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Statement submitted by Huairou Commission, a non-governmental organization in consultative status with the Economic and Social Council

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.



Statement

We, the undersigned non-governmental organizations, urge acknowledgment of the key role that caregivers play in HIV and AIDS response, and demand recognition for the contributions of women-led groups of the Home-based Caregiver Alliance, and support for their sustenance and growth.

The AIDS pandemic has changed the fabric of communities around the world and created a particular burden in the lives of many people, especially women and girls. In many settings where the health-care system is already overburdened, women have stepped in and filled the gap. This has been reinforced and legitimized by the home- and community-based care policies and approaches of HIV/AIDS responses, which in essence have shifted the primary responsibility from State institutions to women's shoulders. Although millions of dollars have been invested in responding to HIV/AIDS, little, if any, of these funds reach people caring for their family members or caregivers working in communities.

Caregiving, most often done by women, across age groups, must be recognized, valued and validated as work. Women volunteer their time, energy, skills and the little financial resources they have as they care for their family members at home and provide their services to the wider community. However, the role that women play in caring for their family members living with HIV and orphaned children made vulnerable by AIDS is rarely recognized or monitored and these women therefore remain unsupported. Community-based caregivers are also not provided with incentives or sustained support to enable them to continue their unpaid work. HIV and AIDS caregivers are not officially recognized as extensions of the health-care or welfare system; therefore their contributions are not mentioned or included in the national accounts.

Caregivers are organized and their contributions to the AIDS response are large-scale and holistic. The organization supports the organization of grass-roots women's Home-based Care Alliance groups, which represent over 30,000 organized caregivers in 12 African countries. These women, many of whom are themselves HIV-positive, widowed or taking care of infected family and neighbours, have their own mutual self-help groups and community-based organizations, and were the first responders in the fight against the pandemic when it hit their communities more than 10 years ago. They have been actively providing direct care and support to those most in need ever since.

Caregivers are grass-roots women, whose work expands far beyond mere service provision to include holistically reducing the impacts of HIV/AIDS as well as its effects. Organized Home-based Care Alliance groups are more important than ever, acting as agents of community development and service delivery. The projected future of treatment and prevention depends on their skills and knowledge.

A 2010 study supported by the organization, for which 1,366 caregivers were interviewed in six countries, found that 97 per cent of the caregivers interviewed conducted home visits but that they also were very involved in other activities, such as antiretroviral therapy monitoring, hospital visits, advocacy, training caregivers, orphan care, searching for schools and bursaries for orphans, distributing supplies, addressing grabbed land from widows and orphans and making or receiving referrals from hospitals. Additionally, caregivers address social stigma, food insecurity and gender-based violence in their work. They are experts of their own local context, in

poor rural areas and urban slums and work tirelessly to address the needs of their communities. They are not seeking hand-outs or training in caregiving, but rather recognition for the work they're already doing, direct support for their organization and leadership development, and inclusion in all levels of AIDS decision-making, programming and implementation.

Caregivers are strong contributors to community development and should be awarded public grants in proportion to non-governmental organization (NGOs). They prioritize mutual self-help and are pioneering innovative collective income-generating activities. Grants would scale up their efforts and reward grass-roots cooperation and leadership. In addition, the investment framework of the Joint United Nations Programme on HIV/AIDS recognizes that communities are a cornerstone of HIV programmes and recommends that Governments invest in community-centred design and delivery, local responses and community mobilization.

Many claim there is a lack of evidence-based research to prove the value of caregivers' contributions. A growing collection of documented, evidence-based research conducted by independent analysts (such as *Compensation for Contributions*, a publication by the UK Consortium on AIDS and International Development, and a new report by the World Bank) confirm the capacity of grass-roots women's groups to foster relationships and collect data and information that enhance accountability and transparency with their Governments.

Despite the growing recognition of the contributions that caregivers make to reducing the spread of HIV and mitigating its impacts, the care, services and resources that home-based caregivers embody are largely unaccounted for.

The agreed conclusions of the fifty-third session of the Commission on the Status of Women, on the equal sharing of responsibility between men and women, including caregiving in the context of HIV/AIDS, was the first document adopted by the States members of the United Nations that addresses caregiving in any detail. In it, Governments recognized the disproportionate burden of care on women and girls and that caregiving includes the support and care of a variety of persons, as well as caring with family kinship and community responsibilities.

Additionally, Governments acknowledged the availability of infrastructure and support services as an important factor in caregiving and the role of national machineries.

Home-based caregivers are first-line responders to AIDS and are sharply aware of its affects in their communities and the types of interventions that are working. Public health services need to become available and accessible to communities, especially in countries that are affected by the epidemic. In many places, agents of formal health systems, hospitals and clinics are integrating home-based caregivers into their own continuum of care plans, primarily through referral systems and training for home-based caregivers.

Through their care work, grass-roots women began noting that, despite the enshrinement of land, housing and property rights for them, they still faced disinheritance due to stigma. A study by the Food and Agriculture Organization of the United Nations in Namibia reported close to half of all women lost cattle, farm equipment and small livestock in disputes with their in-laws after the death of their husbands. In many communities, grass-roots caregivers work to promote women's

inheritance rights and to make land and housing security a reality for women through innovative on-the-ground community justice practices.

Caregivers are playing an important role in helping people to access basic services, food, clean water and medication at an economic cost. In the 2010 study by the organization, 87 per cent of caregivers reported spending their own money on transport costs to do their caregiving work. Households consisting of older people and children are particularly at risk of poverty, a situation worsened by the burden of providing care. Households in Swaziland affected by HIV saw a 22 per cent increase in health costs. Even with the availability of free antiretroviral drugs, associated costs can be unaffordable. Travel costs are a key barrier for people in accessing medicines, while food costs are also increasing.

Unfortunately, as funding for AIDS is threatened and continues to drop or stagnate in many countries, Governments are currently pushing a top-down, business efficiency model of health-care reform that seems to be taking the women and communities most affected by the pandemic out of the picture. Grass-roots caregivers in the multi-country Home-Based Care Alliance are championing a community-based approach to the AIDS response, providing people most in need with access to health services, and working efficiently and holistically to reduce the impacts of HIV/AIDS, curb poverty and marginalization and foster community ownership and Government accountability.

Despite their significant contributions, documented through evidence-based research, grass-roots women's community-based organizations remain fragile and under-resourced, leaders are stretched too thinly and susceptible to burn-out, and their work is being displaced by NGOs who seek to replace or absorb them as service providers (not community developers).

In this context, the organization, on behalf of the Home-based Care Alliance, representing more than 30,000 caregivers across 12 African countries, recommends the following:

(a) Formal recognition of the contributions that women-led Home-based Caregiver Alliance groups make in providing care and support in Africa, through:

- Priority access to governmental health services, medical, protective and food supplies (via certification and identification systems registering and recognizing women's groups as partners) and national directories listing the location, work scope and contacts of women's Home-based Caregiver Alliance groups
- One per cent to five per cent of municipal, AIDS Council and poverty reduction budget to be earmarked for registered community-based women's organizations and Home-based Caregiver Alliance groups that organize local activities on care and support, women's empowerment and poverty reduction
- Seats in planning and decision-making bodies that design and fund community development and social service programmes for poor affected/infected women and families (local to global)

(b) Public and philanthropic financing to be used to grow and sustain the activities of Home-based Caregiver Alliance groups, including:

- Grants to national or multi-State Home-based Caregiver Alliance groups that enable women to undertake income-generating and fundraising activities, health mutual and savings and credit initiatives
- Direct funding for capacity-building, organizing and leadership development
- Public, transparent hearings and consultations on AIDS-related and health budgets that include strong representation of grass-roots women's caregiving groups.

Note: The statement is endorsed by the following non-governmental organizations in consultative status with the Council: Grassroots Organizations Operating Together in Sisterhood, the World Young Women's Christian Association and the Young Women's Christian Association of Nigeria.
