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Follow-up to the Fourth World Conference on Women and to the twenty-third special session of the General Assembly, entitled “Women 2000: gender equality, development and peace for the twenty-first century”: implementation of strategic objectives and action in critical areas of concern and further actions and initiatives: the equal sharing of responsibilities between women and men, including caregiving in the context of HIV/AIDS

Statement submitted by Grassroots Organisations Operating Together in Sisterhood, HelpAge International, Huairou Commission, World Young Women’s Christian Association and YWCA of Canada, non-governmental organizations 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.

* E/CN.6/2009/1.



Statement*

We, the undersigned non-governmental organisations, recognise that 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 legitimised by the home and community-based care policies and approaches of HIV and 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 and AIDS, many times, little if any of these funds reach people caring for their family members or caregivers working in communities.

The International Women's Summit on Women's Leadership on HIV and AIDS convened by the World YWCA (2007), and Grassroots Women's International Academy organised by the Huairou Commission aptly brought forward concerns of caregivers. Caregiving, most often done by women, old and young must be recognised, valued and validated as work. Women volunteer their time, energy, skills and the little resources they have as they care for their family members at home and provide their services to the wider community. However, the role women play in caring for their family members living with HIV and orphaned children made vulnerable by AIDS is rarely recognised or monitored; and these women therefore remain unsupported. Community-based caregivers are also not provided with incentive or sustained support to enable them to continue with their unpaid work. HIV and AIDS caregivers are not officially recognised as an extension of the health care or welfare system, therefore, their contributions are not mentioned or included in the national accounts.

The agreed conclusions of the fifty-second session of the Commission on the Status of Women on financing for gender equality reaffirmed that United Nations Member States have primary responsibility for promoting gender equality and the empowerment of women and girls and that gender mainstreaming and national machineries play a critical role in the implementation of the Beijing Declaration and Platform for Action; but in order for national machineries to be effective, adequate financial and human resources and continued strong political commitment are crucial.

AIDS has pushed leaders and members of civil society to address gender inequality and gender stereotypes that perpetuate the unequal sharing and responsibility between men and women. The greater involvement of men and boys in caring for family members and delivering community care-giving, which many times includes home-based care, is crucial in responding to alleviating the burden of care on women and girls.

Because of their role as caregivers, women, young and old, are deeply affected by AIDS even if they are not infected themselves. HelpAge International research with communities in seven countries in sub-Saharan Africa shows that, on average, 40% of people living with HIV are cared for by older people. A UNICEF study, also in severely affected countries in eastern and southern Africa, similarly found that between 40 and 60% of orphaned and vulnerable children are cared for by their

* Issued without formal editing.

grandmothers. Caring for adult children living with HIV and orphaned grandchildren places a huge economic strain on older people and impacts on their health and emotional wellbeing.

Girls and young women, on the other hand, are almost always the first to be taken out of school when a family member falls ill. This greatly reduces employment opportunities later in life as they do not develop income-generating skills that their male counterparts are privileged to. Young women are more likely to engage in sex work or transactional sex as a means of survival, or enter into early marriages as an escape, leaving them vulnerable to HIV infection.

Caregivers often experience stigma and discrimination, and are presumed to be HIV positive just because they are involved in care work. Occasionally, because of this stigma the patient is cared for secretly and this adds to the caregiver's burden as s/he cannot be identified, trained or supported¹. Psychosocial effects include stress, burnout and exhaustion that affects the wellbeing of the entire family. The frequent lack of training and support translates into a poor standard of care, exacerbating the caregivers' stress. Studies show that "home-based carers experience considerably more stress and distress than medical carers, in the absence of adequate training, mentoring and support."² In response, caregivers have formed groups and networks to provide mutual support and to build their own power. Through these groups and initiatives, caregivers are engaging in peer learning, training and learning to negotiate with local government authorities and decision-makers to access funds and get themselves into decision-making positions. Less progress has been seen in this regard with older carers who remain largely invisible in the HIV response.

In order to be effective, interventions to address HIV and AIDS must take into account the impact caregiving has on women at different stages of their lives. We therefore recommend the fifty-third session of the United Nations Commission on the Status of Women to:

1. Recognise and Affirm Community Caregivers

A health system consists of all actors, institutions and resources that undertake health activities whose primary purpose is to promote, restore or maintain health as a state of complete physical, mental and social well being.³ Caregivers, whether doing formal or informal care work, need to be acknowledged as part of the health care system. The global estimated value of unremunerated work by women is 11 trillion dollars.⁴ Despite the growing recognition of contributions of caregivers to reduce the spread of HIV and mitigate its impacts, the care, services and resources home-based caregivers mobilise, are largely unaccounted for.⁵

Governments and international agencies should formally endorse public roles of caregivers, mandating their participation in decision-making bodies. This would ensure that local challenges

¹ Reducing the burden of HIV and AIDS care on women and girls.

² Campbell, Cathy, 2004, Creating Contexts for Effective Home Based Care of People Living with HIV/AIDS.

³ WHO World Health Report 2008.

⁴ UNDP 1995 Human Development Report, New York Oxford University Press for the United Nations Development Programme (cited in Ogden et al 2006).

⁵ Groots International and Hauirou Commission IWS Statement.

around care-giving inform national and global policy. Caregiving must be acknowledged as a central part of the state response to the epidemic requiring a range of financial, medical and social support. The Commission must recognise and affirm caregiving as work, and therefore, must meet the international standards around decent work.

2. Reduce Household Poverty and the Cost of Care

Caregivers are playing an important role in assisting people to access basic services, food, clean water and medications often at an economic cost to themselves. Households consisting of older people and children are particularly at risk of poverty, a situation worsened by the burden of providing care. Older carers should be supported with social protection measures, particularly social pensions – a straight-forward and cost-effective way to improve the health and income security of children and older people.

Households in Swaziland affected by HIV saw a 22% increase in health costs.⁶ Even with availability of free Antiretrovirals, associated costs can be unaffordable. Travel costs remain a key barrier to people accessing medicines, while food costs increase to ensure the efficacy of anti-retroviral therapy.⁷ One study showed that lack of transport to health services for people living with HIV and AIDS has resulted in some not adhering to their Antiretroviral regime⁸. The reasonable distance suggested for collection of Antiretrovirals is one to five kilometres; yet, many people live more than 20 km away from the hospitals.

Governments and development agencies must increase access to quality basic services at community level, especially health, education, clean water, transportation and food security that supports a functional continuum of care for people living with HIV and AIDS.

3. Increase Quality of Accessible Funding for Caregiving

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. The Global Fund for AIDS, Tuberculosis and Malaria, bilateral and multilateral funding agencies, and national AIDS authorities should prioritise care and caregivers, as they need to be recognised as valued stakeholders through giving them a formal place in decision-making bodies, including Country Coordinating Mechanisms.

Many governments have failed to integrate care into their national budgets, making funds inaccessible to caregivers. Macro and micro funding policies must be strengthened to ensure that funding becomes accessible to the caregiver. To ensure progress, an official role for home-based caregivers to act as monitors and evaluators of AIDS programs should be established at the community level. In addition,

⁶ Budlender 2007: Who cares about the carers? An audit of care work in HIV/AIDS policies in five African countries, Community Agency for Social Enquiry.

⁷ HelpAge International Tanzania, 2007, Building Bridges: Home-based care model for supporting older carers of people living with HIV/AIDS in Tanzania.

⁸ Bicycle Empowerment Network Namibia in partnership with the International Community of Women Living with HIV and AIDS (ICW), the Aids Law Unit of the Legal Assistance Centre (LAC) , August to September 2007.

a minimum percentage of funding should be earmarked to directly support community-led responses to AIDS, particularly those driven by women. Donor accountability is essential if global goals on HIV prevalence reduction are to be met. Donors must ensure that the caregivers have everything they need in order to complete their work safely and efficiently.

4. Properly Resource Health Systems Strengthening and the Continuum of Care

Commitments to strengthen health system are increasing but the reality on the ground and the experiences of home-based caregivers reveals that the health system needs to take into account the entire continuum of care, and to include factors, such as basic services, in order to be effective. The continuum of care provides a framework with equivalent resources needed to foster continuity of care and maximise the provision of care through community-based services. All people have a right to health services. Public health services need to become available and accessible to communities, especially in countries that are impacted by the epidemic. Sustaining a community response that has been in place for generations is important. In many places, agents of the formal health systems, hospitals and clinics are acknowledging this fact by integrating home-based caregivers into their own continuum of care plans, primarily through referral systems and trainings for home-based caregivers.

These partnerships should be mandated or supported by the state; and steps to avoid competition for funds between overburdened hospitals and clinics and overburdened home-based caregivers should be taken. Governments must provide public health facilities and primary health care with proper referral systems that fully integrate home-based caregivers in order to reduce transport costs and waiting time in hospitals and lift the financial and time burdens of AIDS care.

5. Land Inheritance Rights

Around the world, issues of access to, ownership of, and control over land, housing, and other property are enshrined in many national constitutions and international human rights documents. Despite the proliferation of property and inheritance laws and rights, women and girls, particularly in the developing world are denied this right.⁹ The situation becomes even more of a challenge when spouses die from AIDS-related illnesses. The importance of property and inheritance rights increases in the context of an AIDS-related death. A Food and Agriculture Organization study in Namibia reported that 44% of widows lost cattle, 28% small livestock, and 41% lost farm equipment in disputes with in-laws after the death of a husband.¹⁰

In some communities, grassroots caregivers have begun using the pandemic to promote women's inheritance rights, and to make land and housing security a reality for women. Their efforts must be encouraged, supported and built upon in order for women to realise their human rights and participate fully in the community.

⁹ The Global Coalition on Women and AIDS, Report Number 7 – Commission on the Status of Women.

¹⁰ The Global Coalition on Women and AIDS, Report Number 7 – Commission on the Status of Women.