary health care plans.

Since the original publication of this report in July 2010, caregivers have made concrete gains. Here are a few of their achievements:



Members of the Kenya Home-based Care Alliance, facilitated by GROOTS Kenya, have participated in the NACC Kenya National AIDS Strategic Planning and implementation process. Caregivers in multiple regions of Kenya are now receiving funding from Constituency and District AIDS Control Councils. In addition, caregivers are now participating in the Community Health Workers Interagency Coordinating Committee to ensure its work reflects and builds upon the reality of communities.

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Violet Shivutse, Jael Amati Represent Caregivers at ICASA 2011

ICASA 2011, the largest annual conference on HIV/AIDS hosted on the African continent, will take place in Addis Ababa, Ethiopia, under the motto "Own, Scale-Up and Sustain."

From December 4-8, an estimated 10,000 delegates from around the world, including government representatives, scientists, policy makers, NGO staff and people living with HIV and AIDS will use the forum to exchange information and skills, and learn about successful practices in the global fight against HIV/AIDS.

To ensure that grassroots women's voices and realities are presented in Addis Ababa, grassroots leaders from the Huairou Commission network, Violet Shivutse and Jael Amati traveled to Ethiopia, with the goal of creating a space for caregivers and women at the community level, particularly through the Caregivers Networking Zone anchored by the Caregivers Action Network (CAN).

30 years since HIV was first identified, and billions of dollars have been invested on the continent, millions of people in Africa remain vulnerable, people living with HIV in poor communities receive the majority of care from their relatives and neighbors, while government structures, policies and funding

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Grandmother's savings group from Kendu Bay, Kenya

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In Uganda, caregivers working with UCOBAC have participated in the Health Sector Strategic Planning III, leading to the selection of committed home-based caregivers for newly formed Village Health Teams. Caregivers are also now participating in local agricultural committees and saving and credit cooperative societies, making it easier for funds and services to reach the poor in communities.

“When caregivers are involved in decision-making, whole communities benefit”

In Nigeria, 160 caregivers working with International Women's Communication Center in Kwara State have received stipends for their work, and many have been employed at teaching hospitals

in recognition of their important role linking communities and health services

In Zambia and Zimbabwe, caregivers have been inspired by the successes and are now organizing into Alliances and building partnerships with local government, hospitals and health systems.

Caregivers in Malawi and South Africa used the research as a springboard for organizing Home-Based Care Alliances as an advocacy platform through which caregivers can speak on their own behalf and

In Cameroon, caregivers working with Ntankah Village Women Common Initiative group and their CAGWEESA network partners have come together to organize into the Cameroon Home Based Care Alliance and currently 50 caregivers are being trained to look after persons with disabilities. Nutritional assistance has been to 70 caregivers. 200 caregivers have been registered into the mutual health scheme and comprehensive home based care is being integrated into primary health piloted by the Home Based Care Alliance.

When caregivers are involved in decision-making and development projects in this way, whole communities benefit as access to treatment, prevention, care and support is scaled up. These new kinds of partnerships are making global and national AIDS and health initiatives effective for communities, where they are meant to have their impact. They demonstrate the power of partnering with grassroots women's organizations that are leading change in their communities.

Home-Based Care Alliance Expanded Across Africa

Eight years since the founding of the Home-Based Care Alliance (HBCA) in Kenya, HBCA groups across twelve countries are thriving and experiencing high levels of success. As of the summer of 2011, there are approximately a total of 24,648 registered caregivers across Africa. A recent exercise base-lining the current state of organizing in the Alliance reveals that most of the groups have a strong foundation of close to or over 1000 caregivers, who are actively involved in their communities and working tirelessly in improving the lives of people living with HIV/AIDS and advocating for their well-being. Each community, mostly in rural settings, has been diligent in taking steps to build the Alliance from the bottom up. Caregivers start organizing by creating and implementing a mapping process in order to identify all caregivers in their community, and have set up a database of all the caregivers. This ensures transparency and gives way to a comprehensive system in which all caregivers are accounted for.

Organizational structure varies based on local context, but generally groups are structured from the ground up, starting with the home-based care group/caregiver cluster (usually of about 20 people). Each of these groups nominate 1-3 representatives for a district or divisional Alliance, and moving up to the na-

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“24,648 caregivers are registered into Home-Based Care Alliances in 10 countries across Africa”

Ratifinah Moono from Lazarus HBC during the HBC Alliance deliberations in Lusaka recently

My name is Ratifinah Zemba Moono, I am 48 years old and a mother of three children. I am a fifth born in a family of eight. I originally come from Chief Singani's area in Choma district of Zambia. Before I became a Home based caregiver, I was running my own business in freight forwarding which did very well. But about 9 years ago I tested positive to HIV and that brought my business to a standstill because I got sick for a period of more than a year. I was paralyzed and stuck in a wheel chair and during that time a lot of people ministered to me, gave me a lot of spiritual, emotional and physical support especially my family and friends. Soon after I recovered, I started getting involved in a lot of HIV/AIDS work. I attended a lot of training in HIV/AIDS related topics. Eventually in 2009 I was invited to attend a workshop in palliative care. After the training, I was nominated to be the HBC coordinator for a group of 38 caregivers. This was my starting point in care giving and my caregiver leadership.

I became a trained caregiver about two years ago, but my activities as a caregiver go way beyond 2002. I was moved to become a caregiver because I have a passion to work with the underprivileged. In 1997, I joined a caregiver group through my local church.

As a group we ministered to the sick, widows, orphans and other vulnerable individuals. This is where my passion to be a Home based caregiver began. During my period of illness, I received a lot care from the caregivers, and I in turn resolved I should do the same to other members of the community. Because of my zeal for care giving I am known in my family as "Doctor Tinah, without any official degree".

Taking Leadership

I was nominated by the group to be their leader after I shared my testimony and people saw the zeal that I had for care giving. People



Ratifinah, caregiver and leader in Zambia

thought I was the right person because I was not only affected but also infected. I was sharing with other sick people basing on my experience. What moved me to take action for change was the widespread stigma in my area. I wanted to assist people in accepting their status and at the same assist other community members to look at HIV with a different perspective.

I look at the HBC caregiver system as an extension of the government health care system. It alleviates the congestion currently being experienced in Health centers. If we are an extension of the health care system, then we should be subject to the same type of support and this is only possible if we form an alliance.

The one situation that moved me to begin the formation of the home based caregiver alliance was when we ran out of HBC kit supplies. We had a lot of clients to take care of but had nothing to

use or to give them. We tried to mobilize resources from the individual caregivers who were equally in vulnerable situations. We tried to source for funding from stakeholders but we are not

recognized. But if we form the alliance, we will be recognized and we shall attract funders. Being at the grass root we shall be the conduit ensuring that assistance reaches the needy clients.

I am an inspiration to my clients because I speak from experience. I give them hope to live on. The clients I have assisted share the joy they derived from their interaction with me and I usually get calls

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for AIDS remain largely ineffective. Women make up the majority of people living with HIV in sub-Saharan Africa (12 million women versus 8.2 million men are living with HIV) and fill in the large gaps in government and NGO services as caregivers. From the perspective of the Huairou Commission and its members, concrete steps towards redressing the fundamental lack of accountability are needed immediately, and bringing representatives of constituencies of grassroots women into policy-making dialogues in a meaningful way is the most effective way towards a real solution to these challenges.

ICASA began in 1986 largely as a scientific conference, and has grown into an agenda-setting venue where representatives of various advocacy agencies and populations - most notably people living with HIV - come together to exchange practices, hear about policy developments and, ideally, influence priorities of policy makers, scientists and the private sector. Yet, despite the disproportionate effect on poor women, grassroots women's representation at ICASA has consistently been low, stressing the need for continued investment in bringing community perspectives on effective, accountable AIDS responses into international policy spaces.



Caregivers in Kendu Bay with their District Officer

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tional level. In Uganda, a strong grassroots board of caregivers representing the various regions serves as the decision making and planning body for the Alliance. In Malawi, current structure consists of a taskforce, which oversees three districts committees and in turn manage and coordinate the Alliance. Benin, on the other hand, has at least 25 leaders of various types. These include local authorities, health center managers, and NGOs, which organize women providing home-based care. Thus, in order for Lambassa ICA (the support NGO in Benin) to facilitate their work, a network of people living with HIV/AIDS has been created, which allows all members to participate in organized activities and engage in peer exchanges. The Zimbabwe HBCA has worked hard to build an effective, decentralized leadership structure that allows caregivers to participate in village level meetings that they can walk to that feed directly into the district and national coordination of the Alliance.

Solid networking and linkages are the strongholds and foundations for the Alliances, which allows for access to national and international information about health initiatives that is vital for Alliances to make an impact on advocacy. GROOTS Kenya has made significant gains in advancing the position of home-based caregivers and has proven to be an effective model for other countries. The International Women's Communication Center (IWCC) in Nigeria serves as a connection between the international network of women's rights and development organizations to the Nigerian women at the grassroots level. They have established homecare, and organ-

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Caregivers in Kendu Bay celebrate a new office building

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from clients who want to talk to me. The clients have confidence in me and we form a bond that lasts the test of time. They are free to contact me any time. This is a rare case of service which we do not get in a health institution.

Caregivers Working Together

As a group of caregivers we share information through our weekly briefings. We exchange information as to the condition of the respective clients, identify who needs referrals, nutritional supplement or counseling. In this way the clients are able to benefit from the different expertise. As caregivers, we do not restrict our information sharing to weekly meetings; whenever necessary we contact each other.

Although a caregiver is not remunerated in Zambia, we offer the best of our time in terms of quality and quantity. This time is not restricted to the clients only, but also to other members of the household. We also train the secondary caregivers within the household.

Fitting my work as a caregiver in my daily life is very challenging. As mentioned earlier I have no formal source of regular income. According to the conditions of service for caregivers in Zambia, I am supposed to put in only two hours per week. However, due to the number of clients I have and also the condition I might find the clients in, I am unable to restrict myself to the two hours. Therefore, I find myself devoting more time to saving lives than attending to my personal business. I recently attended a training which helped me on how to make succession plans for my business. I am training my children and other members of the household to understand and learn how to run the business so that in the event of me not having ample time or being sick they will be able to run the business successfully.

The obstacles we face as we try to form the alliance are lack of positive response from a few caregivers. Others do not clearly understand what the alliance's objectives are. Also some caregivers expect remuneration. A few caregiver groups are currently enjoying donor support and as such they do not really see the need of forming an alliance.

“I would like to see a community in which the caregivers are trained, remunerated and financially empowered. I would envision a health care system which recognizes and appreciates the role of the caregiver.”

The challenges that we face are transport constraints and lack of food especially when we want to reach far places which will need as to spend longer times in the field. Also a few members lack commitment. Poor time management is also another challenge that we face. As caregivers, we have to share our time with personal businesses that put food on our table and we also have to do our work as caregivers.

Recognition of Caregivers

It would make a difference if government and Non governmental organizations recognized caregivers as health workers and start remunerating them for their work. Additionally caregivers need to be equipped with medical kits and necessary supplies to enhance their work. When it comes to policy and decision making that affects caregivers, caregivers should be involved. When there is funding directed towards HBC activities, there should be transparency in the management of these funds. Government and non governmental organizations should give caregivers the necessary training such as training in income generating activities. Also there should be smooth networking with government and non governmental organizations and linkages to funding organizations.

My vision for my community is one in which caregivers are self sustainable and not dependent on external handouts. I would like to see a community in which the caregivers are trained, remunerated and financially empowered. I would envision a health care system which recognizes and appreciates the role of the caregiver. Furthermore my vision is to have more community based health care centers for the clients. I envision a community in which client referral system is shortened, instead of the client going through a local clinic then to hospital. When you have an idea of what the clients medical problem is, direct referral to a major hospital would be the best option. Finally I envision a community that has free access to ambulance or transfer services.

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ize annual women institute training centers in twelve local authorities in the country. In Rwanda, the Rwandan Women's Network (RWN) facilitates activities and provides capacity building workshops for people who are already working as caregivers. Moreover, RWN's partnership with the Department of International Development in the UK includes working with caregivers who provide care and support for genocide survivors who contracted HIV/AIDS as a result of sexual violence. RWN's caregivers also partner and collaborate with local NGOs and with local government, which helps caregivers to be regarded as advocates and allies within their respective communities.

HCBA's all across are engaging in vital and ongoing activities that respond to the needs of the communities. In Ethiopia, for example, a consultative workshop was held by SHAFON in February 2011 in Hawassa. Additionally, communities on both a regional and international level participate in peer exchanges, which strengthens the Alliances and fosters advocacy by allowing for sharing of achievements and challenges. Rwanda's Alliance has been active in working with local clinics and doctors to provide referrals and clinical trainings for caregivers. Moreover, their partnership with USAID runs the Community HIV and AIDS Mobilization Project (CHAMP) and collaborates with the Rwandan Ministry of Health to train community health workers. Other groups, such as the Grassroots Sisterhood Foundation in Ghana, besides being committed in HIV/AIDS awareness advocacy and the Home-Based Care Alliance, activities also revolve around issues of domestic violence, early marriages, land, and property and inheritance rights.

What is the Home-Based Care Alliance?

The **Home-Based Care Alliance (HBCA)** is a bottom-up federation of grassroots home-based caregivers across Africa. These caregivers are primarily taking care of people living with and affected by HIV and AIDS. They also care for people with other chronic illnesses, the aged and others in their communities who are in need. Although home-based care is a vital, life-giving service in communities, most formal health systems, **governments** and donors do not recognize caregiving for how important it is, and do not include caregivers or their work in their decision-making or resource allocation. So caregivers, most of whom are women, shoulder this burden alone.

The purpose of the Alliance is for home-based caregivers to come together, better coordinate their work, and advocate for recognition, inclusion in formal decision-making structures, and for resources to support their contributions. The work of the Alliance happens locally, nationally and globally. The Alliance members and leaders are grassroots caregivers themselves. NGO staff are principled partners and provide technical support when it is needed.

What is the Difference Between Home-Based Care Work and the HBCA?

Home-based care is the assistance and support given to people infected and affected with HIV and AIDS at home. HBC includes a wide range of services, including nursing care, home visits, assistance with household chores and caring for children, linking to health facilities and social services, psychosocial and nutritional support, training family members to care for the sick, and many other things.

The Home-Based Care Alliance, on the other hand, is a platform that brings together caregivers with a common vision to have one strong collective voice for advocacy. The components of Home-Based Care Alliance work include lobbying and advocacy, resource mobilization, empowerment and organizing caregivers.

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The Home-Based Care Alliance newsletter is a periodical resource for sharing information and updates between grassroots members of the Home-Based Care Alliance across Africa, and for occasionally sharing relevant information from the global level with grassroots caregivers. We hope to compile and send out the newsletter every three months. If you are an active member of the HBC Alliance and have news to share about your efforts to gain recognition and resources for caregivers in your community and country, please write to us and visit the HBCAlliance blog at