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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 Caritas Internationalis (International Confederation of Catholic Charities) and National Board of Catholic Women of England and Wales, 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.

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Statement*

Regarding the theme "The equal sharing of responsibilities between women and men including caregiving in the context of HIV/AIDS" we wish to submit the following. based on the evidence gained from community-based programme responses supported by CAFOD (Caritas England and Wales) and other members of Caritas Internationalis, who between them support initiatives in 107 countries that aim to provide access for all to prevention, treatment and care.

These programmes are often the only services provided to isolated communities far removed from regional health centres or centres of excellence located in larger cities and towns. They most often work through local community and Church-based networks and, as well as having a core of dedicated and skilled staff, they usually rely on a large body of volunteers, drawn from these local communities and well placed to provide effective support in a targeted, well-informed and culturally appropriate manner. CAFOD and many other Caritas members have been supporting HIV-related initiatives since 1987. A large proportion of these initiatives consists of home-based care —a term that encapsulates a myriad of services provided to people living with and affected by HIV. Our combined experience of caregiving in the context of HIV/AIDS shows that:

- The majority of caregivers in almost every community served by Caritas programmes are women and young girls;
- Caregivers are volunteers from the same community and often enduring the same economic
 and social hardships as those they serve. Volunteers receive little if any economic recompense.
 Although usually as poor as those they visit, they often give from their own meagre supplies of
 food or basic materials, particularly where programme budgets or national/international
 funding policies do not cover these;
- Volunteers give not from their spare time but from time they might otherwise use to benefit their own families and their personal earning or schooling opportunities;
- The work of caregivers often goes unrecognised and unquantified in reports of local/national responses to HIV. Yet, the majority of Caritas-supported programmes could not function without the dedication, commitment, generosity and skills of these volunteers;
- Traditions and cultural norms in many societies where Caritas programmes operate dictate that
 only women can provide care. Local taboos and sense of gender roles prohibit men from
 engaging in such work. This can exacerbate the tendency to underestimate or even ignore the
 value of the care provided;
- Lessons learnt, particularly from CAFOD programmes in East and Southern Africa, indicate that, with appropriate community education and mobilisation, men can also be engaged in caregiving. Where this has occurred the effect has been manifold:

* Issued without formal editing.

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- The HIV-related stigma borne out of fear that prevailed in those communities, was dissipated as men gained greater understanding of the infection and insights into the lives of people infected and affected;
- Men became more open to discussing HIV-related concerns that affected them personally and to accessing information, testing and wider support services;
- The value of caregiving received greater recognition and the status of caregivers was enhanced;
- o Communication between women and men was strengthened;
- o It became easier for both women and men living with HIV to be open about their status, without fear of violence, rejection or abandonment;
- O Skills gained in care-giving often benefited both women and men when they sought paid employment in other areas of work.

Recommendations:

- The work and value of caregivers needs to be recognised as an indispensable part of the
 continuum of care required for a holistic response to HIV. To be effective and
 sustainable it needs to be planned for, resourced and costed. This has implications both
 for national strategies and policies and for budgets of governments and international
 funding agencies. Home-based care cannot be considered a as cheap alternative to
 hospital-based services.
- 2. The detrimental effects of conferring the burden of caregiving solely to women and young girls need to be acknowledged and countered through effective policies and budgets to alleviate this burden at national and international levels. Similarly the benefits of involving both women and men should be documented and promoted, with appropriate recognition, training, equipment and support provided to all carers, male and female, and financial recompense for out-of-pocket expenses guaranteed as a minimum.
- 3. The economic and social status of carers should be strengthened by establishing social protection systems and both cash and non-cash mechanisms to ensure sustainable provision of such care. These schemes would serve both to remove the detrimental effects on women and girls who lose employment and educational opportunities because of their disproportionate burden of care, and to encourage men to become more involved in providing some of this care.
- 4. The breadth of issues addressed by caregivers needs to be recognised and used to illustrate that HIV cannot be confined solely to health sector responses, but also has implications for e.g., food security, poverty reduction, legislation to promote equity

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between women and men, inheritance and property entitlements, domestic and community-based sexual violence and more, as well as informing efforts to provide equal access to comprehensive prevention, care and treatment services for women, men and children.

- 5. National policies and programmes should be informed by an in-depth analysis disaggregated by gender and age. The involvement of men as well as women in caregiving should be promoted in national and international strategies.
- 6. The participation of home-based care groups and networks in shaping national policies and in monitoring and evaluating services provided, should be promoted. Their role as active players in a multi-sectoral response is essential and should be ensured.
- 7. Community-based networks, NGOs, and international networks, such as that of Caritas Internationalis, should be engaged in documenting the experiences of caregiving with particular reference to gender considerations specific to women and men, so that this evidence can contribute to the development of increasingly effective strategies and programmes in the future.

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