

# **Brainstorm Workshop on ILO/UNIFEM Programme The Care Economy, HIV/AIDS and the World of Work**

**TURIN, 22-23 NOVEMBER 2001**

## **SUMMARY REPORT**

### **1. Introduction**

A two-day brainstorm workshop was organised to discuss a new proposal for a collaborative programme between ILO and UNIFEM on issues of HIV/AIDS, the care economy, and the world of work. The idea for the programme originated from the ILO Regional Director for Africa, Ms Regina Amadi-Njoku, based on her close understanding of the relative strengths of the ILO and UNIFEM, and was developed in the context of the Declaration of Commitment adopted UN General Assembly Special Session on HIV/AIDS held in June 2001.

Participants at the meeting included ILO and UNIFEM specialists and focal points on HIV/AIDS and Gender, experts and resource persons, a representative of the Africa Regional Office, and included an ILO area office director. (see Appendix II for list of participants). Unfortunately at the last moment, Ms Amadi-Njoku was unable to attend the meeting, but mandated ILO staff to represent her and her office.

### **2. Objectives of the workshop:**

- To review the programme proposal which had been shared with participants in advance. The workshop was not intended to draft a final programme proposal document, but rather to ensure that the programme's aims and objectives are relevant, appropriate and achievable, and to inject new thinking and ideas into the conceptualization and design of the proposal.
- To understand the comparative strengths of ILO and UNIFEM to build partnership and to define the roles and responsibilities of ILO and UNIFEM in implementing the programme
- To achieve a common understanding of the interface between HIV/AIDS, gender and decent work in the formal and informal economies.
- To develop a common understanding of the care economy, clarify terms, and agree a conceptual framework for the purposes of this programme
- Agree a framework for understanding the linkages between the care economy, HIV/AIDS and the world of work explored in the proposal
- To agree expected results and strategies for the proposal to address mitigation of the impact of HIV/AIDS-related care and support, particularly for women workers in paid and unpaid work.
- To develop specific ideas and proposals which address the needs of women and men workers affected by or living with HIV/AIDS in the formal sector and informal economy, which include issues of rights, social protection, employment/income

security, and voice. These proposals should be developed in the areas of: knowledge building/research, advocacy, and technical cooperation/service provision.

- To decide the time frame, the geographical scope of programme and to begin to identify potential pilot countries and projects.
- To agree next steps after the brainstorm workshop and recommendations for potential sources of funding, and begin to address the institutional framework for this collaboration

It was hoped that the outcome of the workshop would be:

- A common vision for the programme
- Agreements on the next steps to secure donor funding for the programme

### 3. Brainstorm workshop programme

Please see Appendix 1 for an annotated agenda of the workshop.

The workshop was designed to focus on the key elements of the programme, achieving a balance of information sharing and presentations with group work to facilitate the process of brainstorming as much as possible. The draft proposal provided the reference point for discussion, comment and ideas, but the expertise of specialists, experts and resource persons was drawn upon to add new perspectives, and to bring fresh thinking to the table.

### 4. Issues discussed

- Areas of discussion during the workshop included:
  - The institutional framework for the collaboration and relative mandates of ILO and UNIFEM
  - the concept of decent work and the ILO's decent work agenda;
  - conceptual framework for understanding the care economy;
  - macro-economic and household-level perspectives on the care economy, particularly in relation to HIV/AIDS, including public sector expenditure priorities and possibilities.
  - perspectives on issues of HIV/AIDS in the formal and the informal economies;
  - socio-economic impact, especially at a household level of HIV/AIDS and increased care burdens, including inter-generational dimensions;
  - social protection and innovative financial instruments for people living with or affected by HIV/AIDS;
  - employment and income security options especially for carers of PLWAs;
  - impact of HIV/AIDS related care on enterprises and economic development at local, regional and national levels.
- For the purposes of this report, a 'shopping list' of ideas and perspectives that were raised during the brainstorm has been set out in Appendix III. Rather than write a detailed account of who said what, many of these ideas will be reflected in the revised programme proposal document. At the same time, the need to ensure coherence of the scope, mandates of the respective partner agencies and viability of

achieving the programme's overall aim and objectives remains paramount, so some selectivity will be needed.

#### 5. Agreements reached

- ? It was agreed by all the participants that this programme is timely, and will be an important contribution to addressing the socio-economic impact of HIV/AIDS. It also fits directly within the framework of the UN system follow-up to the Declaration of Commitment adopted at the UNGASS on HIV/AIDS 2001.
- ? The programme should run over a minimum period of three years, instead of two, as the original proposal suggested.
- ? The programme should be global in scope, but will focus on Africa during the first year. Given the scope and mandate of the programme, its activities will be directed at policy level interventions and recommendations.
- Recommendations were made for identifying pilot countries based on a list of criteria:
  - High, medium and low prevalence countries
  - Countries with visible and organised informal economy workers, and countries/sectors where informal economy is 'invisible' or hard to organise
  - Countries/communities where there are strong community based organisations, particularly women's organisations
  - Countries in which the state provides some degree of social security benefits, eg. pensions, unemployment or occupational health benefits.
  - Countries with enabling policy environments, and those without. This includes illustration of countries/communities where, for example, there are good institutional/legislative and policy support for HIV/AIDS, countries which have conducted nation-wide time use surveys, where labour market policies on HIV/AIDS have been developed, where good workplace policies exist, or where there are supportive community-based initiatives to address the burden of HIV/AIDS related care. (a matrix will be developed to identify these issues)
- ? ILO and UNIFEM have comparative advantages to work as partners, and staff from both agencies will work jointly and/or in complementary areas of activity in the field as well as headquarters in executing this programme.
- ? The draft programme will be revised to incorporate comments, ideas and suggestions made during the brainstorm, and will be circulated for comment mid-January in order to have a final version by the end of January 2002. Thereafter it will be taken to donors for funding.
- ? There is a strong commitment to work with a range of other partners - institutions, experts and other stakeholders. The intention is to complement work that is already ongoing, and to support existing initiatives in specialist areas of interest. These include ILO's tripartite social partners, women advocacy groups, UNAIDS cosponsors, Commonwealth Secretariat, WIEGO, regional and sub-regional

institutions such as ECA, SADC, gender-budgeting initiatives, NGOs, faith-based associations, organisations of people living with HIV/AIDS, youth and the elderly organisations, and others, as appropriate.

6. Follow-up and next steps

- ? Programme proposal will be revised and circulated to all participants by mid-January 2002 for final comments and final revision deadline by the end of January 2002. It will then be submitted to donors for funding.
- ? Identification of the best institutional framework agreement for this partnership will be discussed with CODEV/COMBI, and within UNIFEM. Possible scenarios are Memorandum of Understanding, lead agency with transfer of funds to implementing partners, funding provided for separate areas of work within overall framework, etc.
- ? A vision-building workshop was proposed to be held with with global partners and stakeholders in Africa in March/April 2002.
- ? It was recommended that there should be an ILO/UNIFEM Panel on the Care Economy, HIV/AIDS and the World of Work at the next International Conference on HIV/AIDS to be held in Barcelona, July 2002.

## APPENDIX I

### **Brainstorm Workshop on ILO/UNIFEM Programme The Care Economy, HIV/AIDS and the World of Work (Turin, 22-23 November 2001)**

#### **PROGRAMME**

##### Wednesday, 21 November

19.00 *Welcome reception followed by dinner for participants*

##### Thursday 22 November

08.30 – 10.00      **Opening Session** (*Chair: Catherine Hein*)

- Welcome on behalf of the Turin Centre (*Lynn Villacorta*)
- Statement on behalf of the ILO Regional Director for Africa (*Grace Hemmings*)
- Introductions by all participants (*Facilitator: Simonetta Cavazza*)
- Introduction to the workshop programme and objectives (*Cindy Berman*)

10.00 – 10.30      **Institutional framework and guiding principles for the collaboration  
between ILO and UNIFEM**

- ILO Decent Work Agenda and Code of Practice on HIV/AIDS in the World of Work – a gender perspective (*Judica Makhetha*)

10.30 – 11.00      *Coffee Break*

11.00 – 12.45      **Institutional framework and guiding principles for the collaboration  
between ILO and UNIFEM (continued)**

- Gender and HIV/AIDS in the Informal Sector (*Pia Nyman*)
- UNIFEM mandate and HIV/AIDS programme framework (*Madhu Bala Nath*)
- The Care Economy (*Paula Donovan*)
- UN General Assembly Special Session on HIV/AIDS – Declaration of Commitment (*Stephanie Urdang*)

12.45 – 14.00      **Lunch Break**

14.00 – 15.30      **The Care Economy, HIV/AIDS and the World of Work  
Problem Identification and Analysis**

- Brainstorm in two groups, based on brief overview of programme proposal. Participants will divide in two groups, according to their preferred area of interest (a) Formal Sector; (b) Informal Sector. They will highlight all dimensions of the problem, and begin to identify possible areas of response/solution.  
(*Simonetta Cavazza & Elena Gastaldo - facilitators*)

15.30 16.00 **Feed-back in plenary**

16.00 *Coffee Break (in working groups)*

16.00 – 18.00 **Working Group brainstorm on objectives and strategies**

Participants will divide themselves into three groups:

- Knowledge Building / Research
- Advocacy
- Service provision / Direct Action

to brainstorm ideas based on problem identification and analysis from the previous session. They will analyse objectives and strategies. They shall propose modifications, as well as add new ideas.

19.45 Group dinner outside of Turin Training Centre

### **Friday 23<sup>d</sup> November**

08.30 – 10.00 **The Care Economy and HIV/AIDS** (*Chair: Stephanie Urdang*)

? The Care Economy – how we understand it (*Diane Elson*)

- UNIFEM case study on the care economy and HIV/AIDS: Presentation of study on the socio-economic impact of HIV/AIDS in Zimbabwe (*Emmanuel Chirebvu*)

Plenary group discussion

10.00 – 10.30 *Group photo and coffee break*

10.30 – 11.30 **Innovative financial instruments and policies for managing the HIV/AIDS epidemic** (*Jim Roth*) followed by plenary discussion

12.00 – 12.30 Presentations on small group work from previous day and plenary feedback and discussion on proposals for research and knowledge building, advocacy and direct action/service provision

12.30 – 13.30 **Lunch break**

13.30 – 15.00 **Working groups addressing care economy issues in the world of work**

In light of the morning presentations, participants will brainstorm in two groups:

- The Care Economy and HIV/AIDS in the Formal Sector
- The Care Economy and HIV/AIDS in the Informal Sector

They shall be asked to revisit the proposal, putting forward ideas for pilot countries, potential partnerships and roles for agencies.

15.00 – 15.30 *Coffee break*

15.30 – 16.30 **Plenary presentation on outputs of working groups**

16.30 – 17.30 **Conclusions and Recommendations**

- Summary of outcomes of the workshop
- Recommendations for follow up and next steps

Evaluation of the workshop and final closing

## Appendix II

### **Brainstorm Workshop on ILO/UNIFEM Programme The Care Economy, HIV/AIDS and the World of Work (Turin, 22-23 November 2001)**

#### **LIST OF PARTICIPANTS**

*Ms. Judica AMRI-MAKHETHA*

Senior Specialist - Gender

**ILO SAMAT**

**ZIMBABWE**

*Ms. Cindy BERMAN*

Technical Officer & Gender Advisor

**ILO New York Liaison Office to the UN**

**Mr. Emanuel CHIREBVU**

Independent researcher,

**ZIMBABWE**

*Ms. Nazneen DAMJI*

Programme Specialist/Gender and HIV/AIDS

**UNIFEM, USA**

*Ms. Paula DONOVAN*

Advisor for Africa/Gender and HIV/AIDS

**UNIFEM, Kenya**

*Ms. Diane ELSON*

Professor of Global Social Change and Human Rights

Department of Sociology

**UNIVERSITY OF ESSEX, UK**

*Mr. Marc FILLIEUX*

Programme Officer

**ILO/AFRICA LIAISON OFFICE**

*Ms. Catherine HEIN*

Director

**ILO AREA OFFICE IN ANTANARIVO**

**Ms. Grace HEMMING-GAPIHAN**

Senior Technical Specialist  
**ILO/EMAO**  
**ABIDJAN**

**Ms. Madhu Bala NATH**

Regional Adviser/Gender and HIV/AIDS/ASIA  
**UNIFEM, India**

*Ms. Pia NYMAN*

Associate Expert  
**ILO/AIDS**

*Ms. Naoko OTOBE*

Gender Technical Specialist  
**ILO/GENPROM**

*Mr. Peter MWAROGO*

Deputy Director  
**FAMILY HEALTH INTERNATIONAL**  
**KENYA**

*Mr. Jim ROTH*

Economist  
**ILO/SOCIAL FINANCE UNIT**

*Ms. Amrita SIETARAM*

Workers' Education Specialist  
**ILO/ACTRAV**

*Ms. Sonia SMITH*

**ILO/AIDS**

*Ms. Nancy SPENCE*

Director/Gender and Youth Division  
**COMMONWEALTH SECRETARIAT**  
**UNITED KINGDOM**

*Ms. Stephanie URDANG*

Advisor, Gender and HIV/AIDS  
**UNIFEM, USA**

*Ms. Cinthia Olufunmilayo YINUSA*

Programme Officer  
**ILO AREA OFFICE**  
**PRETORIA**



**TURIN CENTRE**

***Ms. Marion CHISTOPHE***  
Programme Secretary  
Social Protection Programme

***Ms. Simonetta CAVAZZA***  
Coordinator  
Gender Coordination Unit

***Ms. Elena GASTALDO***  
Consultant  
Gender Coordination Unit

***Ms. Irene NORI***  
Programme Secretary  
Social Protection Programme

***Ms. Lucia PANDOLFI***  
Assistant  
Social Protection Programme

***Ms. Lynn VILLACORTA***  
Manager  
Social Protection Programme

## Appendix III

### **Brainstorm Workshop on ILO/UNIFEM Programme The Care Economy, HIV/AIDS and the World of Work (Turin, 22-23 November 2001)**

#### **SOME KEY ISSUES DISCUSSED DURING THE BRAINSTORM**

##### 1. Introduction

Catherine Hein, Director of the ILO Area Office in Antananarivo opened the meeting and welcomed participants. Lynn Villacorta, Manager of the Social Protection Programme welcomed all participants on behalf of the ILO Turin Centre and the Social Protection Sector. The ILO Programme on HIV/AIDS in the World of Work was thanked for its support in hosting the meeting. Simonetta Cavazza, Coordinator of the Gender Unit at the Turin Centre, and facilitator of the workshop, (together with her colleague Elena Gastaldo), introduced the programme for the workshop. Cindy Berman, Technical Officer and Gender Adviser for the ILO AIDS Programme and coordinator of the ILO/UNIFEM programme outlined the objectives and intended outcomes for the workshop.

##### 2. Institutional framework and relative mandates of collaborating organisations

###### 2.1 The ILO, HIV/AIDS and Gender - presentation delivered by Judica Amri Makhetha, Senior Gender Specialist of the ILO. (Powerpoint presentation may be made available on request)

- ILO concept of decent work, and the four strategic areas of work guiding its decent work agenda: rights at work, employment, social protection and social dialogue.
- ILO's Code of Practice on HIV/AIDS in the World of Work, HIV/AIDS and gender issues in the formal sector, including gender dimensions of the Code of Practice
- Discussion included potential for this programme to highlight ILO Conventions on Workers with Family Responsibilities, Home Work Convention and others.

###### 2.2 Gender dimensions of HIV/AIDS in the informal economy – presentation by Pia Nyman, Associate Expert, gender & HIV/AIDS focal point, Addis Ababa.

- Analysis of problems and issues faced by people in the informal economy living with or affected by HIV/AIDS

- Recommendations made for further analysis and activities to address these issues. (This presentation can be made available electronically in powerpoint format).
- Discussion included the fact that the forthcoming ILO Labour Conference will devote a major item of its agenda to this issue.
- Importance of identifying pilots that reflect whether and how workers in the informal economy are organised, as well as wider networks of women's organisations and associations, and the impact that makes on coping strategies to address care dimensions of HIV/AIDS.

2.3 Overview of UNIFEM's work on gender, human rights and HIV/AIDS – presentation by Madhu Bala Nath, UNIFEM's Regional Advisor for Gender and HIV/AIDS in Asia and the Pacific.

- Outline of UNIFEM's work in linking policy, research and outreach strategies related to gender and HIV/AIDS. The HIV/AIDS programme focuses on building bridges of support, advocacy, and activism at the global, national, and regional levels – within the women's movement, key stakeholders working on HIV/AIDS, and policy makers. Community based data collection and research has been conducted in several countries, followed by orientation workshops focused on raising awareness on the link between gender, human rights and HIV/AIDS, and also included media training. The presentation also provided insight into UNIFEM's current work in developing "gender equality zones".

2.4 The care economy in the context of HIV/AIDS – presentation by Paula Donovan, UNIFEM's Regional Advisor for Gender and HIV/AIDS for Africa.

- What is meant by the "care economy" in terms of the social and economic impact of the epidemic on women *affected* by HIV/AIDS.
- With the onset of AIDS, health systems are debilitated much more and there are now women who are doing things they did not have to do before HIV/AIDS, more of what a "paid" health worker would do.
- UNIFEM's work on the costs of care – the costs to women's development, the costs on social capital, etc. Paula's presentation included a touching story of 'Christine' to highlight many of the HIV/AIDS related care dimensions.

2.5 UN General Assembly Special Session on UNGASS and the Declaration of Commitment – presentation by Stephanie Urdang, UNIFEM Global Gender and HIV/AIDS Advisor.

- Significance of a Declaration of Commitment endorsed by participating governments in terms of the successes in addressing gender issues. The Declaration also succeeded in placing gender firmly within the framework of human rights, and women are not seen solely as a "vulnerable group".

- Declaration provides very strong entry points for UNIFEM's work on HIV/AIDS and for this collaborative proposal.
  - Questions and discussion in plenary related to a need for research on coping mechanisms
  - Importance of highlighting the empowerment of women as a key outcome of the UNGASS and using this to garner political commitment (such as that being done by the Commonwealth Secretariat).
  - Discussion about a small study attempting to cost care done largely by women, including opportunity costs. However there are many complexities due to the fact that the household is a dynamic entity, but such an exercise remains useful, particularly from an advocacy and policy perspective. Discussion included the importance of understanding the real and perceived gender division of labour in the household. There has been a significant paradigm shift – from the 'double' burden to 'quadruple' burdens on women and the impact on gender equality goals and the empowerment of women.
3. Problem identification and issues for further information, analysis, research, suggestions for strategies and actions to address HIV/AIDS, the care economy and workplace issues Discussed in two working groups – one examining the formal economy, and the second examining these issues in the informal economy. Some feedback from these groups included:

### 3.1. The formal economy

- Women are paid less than men for the same work
- Exclusion and discrimination - in markets – labour, capital, health and insurance markets (i.e. insurance and burden of funerals)
- Maternity protection issues – issues of discrimination, leave pay and stigma for HIV positive women
- Inflexibility of employment – (impact particularly in terms of the care responsibilities)
- Inflexibility of pension schemes
- Lack of information on how the care economy impacts on workers
- Inadequate social security schemes for many workers (pensions, medical, disability)
- Care economy has been informalized and is largely unpaid
- Role of collective bargaining to access health schemes, address discrimination and gender issues
- Terminal care is a problem – even where there are good workplace policies
- Sexual harassment at work – sexual violence – such as in domestic work in terms of spreading of AIDS
- Lack of provision of ARV -- some sectors are already doing this – interesting to see the impact on the care economy (because hopefully they

- have drugs) – and also palliatives (even those are not available through formal schemes)
- Section 9.8 of Code – employee and family assistance programmes - may help to alleviate some of the burden of HIV/AIDS related care work
- Problem of lack of ratification of Convention 156 – Workers with family responsibilities. Even where this Convention has been ratified, need to ensure application and monitoring
- Programme should seek to reduce discrimination in formal labour market
- Programme should seek to improve partnerships between governments, employers and workers to care for HIV/AIDS affected workers
- Prevention, care and support needs to be integrated

### 3.2. The informal economy

- Lack of access to social protection, care infrastructure
- Management of care at a household level – domestic and health care needs
- Gender roles of care at a household level, different for men and women
- Need to address the macro-economic context of care in the informal economy: national planning does not include the informal economy, not reflected in human resource development strategies. Need to examine public expenditure priorities, allocation of budgets, analysis of social budgets
- Invisibility of the informal economy, especially in rural areas and in some sectors, such as domestic labour
- Public sector service delivery does not reach informal economy, absence of institutional mechanisms to locate invisible sector and provide appropriate levels of support, especially in context of destruction of the public sector and social security systems where they exist.
- Many people are employed in formal and informal economy activities simultaneously in order to supplement income
- Increasing household dependency ratios as fewer breadwinners in immediate and extended family structures. Social capital is a LIMITED RESOURCE that is fast running out!!
- Need to address sectors, types of work where the risk of contracting HIV/AIDS is higher – need to examine socio-economic context, e.g. mobile, migrant workers, conflict-affected areas, single sex living arrangements or transient workers sleeping on streets etc.
- Problem of communication for workers in the the informal economy – e.g. to get appropriate information and prevention messages
- Programme should ensure reflection of basic premiss that all women and working women, and not target or highlight vulnerable groups only, such as sex workers, truckers etc. Also, the programme should address people affected by and people living with HIV/AIDS – to ensure the care dimensions are adequately addressed – impact of HIV/AIDS on households and families.

- Inter-generational dimensions of care, infection and need for intervention to address impact mitigation of the epidemic.
- Programme could also look at empowerment strategies for women – what has the impact of these interventions been for women workers – extent to which it has accelerated prevention efforts, and/or effectively addressed HIV/AIDS related care dimensions.
- The need to analyse coping strategies developed by organised and unorganised workers in the informal economy to address the impact of HIV/AIDS related care.
- Identify potential systems of support and social protection that macro-economic policies do not address

### 3.3. General recommendations

Problem Analysis could be addressed at three different levels:

- macro – government level
  - lack of investment in social issues
  - need to calculate appropriate percentage of national budget
  - extension of social protection
  - poverty strategies – inclusion of HIV/AIDS and care dimensions (e.g. PRSPs)
  - lacunae in terms of human resources development and projections – need to develop strategies to respond to these gaps
  - labour-intensive public sector infrastructure development and other multilateral and bilateral initiatives – paying for care as contribution to national economy, recognising cost of care, creation of jobs, making visible the invisible dimensions of care
- meso – community/organizational
  - need for organizing the unorganized
  - communication channels
  - inadequacies of school and health systems
- micro – individual/household
  - health care and personal care
  - extended family
  - care at home
  - household dependency ratios

## 4. The Care Economy

4.1. Conceptual framework for understanding the Care Economy presentation by Diane Elson, Professor of Global Social Change and Human Rights, and UNIFEM Consultant. This presentation was based on conceptual framework developed for UNIFEM publication - Progress of the World's Women in 2000. The section on the care economy had been circulated in pdf format to all participants in advance, and copies were also made

available.

- Understanding the care economy is important because it helps us move the discussion forward on HIV/AIDS related care, and how that relates to the gender division of labour
- Some work has a set of official names – such as those in labor force statistics or in national accounts – what counts as participation in the economy. Then there are those types of work that don't have a name, because it falls outside the boundary of the national accounts systems and outside official labour market statistics. Labour statistics do have a category “unpaid family worker” for people who work without direct remuneration – usually in family businesses, but nevertheless oriented towards the market, and is therefore officially part of the economy. Although this is a recognised category, it is usually men who are accounted for in these statistics.
- Unpaid care work provided in the household and community, including unpaid HIV/AIDS related care work, falls outside the boundary of the formal labour market since is not recognised as having direct market value. Therefore there is a need to revision the economy through women's eyes in order to bring in issues that are particularly relevant for women. The domestic sector – including many types of unpaid activities – interpersonal services performed, and non-monetized relationships are not counted in national accounts or statistics.
- The NGO sector is an interesting case, because as a result of public sector restructuring, a great deal of public sector work is sub-contracted out to NGOs in paid and unpaid forms.
- Informal and formal sector – defining is difficult – but they are interlinked – often there are important linkages
- Social reproduction is sometimes the term that is used for the work of the domestic sector, but the concept and terminology has drawbacks, and is not generally used as a helpful organizing concept
- Macro-economic restructuring has produced a change in the relationship between the private sector and the public sector, and is being done in the name of efficiency. The idea is that downsizing increases efficiency, and the costs are transferred to the unpaid voluntary work, to the NGO sector and to unpaid care work. Because these costs of care and social reproduction are largely hidden and are not accounted for in statistics, this strategy is said to be more efficient. What looks like efficiency is not in fact all that efficient given that it has changed the way people are cared for, and has transferred these

burdens to the community. This has a cost – increased absenteeism, loss of productivity, less time to devote to paid care, and possible removal from formal labour market jobs because of increased burden of care. Also there is a decrease in agricultural output (and food security) and decrease in the quality of care in many cases because of a lack of resources and time on the part of carers.

- It is also not sufficient to have care burdens shared more equally between men and women – the inefficiencies will remain, and the capacity of households to absorb the strain – particularly with the HIV/AIDS pandemic – is fast diminishing. Older people who have spent their lives working are having to care for others instead of being cared for, and whilst already exhausted, in many cases are forced back into economic activity at an old age. Adolescent and young girls are forced to sacrifice the education and prospects for gaining decent work opportunities because of the need to take on caring responsibilities in the household and community.
- It is critical that the hidden costs of care are made visible, and to ensure that it is reflected in national statistics. “If it’s not counted, it won’t count!”
- How does one count the cost of care? The Beijing Platform for Action raised this issue forcefully, and as a result there has been an attempt to develop national time use surveys, household data mapping, calculating opportunity costs and replacement costs of care. UN Statistics Department has a large project to collect statistical time use data at national levels. (This has been done in South Africa and some other countries).
- It is very difficult to measure unpaid care work, and there are a number of flaws with existing time use surveys. Some of the problems of measuring care work include: difficulties of measuring productivity; certain types of work are seasonal; measuring multiple tasking activities; different types of unpaid care work involves levels of energy expenditure; difficulties of placing a monetary value on certain types of activity, such as the amount of time taken over a task, and so on. Further work is needed to address these.
- More research is needed on the impact of these macro-economic policies, including:
  - Understanding the way the public sector organizes its services, especially in a context in which the ability of the state to deliver basic social services is greatly diminished by the HIV/AIDS pandemic
  - Analysing relative efficiency and inefficiency of transferring the costs of care, especially to the poorest



- The impact on pressures to cut subsidies in areas such as education, human resource development, nutritional status etc.
- Challenge to examine more closely the geographical location and inter-connection of paid, unpaid work and care provision (e.g. home-based workers, informal and formal economy interface in same social space).
- There are significant gender differences in work patterns. The formal private sector tends to be more male than female; informal economic activity is more female than male; the public sector in south is more male than female; the paid voluntary sector is more male; unpaid NGO work more female; the domestic sector is disproportionately female. Taking into account all these types of work – poor women are at the greatest disadvantage.
- Questions and discussion addressed replacement and opportunity costs of care work. Replacement costs would be based on inputs, for instance, if woman is caring at home for an HIV patient compared to what a nurse would get in a hospital? These could also be based on outputs, for example, how much would the meal cost in a restaurant? Opportunity costs would be calculated on an assessment - if they were doing something else – what could they have received for that? There are pros and cons of all of these – calculating opportunity costs, there is the problem that women receive less money for the same work so the calculation would be lower if provided by female labour. In any event, it was agreed that despite the difficulties, it is imperative that unpaid care work is made visible.
- Questions were asked about where HIV/AIDS care work fitted with this conceptual framework. Was there a space for slave labour and child labour? Child labour can be accounted for in this framework, but more difficult for slave labour. The point was made that whilst it is important not to romanticize unpaid care work as being performed with benevolent, altruistic motives, one should also beware of seeing it solely as a relationship of conscription and exploitation. It is helpful to look at familial relationships as cooperative conflict relationships.
- Questions about costing and evaluating the wider impact of the quality care work provided. When people are under pressure and do the work in a hurried way, or having assistance of domestic appliances to enable greater speed with some types of work. In the economic restructuring and shifting the burden of care to the individuals in the community or subcontracting the NGO sector to provide public services, it is difficult to write the contracts in ways that ensure accountability for a service performed adequately. Also, there are enormous difficulties with monitoring the standards and quality of care. Nancy Folbre argues that socio economic pressures are making it

harder to care – unpaid or paid, Since there is enormous pressure to extract profit, to be more cost efficient, and therefore to perform tasks very quickly, invariably this is to the detriment of the quality of care.

- Policy level interventions and recommendations will be a useful outcome to address the issue of care. However, in countries where the health sector has been virtually decimated by a combination of economic restructuring and HIV/AIDS, what can realistically be achieved? This is especially the case when examining the expectation for the type of care work needed, in resource-poor environments, and when there are no resources to finance basic treatment, let alone drugs.
- There was a call for a more politicized approach to time use investigation: it should be used as a mobilising tool – involving governments at a local level, addressing allocation of public resources and expenditure, giving voice and representation to carers etc. Coalition building is very important, and should be reflected strongly in the programme proposal, especially with important stakeholders such as employers.

#### 4.2. UNIFEM Case study of HIV/AIDS and Care Economy:

“Socio-Economic Impact of HIV/AIDS in Zimbabwe – A community based study” presentation was made by Emmanuel Chirebvu, independent researcher, based in Harare. The powerpoint presentation may be made available electronically on request. The research paper itself was shared with workshop participants electronically after the workshop.

- Following the presentation, there was lively discussion and questions, including:
  - Follow-up to the study – advocacy and policy recommendations were being taken up by UN theme group. Some findings included 76% of young girls in the areas surveyed were being taken out of school to care for PLWAs and their dependents; recognition that home-based care – even with few or no resources – will be preferred and of better quality than that found in government hospitals and clinics.
  - Other areas touched upon inter-generational care dimensions; impact of high inflation and high levels of unemployment on the wages of men, and their ability to secure jobs; attendant problems of dependency on women for income operating in the informal economy. In many areas, there is a stigma about male involvement in informal economic activity, but this is changing rapidly. In reality, rather than remain in the home and rely on the incomes of women, men tend to abandon the

household when there is a trace of HIV or AIDS in the home. They feel frightened, and do not want to deal with the heavy emotional burdens of sickness and death in the family. However, usually when men get sick they return home to be cared for and die. HIV and AIDS have changed normative patterns and behavior. Women are more ready to be tested and to declare their status and to get support from their families and communities; men tend to die in silence.

- Since mainly women are responsible for agricultural activities in the household, caring for HIV patients directly affects food security in the household and the community in general
- HIV/AIDS has created a 'negative income shock'. Families that are already struggling to survive in the face of high unemployment, lack of access to social services and any form of social protection are now faced with the enormous costs associated with HIV/AIDS – tending to the sick and dying, preparing for and paying for burials, additional dependents as a result of loss of income from breadwinner infected with or having died from AIDS.
- Some coping strategies include: selling assets – e.g. livestock and other property; developing coops for market gardening; collecting wild fruit to sell in the market; girls moving to the urban areas to find 'sugar daddies' to pay for food, clothes and housing.
- Problems are that inheritance laws and customs discriminate against women, and very often the property of the deceased male will be given to his brother or another male relative. Wives are inherited along with property, and at the same time, HIV is spread.
- The stigma of AIDS inhibits families from taking in orphans and dependents of people whose family members are/were living with AIDS. In addition, the capacity of households to absorb additional dependents is fast diminishing, with fewer and fewer resources to go around.
- Traditional healers in many cases are not playing appropriate roles. They may give inappropriate advice; or may actively perpetuate the spread of AIDS through certain practices. However, they have the potential to play a critical role in prevention and treatment efforts, and in some areas are already doing this.
- Recommendation to shift from macro-level analysis to micro-level analysis and intervention in order to understand the lived experience of PLWAs. A gender sensitive role is critical.

5. Social protection and innovative financial instruments for people living with or affected by HIV/AIDS;

5.1. Using Innovative financial instruments in managing the HIV/AIDS epidemic presentation by Jim Roth, .... Of the Social Finance Unit in the ILO. The presentation is available in powerpoint format on request.

- When HIV positive workers don't have access to health insurance markets, they have no option but to be cared for by people in their households, therefore inclusion of workers with HIV/AIDS into insurance schemes would alleviate the burden of care considerably
- The reason HIV positive workers are excluded from insurance markets is because the risks of dying are high, and insurance companies are concerned about the high costs associated with this, and their viability. They calculate the cost of insurance policies on a risk assessment and projection.
- Idea of an "AIDS equalization fund" to pool risk, and developed as a public-private partnership
- Current regulatory and legislative responses need to be revisited. There is a need to lobby against over-regulation of insurance markets that discriminate against HIV positive people
- Focus of research is on formal sector workers in the public and private sector, currently receiving some employment benefits, but where workers with HIV/AIDS are excluded from health insurance
- In context of World Bank and IMF policies that encourage governments to privatize insurance schemes, it is important to challenge these discriminatory and short-sighted measures. Need to do long-term analysis of cost-benefit of making health insurance accessible to PLWAs.
- In the context of the informal sector, it is useful to examine closely the micro-insurance schemes that are being established. Even in those schemes, HIV positive people are being excluded. The ILO has begun to explore re-insurance schemes for micro health insurers – an idea for a global reinsurance fund.
- Useful to look at examples like Treatment Access Campaign in South Africa which are challenging the South African government in the Constitutional Court that current home ownership insurance legislation excludes people with HIV/AIDS, and argue that this is a denial of the basic human right to housing.
- Problem of affordability for private health insurance companies: they are able to provide for less and less of their average client's health expenses, and even those not living with HIV are finding they are paying more and more for less and less benefit.

5.2. HIV/AIDS, the Informal Economy, and Social Protection: Experiences From South Africa Paper by Cathy van der Ruit, Researcher at the

University of Natal, South Africa. The paper was commissioned for the purposes of this brainstorm workshop, but unfortunately Ms van der Ruit was not able to be present at the workshop. The paper was circulated to all participants for reference and comment, but unfortunately there was no time to discuss this in any detail in the workshop. However, several points are worthy to note from this paper for the purpose of a reflection on social protection issues for workers in the informal economy.

- Workers in the informal economy have limited access to social protection. HIV/AIDS poses a further threat to workers in the informal economy, leading to added insecurity and poverty. Micro-finance initiatives are being promoted as possible forms of social protection. However HIV/AIDS may undermine the viability of these programmes.
- Social protection becomes increasingly urgent in societies suffering the effects of the HIV/AIDS epidemic particularly for workers in the informal economy who are highly vulnerable to the multiple effects of the HIV/AIDS epidemic.
- In the absence of public and private social security poor communities are fulfilling these roles. This amounts to downloading the costs of care to the communities. Furthermore, the ability of informal networks to provide comprehensive coverage is limited. Alternatives to informal community networks are micro-finance institutions (MFIs) which are beginning to explore programmes for insurance provision.
- Arguments in favour of a role for MFIs in social protection are premised upon two factors: firstly, innovations by MFIs, using the group solidarity method, proved that the poor could be reliable debtors without credit references and collateral. Secondly, some MFIs became financially sustainable and were able to graduate to commercial service providers. Furthermore MFIs are seen to be important vehicles for women's empowerment. Micro-finance, particularly savings schemes, has played a role in assisting households in strengthening coping strategies, reducing vulnerability and supporting livelihoods. Furthermore loan provision is a central strategy in coping with crisis and unexpected expenses.
- MFIs have begun to expand their services beyond savings and credit to encompass social protection. The most popular initiatives appear to be health insurance, health care, loan insurance, and life and disability insurance.
- MFIs in Sub-Saharan Africa have introduced programmes to assist clients coping with the HIV/AIDS epidemic, and some MFIs are adjusting their products to suit the needs of their clients. Most MFIs have established loan insurance schemes, many of which are compulsory. Increasing numbers of MFIs are providing AIDS education programmes. Other products include health insurance, and life cover. However, closer scrutiny of these products shows that the benefits for HIV positive clients are limited. Life insurance schemes either exclude HIV positive clients or restrict the numbers of family members covered by the scheme. Health

insurance may cover treatment for HIV positive clients but excludes medication.

- The paper argues that HIV/AIDS is likely to undermine the sustainability of MFIs, as clients affected by the epidemic may default on the loan or may exit the programme. Furthermore there is a trade off between introducing innovative insurance schemes and attaining financial and institutional sustainability. Innovative insurance schemes are costly to implement and likely to reach smaller numbers of clients. Financial sustainability is premised upon cost effective, standardised products that may impose added costs for the client in order that the institution is able to overcome the risks of HIV/AIDS. Initiatives such as loan insurance reduces the risk for the MFIs, but heightens the costs of membership for clients and is a barrier for client participation. Therefore micro-finance may not be the most appropriate vehicle for social protection in communities experiencing high rates of HIV prevalence.
- Research findings suggest that MFIs have an important role to play in supporting client coping strategies particularly in relation to savings. However organisations should not underestimate the devastating impact that the epidemic is likely to have on institutional sustainability. Comprehensive social protection requires the involvement of a range of public and private stakeholders which are potentially better able to absorb the risks of HIV/AIDS.
- Research and policy work is needed to explore the relationship between HIV/AIDS and informal work places, and the spaces for social protection. The paper proposes some areas for further work.

#### 6. Proposed programme strategies

This was discussed in three groups, and feedback given to plenary. Each group addressed a different area of intervention for this programme: knowledge-building and research; advocacy, and technical cooperation / service provision. Set out below is a list of some of the issues raised:

##### 6.1. Knowledge building for advocacy and policy:

- Costing of care economy
- Pricing and charging for care
- Policy research on labour market opportunity cost forecasting for women
- Research on the impact of provision of ARVs and other medication for women in the care economy
- Research on discrimination against women in the access to capital market, life insurances, etc.

##### 6.2. Advocacy:

- Promotion of networking amongst all workers
- Promotion of the economic value of the care economy, strengthening of groups that can lobby for attitudes changes, etc,

- Preparation of HIV/AIDS and Care Economy awareness raising material (training kit, audiovisual materials, dissemination of studies, website, etc)
- Share case studies, examples with data and statistics
- Strategies:
  - Build capacity for dissemination of appropriate information
  - Promote networking among change agents, including ILO social partners and women's organisations
  - Strengthen groups that can lobby for change
- Some proposed activities:
  - Organise conferences and workshops
  - Develop staff skills for advocacy
  - Conduct high-level advocacy

### 6.3. Direct Action/Service Provisions:

#### *Formal economy:*

- Provide technical advice and support to employers, government, workers, organizations to develop workplace policies to reduce the burden of HIV/AIDS-related care responsibilities e.g.
- Flexible work arrangements
- Health Insurance
- Access to treatment
- Sexual harassment and sexual-based violence at work
- Research on innovative company policies and programmes which provide care-friendly workplace policies and NGO involvement (ALUCAM, Cameroon; Richards Bay Steel, South Africa)
- Pilot: One good practice example and one intervention group
- Develop regional/sub-regional policy frameworks (e.g. SADC) for supporting national policies and programmes in areas of social security and social dialogue (multi-sectoral approach involving employment and labour sector, Gender Unit, women's organizations, NGOs, and national AIDS councils)
- Support job creation in the area of HIV/AIDS-related care provision and other household responsibilities

#### *Informal Economy:*

- Build the capacity of organized informal workers' associations to address HIV/AIDS care related needs
- Build the capacity of informal workers organizations to ensure rights, social protection, income security, and voice/representation around care responsibilities (pilots)
- Develop innovative partnerships to address income security e.g. with small businesses, local governments, relevant UN agencies in the areas of agricultural production, food security, market access and infrastructure

Support governments to reallocate resources to address the care dimensions of HIV/AIDS in the context of poverty alleviation policies and programmes, such as through PRSPs, the Global Fund, Jobs for Africa, Gender Budgeting initiatives

#### 6.4. Other ideas raised in plenary discussion:

- Need for more research, statistical data on opportunity costs and replacement costs of HIV/AIDS related care
- Potential for government public works funding for job creation in the area of care provision, to be subsidized by donors and multilateral agencies
- Need to calculate benefits of care provision on economies of scale – e.g. centres where care provision is offered, child care provision, pooling of agricultural outputs for markets etc.
- Examine innovative uses of cooperatives and strategies to build on community organisation
- Need closer examination of the differences between HIV/AIDS related care work issues on public vs. private sector employment
- Need to work with gender budget initiatives and gender advocacy groups on public sector resource allocation
- Need to involve men's organisations addressing HIV/AIDS and gender issues
- Explore ways of integrating care issues and HIV/AIDS into PRSP processes
- Need to explore potential for partnerships with faith-based and other CSOs/NGOs
- Need for audit of HIV/AIDS related care studies and data
- Work as much as possible with existing data and initiatives

#### 7. **Criteria for pilots**

Reflected in overall summary report

#### 8. **Next steps:**

- ILO and UNIFEM to explore the best means of executing the programme, and sharing funds when and if provided by donors. Need to explore with ILO funding unit, COMBI and UNIFEM programme on possible scenarios.
- Pilot countries and projects to be determined on basis of set criteria
- Africa focus in the first year, but global focus. Initiatives can begin in other regions
- Once programme document has been revised, and once funding has been identified, vision-building workshop should be organised for global partners and stakeholders in this programme



- Panel to be organised for International Conference on HIV/AIDS in Barcelona 2002