Noerine Kaleeba chaired the meeting and introduced the subject. As founder of TASO Uganda, one of the first home and community based care programmes and now UNAIDS Programme Development and Community Mobilisation Officer, she spoke of her own experience as a woman whose husband became ill and died of AIDS, as a mother, and a community leader. She outlined the massive care burden for women, especially in her own country, Uganda, where there was simply no support for women to take care of family members in their home. But voluntary initiatives are not enough, she said, there needs to be a systematic effort to address the issues of poverty and care in the longer term.

Bolelwa Fako-Falten opened the discussion as the first panellist. She spoke of her experience as a woman worker in a Taiwanese garment factory in Lesotho, and gave a moving, but shocking account of discovering that she was living with HIV. She described her treatment by health workers, factory managers, her peers at work, as well as politicians and policy makers when she declared her status. In closing, she called upon governments to own up to their responsibilities, and to ensure that the care burden does not fall squarely on the shoulders of women.

Nalini Burn, technical specialist on Gender and Economics, as the second panellist, explained in very accessible terms, the notion of the Care Economy. She explained the link between the care economy and the money economy, and outlined issues of opportunity and replacement costs of labour, and how there have been attempts to calculate this in Time Use Surveys. Some of the key questions she asked in relation to HIV/AIDS, care of the sick and dying – in and outside of the household: who does what, for whom, how, why and when? Who else does what? This enabled the audience to understand more clearly how the notions of the ‘productive’ and ‘non-productive’ economies are flawed and demand re-thinking and re-conceptualising.

Madhu Nala Bath, UNIFEM’s Regional Adviser for Asia gave a presentation on Gender, HIV/AIDS, Human Rights and the Care Economy. Her paper was provocative in that it addressed issues of corporate rights versus individual rights (and outlined some of the dilemmas about access to drugs and treatment), structural constraints and human rights (issues of poverty, adequate facilities to enable protective sex), care, rights and the community (basic human rights and care burdens), impact of the care economy at macro level, especially in high prevalence countries, care rights and the state (lack of health care facilities and social service infrastructure), rights and entitlements and making governance accountable (the need to re-prioritize national spending, improving social services, and redefining development paradigms – the quadruple burden on women – no longer the triple burden!).

Lin Lean Lim, Director of the ILO’s Gender Promotion Programme, whose aim is create more and better jobs for women, gave an analysis of the relationship between the concept of decent work, the care economy and HIV/AIDS. The notion of decent work includes balance between work and family, and speaks to the right of each worker – paid or unpaid, in formal or informal work – to work with dignity, in
conditions of security and protection. The ILO seeks to promote the goal of Decent Work in four strategic areas: rights at work, access to decent employment opportunities, social protection and social dialogue. The HIV/AIDS epidemic has posed a significant challenge to the realisation of these goals because all elements of society are affected, and the virus attacks those in the prime of their working life. This has implications for the life cycle, since it is altering the pattern of inter-generational care, is eroding protections and benefits at work, and is also affecting the productivity and viability of enterprises. The ILO’s Code of Practice, as well as relevant ILO Conventions and ongoing programmes, are aimed at ensuring that especially for women, there are appropriate policies and strategies in place in the workplace and at national and international level.

Cindy Berman concluded by outlining the ILO/UNIFEM Programme on the Care Economy, HIV/AIDS and the World of Work. She argued strongly for the need for care economy issues to be included in PRSPs, in National AIDS strategies and programmes, in UN programmes, or they will fail to tackle the social, economic and gender impacts of the epidemic. Gender inequalities and unequal power relations between men and women are both driving the epidemic, and reaping its effects. She called upon governments, the multilateral institutions, donors, the UN system, policy and research institutions to feel an urgent sense of responsibility and ownership to tackle the untenable and unsustainable burden of care for women. Social safety nets and protections need to be put in place to alleviate the poverty and care burdens on families, and especially on women; employment and workplace policies must be made more flexible and gender-sensitive; creative strategies and solutions need to be found by employers, workers and governments in partnership to ensure that that the social and economic impacts of the pandemic, especially for women, are mitigated.

Stephanie Urdang, Senior Gender and HIV/AIDS Adviser in UNIFEM moderated the discussion that followed. A number of questions and comments were raised from the floor. Some concurred that women are indeed bearing the hardest impact of the pandemic, and the implications for children’s schooling, food security, social cohesion etc. are enormous. The point was made that some women choose willingly to care for their loved ones, and that care should not simply be seen as a burden. Nalini Burn endorsed fully this sentiment, and said that the care dimensions are what need to be preserved and nurtured, but the additional stress and work that is associated with this critical care (such as fetching water and fuel, having insufficient health care supplies and hygienic materials) are what need to be addressed urgently by policy makers and resource providers. One person asked what the UN system was doing to for its own staff, and this item was reported in the AIDS Today magazine. There was insufficient time to answer this question adequately, but it did provide food for thought on who cares for the carers, and why is it simply taken for granted that women provide, and will continue to provide care and support to family members and loved ones, with no sense of the cost and value of this work to society and to the economy in general. As the impact of the pandemic is felt in increasing ways, the ability of women to continue to be the mainstay of their families and communities is becoming unsustainable, unless some urgent measures are taken to tackle the real impact of the pandemic.