

EGM/ESOR/2008/BP.4

2 October 2008

ENGLISH only

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United Nations

Division for the Advancement of Women

Expert Group Meeting on “Equal sharing of responsibilities between women and men,  
including care-giving in the context of HIV/AIDS”

United Nations Office at Geneva

6-9 October, 2008

## **Caregiving in the context of HIV/AIDS**

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*\* The views expressed in this paper are those of the authors and do not necessarily represent those of the United Nations.*

## **Caregiving in the context of HIV/AIDS**

### **Introduction**

This discussion paper was developed by UNAIDS, UNIFEM and partners at the request of the United Nations Division for the Advancement of Women as a background document for the expert panel meeting on the equal sharing of responsibilities between women and men, including caregiving in the context of HIV and AIDS to be held in Geneva, Switzerland 6 - 9 October 2008. Its purpose is to present key issues for discussion with regard to caregiving in the context of AIDS and the gender dimensions of caregiving, highlighted in paragraph 25 of the Aide Memoire prepared by the UN Division for the Advancement of Women Expert Panel Meeting

([http://www.un.org/womenwatch/daw/egm/equalsharing/egm\\_equalsharing.htm](http://www.un.org/womenwatch/daw/egm/equalsharing/egm_equalsharing.htm)). The burden of care on AIDS affected households, and in particular on women and girls, is a major concern in the AIDS-affected societies. While promoting the equal sharing of caregiving responsibilities between women and men could reduce the burden of care on women and girls, redistribution of care between members of poor households would not sufficiently alleviate the often debilitating burden of care at the household level. Such approaches must be part of broader long term national strategies to reduce the overall impact of AIDS on affected households and communities. .

### **Care work in the context of HIV and AIDS**

Community and home-based care is defined by the World Health Organisation as any form of care given to people within their homes and includes physical, psychosocial, palliative and spiritual interventions. AIDS related care is part of the wider and largely invisible care economy, including childcare, elder care, and care for the infirm, which takes place largely in the home, and which extends to the provision of care in formal healthcare settings in low resource environments, where the provision of food, daily care and transport for hospital settings is often required.

It is now well-recognised that the majority of care work due to illness takes place in the home<sup>1</sup> for a number of reasons, including the lack of a coordinated public policy addressing care needs, inadequate health infrastructure and human resources, and the preference of patients.<sup>2</sup> The vast majority of care costs and burdens are borne, therefore, by households and individuals, often those most in need, as well as by the non-governmental sector, volunteers in coordinated home-based care programmes, unpaid caregivers in the home, and sometimes by the private sector which is unaffordable to the very poor. The costs of care are largely hidden and are generally not accounted for in national statistics, nor have they been considered in the context of public health and macroeconomic policies addressing the broader care economy. Promoting the provision of care in the home may be a cost-effective strategy for governments and the private sector, but gives little consideration to the physical, emotional and economic costs to households and the caregivers<sup>3</sup> themselves who take on the additional burdens, many of whom are often poor and themselves living with HIV. Women account for two thirds of all caregivers for people living with HIV in Africa;<sup>4</sup> this is of great concern as women also comprise 70% of the world's poor and two-thirds of the world's illiterate. The impact of the burden of care is greater in resource-poor settings, particularly for rural and grassroots caregivers,<sup>5</sup> and for those that are unlinked to coordinated home-based care programmes.<sup>6</sup>

UNAIDS estimates that 33 million people are currently living with HIV, with the estimated annual number of new infections being 2.7 million.<sup>1</sup> The annual number of AIDS related deaths is 2 million. About 12 million children (under age 18) have lost one or both parents to AIDS in sub-Saharan Africa.<sup>1</sup>

HIV and AIDS related care generally refers to care for people living with HIV and AIDS who fall ill as well as care provided to children and/or families affected by HIV and AIDS. These distinct but overlapping care needs imply different strategies and tasks and many carers do both, often at the same time. This paper focuses on those caregivers who have either (or both) of these roles. For caregivers who assume the role of parent for a child, they are likely to become the sole or main providers of all the emotional, material and financial support. For adults in need of care, carers are most commonly depended upon for emotional support, physical care and nursing care.<sup>7</sup> In the context of HIV, physical care extends to bathing, eating, dressing, as well as fetching water and gardening; nursing care includes pain management, treating wounds, and supervising the taking of medication. Caregivers also spend a significant amount of time advocating with hospitals and other administrative and governmental offices to gain recognition as the primary carer for the people they care for, in order to carry out necessary administrative paperwork to cover benefits, as well as to assist families in arranging for burial fees, death certificates, and inheritance issues for spouses and children. A full time caregiver may also bear extensive financial burdens for transport, treatment, food, and anything else the patient needs. Universal access to anti-retroviral therapy (ART) has the potential to reduce the HIV related burden of care as it enables people living with HIV to live healthy and productive lives for much longer, and to remain parents. However, while access to anti-retroviral therapy has been expanding (in 2007 an estimated 3 million people globally received access to ART, representing one third of those in need globally), there are an estimated five new infections for each new person accessing treatment.<sup>8</sup> The long term impact of HIV treatment on care needs, including co-morbidities and side effects, could present future challenges on both home carers, volunteer care workers and the formal health sector.<sup>9</sup>

## **Carers and their challenges**

### ***Women***

Evidence now abounds on the unequal AIDS related care work responsibilities which are assumed disproportionately by girls and women of all ages as compared to boys and men.<sup>10 11</sup>

- In Southern Africa numerous studies reveal that two thirds of primary caregivers in households surveyed are female, one quarter of these are over 60 years of age.<sup>12</sup>
- In South Africa, a national evaluation of home based care found that 91% of caregivers were women.<sup>13</sup>
- A survey of 62 organisations, deploying a total of 2,635 volunteers in three Ugandan districts, found that 68% of volunteers were female.<sup>14</sup>
- Although the caregiving impact on women is most visible in Africa, the trend is growing across the developing world; in Thailand, two thirds of people living with HIV and AIDS are nursed at home by their parents, usually their mother.<sup>15</sup>

Older women and married women are significantly affected. Care responsibilities fall to older women because a substantial proportion of people living with HIV and AIDS move back to their communities of origin at some stage of the illness to be cared for by their parents, and women take responsibility for their grandchildren if necessary.<sup>16 i</sup> Grandmothers

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<sup>i</sup> Research undertaken by HelpAge International shows that the number of people living with HIV and AIDS in Vietnam doubled between 2002 and 2006 and more than half of those needing care were being looked after by their mothers (HelpAge International 2008 Clubs that ease the stress of caring, Ageways HIV and AIDS Issue 71) Households headed by

and older women have traditionally always had a role in the care of children and of the sick but not on the current scale: the combination of deaths of parents and other caregivers of productive age and poverty-driven migration results overall in a shortage of prime-age adults.<sup>17 ii</sup>

Married women are affected significantly because studies have shown that for married men, where care normally takes place in the family and in the home, the carer is most likely to be their wife.<sup>18 iii</sup> Men are less likely to be open about their HIV status and seek external support, even from home-based care programmes, relying on the commitment and discretion of their wives to care for them.<sup>19</sup>

A lesser percent of the care burden – though still significant share – of care work falls on younger women. And where children provide care for parents, two thirds are girls.<sup>20</sup>

The impact of care work is far-reaching. The physical labour of fetching water,<sup>iv</sup> a task which principally falls to women and girls, the strength required to lift patients to help them to the toilet or to wash them, the cooking, cleaning and farming, and the lack of resources to spend on their own medication, all can have detrimental effects on the carer's own health.<sup>21</sup> The physical and psycho-social impacts of caring on women's well-being are rarely acknowledged, as women often ignore their own health concerns.<sup>22, 23</sup> Without proper training, information and supplies, there is also the risk of exposure to communicable opportunistic infections. Fear of HIV infection can cause considerable anxiety on the part of caregivers, especially if they are not well informed about the actual risks.<sup>24</sup> Many carers are living with HIV themselves and need to take care of their own health concerns.<sup>25</sup> As public health services are downsized for the sake of cost-efficiency, norms and expectations on women's 'traditional' gender roles as housekeepers, nurturers and caregivers are reinforced.<sup>26</sup>

A significant challenge for older caregivers (both men and women) is that they are often at a time in their life when they expect to be cared for by their children, and they are neither emotionally, financially nor physically prepared to fully provide for their newly acquired dependents.<sup>27</sup> Physical ailments affect many older caregivers, including strained muscles, fatigue, arthritis, high blood pressure, diabetes, and hearing, vision and mobility problems.<sup>28</sup> Older women face age discrimination when they are considered to be beyond productive working age, impeding their income earning abilities, a situation further exacerbated for those who have lower levels of literacy and education than their male counterparts.<sup>29</sup> Women are less likely than men to receive a pension from being in the formal employment sector (except in countries like South Africa where there is a social pension). Age discrimination also occurs when older people are refused access to HIV services and information on the assumption that AIDS do not affect them. Gender discrimination sees older women

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older women in sub-Saharan Africa are twice as likely to include orphans as households headed by older men, and older women also care for more orphans than older men (Monasch 2004). 40-60 per cent of orphaned children (not living with a surviving parent) in Botswana, Malawi, Namibia, South Africa, Tanzania and Zimbabwe and are cared for by their grandmothers (UNICEF 2007 State of the World's Children). Similar statistics were found by HelpAge International in its project areas. In Tanzania approximately 40% of OVC in project sites were being cared for by older people and in Kenya, the figure rose to around 70%. In both cases older people were caring for an average of three vulnerable children (Monasch, 2004).

<sup>ii</sup> Extreme examples of this demographic change can be seen in parts of Kenya where some communities have very few middle aged adults but four to ten times the proportion of older people than the national average.

<sup>iii</sup> For example the specific dynamics of national contexts like Thailand mean that men are typically infected through commercial sex (often when still single) and only later transmit the virus to their wives.

<sup>iv</sup> It takes an estimated 24 buckets of clean water to provide every day care to a person living with HIV to wash them, clean soiled sheets and clothes, and wash dishes and prepare food (Columbia University cited in Ogden, 2006)

caregivers with often few or no rights to inheritance and property, impacting particularly on women who are widowed. While the role of older caregivers, particularly older women, has been gaining increasing recognition throughout research<sup>30</sup> and at international level,<sup>v</sup> national policies and programmes have been slower to respond to their needs.

With regard to children who are involved in caregiving, one of the main impacts is their removal from school, disrupting not only their education but also their future earning potential. Households which need to reduce expenditure and increase human resources to care for their sick members can sometimes meet both of these needs by taking someone, usually a girl, out of school. In a study of caregivers in South Africa, 20 percent of households took someone out of school.<sup>31</sup> In Swaziland, school enrolment is reported to have fallen by 36 percent due to AIDS, with girls most affected.<sup>32</sup> In most countries, children who have lost both parents are less likely to be in school than children whose parents are both still alive, although the gap is narrowing.<sup>33</sup> The long term effects are that the girl's and the household's future income earning potential is limited by lower levels of literacy and education. Their lives are further impacted, as not having had the opportunity to go to school, many young girls fall into situations or engage in behaviours that place them at risk of contracting HIV, such as transactional sex or sex work. In some cases, orphans and other vulnerable children may be forced to head households and assume responsibility for their siblings; these extremely vulnerable households are tragic expressions of social breakdown and neglect by state and civil society services.

### ***Men providing care and supporting AIDS-affected households***

While women and girls carry the majority of the burden of caring for those living with HIV and AIDS (estimates above range from 70%-90% by country context), a lesser but not insignificant number of men do provide care in the home and volunteer in home-based care programmes. There is, however, limited analysis of the contributions of men in volunteer programmes,<sup>vi</sup> in the home and in supporting women who provide care.<sup>34</sup> What is clear is that 'traditional gender norms' which result in more women and girls providing care, also create the social barriers to men and boys becoming caregivers, exacerbating the burden for women and girls.<sup>35</sup> Men and boys who provide care may be invisible and under-reported because it is socially unacceptable for them to be caregivers.<sup>36</sup>

The most commonly cited reasons for men's lack of participation in home-based care programmes are cultural and socio-economic factors.<sup>37</sup> Attitudes about "women's work" still persist widely across societies,<sup>38 39</sup> as do social expectations of men to provide economically for their families.<sup>40</sup> Strong beliefs put men are under pressure from other men as well as from women which results in re-enforcing the socially constructed gender division of labor. The lesser involvement of men in caregiving also relates to their position as the main income earner in some of families (and thus the greater opportunity cost, e.g. loss of income that would be entailed if they devoted their time to caregiving).<sup>41</sup>

- Voluntary Services Overseas (VSO) partners from Zambia stated that there are some men who would like to get involved in home-based care activities, but are afraid of

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<sup>v</sup> For example in the UNGASS commitments and Universal Access by 2010 declaration

<sup>vi</sup> Evidence on the motivations of those men who do provide care and strategies to overcome the barriers for men who do not participate is little understood. In a study of volunteering, among male care-givers, fifty one percent reported that they felt a need to provide care to the sick because there was a need to help the sick and vulnerable in the communities (Tumwine, 2007)

what other males would say, also attributing this factor to why very few Zambian males join the nursing profession.

- A study in Namibia described the ongoing beliefs in the division between men and women which results in men regarding 'light' work as work for woman while 'heavy' work is for men<sup>vii</sup>
- Female home-based care volunteers in South Africa made the following generalizations about men, despite 22% of the volunteers being male: *"Fathers can't take care of the sick; they only help out with money once in a while."* *"A man can't take care of a sick person. It is obvious the woman or mother is the one who takes care of the sick one."* *"You know males they are not that sensitive. Mothers can take care of so many things. Most males don't like taking care of sick people... women are patient and caring. Men can't be like that."*<sup>42</sup>

Some evidence, however, is emerging about men's participation and involvement in caregiving. Some men do have a role in the caregiving picture in the home context as primary personal carers.<sup>viii</sup> As well as being more likely to provide financial support<sup>43</sup> men provide instrumental help such as transportation, and help when greater physical strength is needed, such as in lifting or carrying the ill person.<sup>44</sup> Thus, while men may play a minor role in routine care, they can be of critical importance when special tasks are required. In terms of caring for children, there is little data on the role of men but one survey found that more older men than younger men take in orphaned or vulnerable children.<sup>ix</sup>

### **Clients and patients of home-based care programmes**

Perhaps interestingly men are not only less likely to be primary carers, but they are also less likely to be the recipients of formal home-based care programmes;<sup>45 46</sup> rather men are more likely to be cared for in the home by female family members. The dominance of women among beneficiaries of home-based care programmes could in part be due to the fact that women are more likely to acknowledge their status and their need for external assistance from other women in the community. Men may also be less prepared to care for wives and women in their household who are ill, leading to a need for external support from family or home-based care programmes. This, combined with the greater willingness and preparedness of female family members to care for men in their household who are ill, without accessing external home-based care support for either themselves or their male family member, leads to the larger number of women than men accessing formal home-based care programmes.

### **Current gaps in our knowledge about caregiving**

While data on organisation-based home-based care is sparse, data on the informal provision of care in the household is virtually non-existent outside of very small-scale studies.<sup>47</sup> There is little systematic data collection at national or international levels on age and sex breakdown

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<sup>vii</sup> Stereotypical attitudes about male and female caregiving are also likely to be reinforced by the experiences of men and women at different times of access to health services. For example, maternal care is considered "women's domain" and those husbands and partners who attempt to take a more active role can find themselves excluded from information and participation by the healthcare system (ICRW- FHRS Qualitative research into husbands' participation in maternal care for young wives).

<sup>viii</sup> In a survey of adults living with HIV who had returned to their parents, 15% of fathers were the primary personal caregiver (Knodel/UNAIDS 2001)

<sup>ix</sup> in Southern Africa, 24% of older male-headed households take in orphans compared to an average of 12% for all male-headed households (Monasch & Boerma, 2004)

of carers, the physical and psycho-social impact of providing care or its costs or on the impact of care giving on households.<sup>48</sup> For example, there are no UNGASS indicators for tracking progress of commitments in the implementation of the United Nations Declaration of Commitment on HIV/AIDS targets which address who is providing AIDS related care.<sup>49</sup> Gaps in our knowledge about caregiving extend to a broader lack of gender and age disaggregation of HIV related and other household data. At household survey level data needs to be collected to measure care and support needs and monitor barriers and facilitators to accessing health and other public sector services.<sup>50</sup>

## **The Costs of Care**

### *a. Financial costs*

Households already in poverty which are burdened with financial costs of care giving face the possibility of moving further into indigence. The increased financial costs related to caring for the sick ranges from costs incurred to provide immediate care (gloves, medicines, water, etc.) to financial outlays for medicines (prescribed, over the counter, from clinical therapists or traditional healers)<sup>51</sup> and user fees for accessing health care services, transportation costs involved with attending clinics, rising food costs, and others.<sup>x52xi</sup> Even with the free availability of anti-retroviral therapy, associated costs have often not declined; transport costs to health centers to obtain ART remain a key barrier, which impacts negatively on adherence,<sup>53</sup> while food costs increase to ensure the efficacy of anti-retroviral therapy.<sup>54</sup> Women face particular financial burdens in caregiving, particularly in diverting their time from other productive chores. Women produce between 60-80 percent of the food in most developing countries and, while women's employment in the informal sector and the impact on household economy is poorly documented<sup>55</sup> and excluded from macroeconomic modelling,<sup>56</sup> studies have shown that the extra responsibilities of AIDS related care can divert their labour from productive agricultural work creating further household food insecurity.<sup>57 58</sup> Households with a sick family member face the opposing pressures to work fewer hours to spend more time caring, or to work more hours to earn more money to pay for increased expenditures.<sup>xii</sup> Gender differences in employment opportunities also impact on women's caregiving responsibilities. If one of a working couple needs to spend time at home to care for a family member in need of care, the person with the most flexible working arrangement or lower income earning capacity – in both cases usually the woman – will be the person to sacrifice income earning opportunities for caregiving time.<sup>59</sup>

Furthermore, women employed in the formal sector but without the flexibility of reducing their hours manage both their paid job and their role as primary carers in the home. One study found that one in five Kenyan health workers was caring for an immediate family member living with HIV.<sup>60</sup>

Women as volunteers in home-based care programmes have to sacrifice or manage competing demands for their household's needs: farming, time with their family, especially children who need guidance with their school-assigned homework, and their own businesses.<sup>61</sup> Gender bias is found in the under recognition and low value assigned to the 'care economy' which is part of the unremunerated work performed by women. The global estimated value of unremunerated work by women is 11 trillion dollars.<sup>62</sup> The care economy including AIDS related care work in the home, is largely taken for granted in both

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<sup>x</sup> Households in Swaziland affected by HIV saw a 22% increase in health costs (Budlender 2007).

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<sup>xii</sup> In Swaziland 31% of households diverted labour to care for the sick as a result of HIV and AIDS (Budlender 2007).

governmental and non-governmental efforts to mitigate the impact of the disease.<sup>63</sup> Both the importance of this caring work, and its costs for those who undertake it, go unrecognized in national accounts, and unaccounted for in national and international HIV and AIDS policy and programming.<sup>64 65</sup>

Accessing existing external financial support is also a challenge to carers. Many households in South Africa rely on pensions as unemployment is so high.<sup>66</sup> Where social grants are available (e.g. foster care grants) access can be problematic when guardians cannot trace their dependents' remaining living parents (i.e. an absent mother or father) to obtain signatures on the required documents or lack the necessary registration documents of themselves.<sup>67</sup> Strategies to pay for medical interventions and other care costs include taking on extra work, selling assets, taking children out of school to save on school fees, and most commonly borrowing money.<sup>68 69</sup> In Thailand almost half of parents who were primary carers of someone living with AIDS borrowed money, and many never expected to get out of debt.<sup>70</sup> The financial cost to older carers is exacerbated by a loss of financial support from their adult child when they become sick, particularly in communities where there is a high co-residence rate between older parents and their children.<sup>71</sup> Economic pressures from the burden of care can lead to sexual risk taking by carers of all ages, increasing their susceptibility to HIV infection by engaging in income earning activities and survival strategies, including exchanging sex on an informal transactional basis.<sup>72 73</sup>

#### *b. Psycho-social impacts of caregiving*

The emotional stress on carers of all ages and gender can be significant. Children without adult supervision, having experienced the grief of losing their parents, face the responsibility of feeding and clothing their siblings which puts them at risk of exploitation and harm. Parents caring for numerous children of their extended families and neighbours increase their worry and anxiety. The greater responsibility exacerbates poverty as having more mouths to feed means less food for those already in the family. Some adults care for their partners and loved ones and, for those that don't return to health, experience the pain of watching them die. Many of those in caregiving roles are also themselves living with HIV; this can cause additional psycho-social trauma for the caregiver. Many grandparents, parents and other carers often find they have little time to grieve as they have to be emotionally and physically strong to support and look after the dependent children left behind.<sup>74 75</sup> The demanding nature of caring for both sick adults and for children means that carers can face social isolation.<sup>76 77</sup> For older women and men looking after grandchildren, the role of parenting does not necessarily come easy to them simply because they have been parents in the past.<sup>78</sup>

#### *c. Lack of Access to external support: information, treatment and care*

Many people living with HIV and their carers struggle without a formal diagnosis of the disease that is affecting them which means that they do not access home-based care and other related programmes that could provide much needed support.<sup>79</sup> Gender inequity in decision-making around health means that women may not be able to fully access external support either for themselves or their families because they need permission or consent from their husband.<sup>80</sup> Even where households receive external support, for example from trained home-based caregivers, the outside caregivers serve more as a complement to the household caregivers than a substitute, so the burden and information needs remain high.<sup>81</sup> The many carers that are 'unlinked' to programmes face many challenges including caring in a void of training, support from other programmes including material inputs like gloves and medication.<sup>82</sup> Older carers find it difficult to access medical care and the health system for



themselves and their dependents.<sup>83</sup> Barriers include negotiating the service, long waiting times, transportation difficulties, unhelpful staff, and inaccessible services.

#### *d. Stigma and discrimination*

Many patients ask their carers not to disclose to others the nature of their illness when it is HIV related,<sup>xiii</sup> causing further isolation for the carer and the patient. Carers themselves sometimes try to keep the status of those in their care a secret for fear of the stigma and discrimination they may suffer, while volunteers in home-based care programmes are often assumed or suspected to be HIV positive themselves.<sup>84 85</sup> With the increased availability of anti-retroviral therapy, some stigma and discrimination (and fear of discrimination) has declined but it remains quite prevalent.<sup>86 87</sup> Perceived and actual stigma means that carers fail to access the available support for those in their care (and for themselves) and miss out on important information and advice on HIV and AIDS.<sup>xiv</sup> If clients cannot be sure that their status will be kept confidential by formal healthcare workers or caregivers are mandated to disclose their client's HIV status, distrust may build between people living with HIV, caregivers and the formal health sector. This could deter people from being tested and in the long run they will develop AIDS-related illnesses resulting in communities continuing to carry the burden of care. HIV related stigma can also be found where there is limited understanding of the nature, cause and transmission of HIV: in Sukumaland in Northern Tanzania, there is widespread belief that AIDS-related deaths are caused by witchcraft. Witchcraft accusations lead to intimidation and victimisation of women, particularly older women, including physical attack and murder, destruction of property, eviction from family property and ostracism. Older men are also, albeit less frequently, subject to witchcraft allegations. The rights of children and women of all ages are violated when their property or land is claimed by other family or community members after the death of the male head of household.

### **Recommendations for reducing the burden of care on poor households and on women**

Increasing the involvement of men in care work is likely to reduce the burden on women. It may also increase the number of men who access HIV related services. However, the redistribution of care work between men and women within the household or community is unlikely to sufficiently address the profound issues of poverty, strain and hardship of caregiving on families and households. Nor is it likely to meet the ever growing gaps in services and safety nets on the part of governments associated with health sector reforms, decentralization, privatization and cuts to social spending. Caregiving must be addressed through a mix of strategies and development lenses, adapted to different social and economic contexts, in order to address the economic, social and psychological burden of caregiving on individuals, families, communities and economies. At international level, a number of governments have defined a policy framework that is required to strengthen families in the context of HIV in both Africa<sup>88</sup> and Asia.<sup>89</sup> More work to monitor, evaluate and document the implementation and impact of such broad-based strategies is required. Addressing caregiving will require a range of strategies and lenses which embrace health systems strengthening and the continuum of care, social protection and poverty reduction, promoting

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<sup>xiii</sup> Stigmatisation of people living HIV is often because of judgments made about the assumed route of transmission, be it heterosexual or same sex transmission, vertical transmission or through contaminated needles. Stigma experienced and feared by males who have sex with males remains high in Africa creating strong disincentives to reveal one's HIV positive status among (Horizons Research Summary: Implementing STI/HIV Prevention and Care Interventions for men who have sex with men in Dakar, Senegal, 2007).

<sup>xiv</sup> In Tanzania home care visitors in four research sites reported that older carers declined to be visited on a frequent basis to avoid raising suspicion in the community (HelpAge International 2004 The Cost of Love – Older People in the fight against AIDS in Tanzania).

gender equality, and increasing the knowledge and research on caregiving and its economic and social impacts.

Recommendations include:

1. *Recognise and value care work and its impact on women*

To begin to address the needs of carers, it is important that there is a recognition of who the carers are and an understanding of the services they provide.<sup>90 91</sup> Home-based care is not a cheap alternative to public health service provision, and costing this work is a necessary first step to recognizing, valuing and including unpaid AIDS care work in public health and other policy-making processes.<sup>92</sup> Policy makers must make the connections between the income and non-income dimensions of poverty, captured through human development indicators, for example by calculating how women's unpaid work helps reduce poverty and support human development. National accounts and statistics should reflect the domestic sector – including many types of unpaid activities – interpersonal services performed, and non-monetized relationships. It is critical that the hidden costs of care are made visible.<sup>93</sup> International and national commitments on care giving and women's work must incorporate indicators on care. International health policies and national AIDS programmes must incorporate an understanding of the paid and unpaid care economy into its frameworks and strategies for action, with particular focus on the caregiver.<sup>94 xv</sup> Opportunities at the national level must be created so that caregivers themselves can participate in decision-making processes to claim the work they do and recommend their own solutions to ease their burdens.

2. *Promote stronger cross-sector linkages to create a continuum of care*

The continuum of care<sup>xvi</sup> is being prioritised across sectors in countries like Cambodia,<sup>95</sup> and evidence of its increasing profile can be found in, for example, Uganda's national HIV strategy which aims to ensure a functional continuum of care between health facilities, home, community and other HIV related services.<sup>96</sup> Yet while many national frameworks recognise the disproportionate burden of care work on women and girls, the necessary accompanying policies and budgets to enable action to alleviate this burden are often absent. In addition, where policies distinguish between informal home care and coordinated programmes, home care generally receives far less attention than volunteer programmes. These two types of care are different in many respects, and policy solutions will need to differ.<sup>97</sup> The continuum of care must be comprehensive to reach people living with HIV and their carers, and it must also include care and support for caregivers. Weak health systems need investment and strategies to address accessibility, quality of services, and labour shortages and connections between facility-based and home-based care strategies need to be reinforced.

3. *Develop multi-sectoral and integrated responses to caregivers*

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<sup>xv</sup> A number of organisations have already developed specific strategies or programmes to reduce the burden of HIV and AIDS related care on women and girls: VSO-RAISA has developed a strategy for itself and its partners and made it available to be used by those tasked with advocacy for HIV and AIDS including grassroots communities and organizations, national structures and NGOs, regional and international networks and NGOs (VSO-RAISA 2007: Reducing the burden of HIV and AIDS care on women and girls, Advocacy Strategy Document 2007-2010). HelpAge International promotes key advocacy messages for policy makers to recognise and reduce the burden of care on older women (HelpAge International cited in VSO-RAISA 2007a Regional Conference Report, Challenges of care). GROOTS Kenya and the Huairou Commission have together established a "home-based care alliance" to support home carers by bringing them together providers to share knowledge, skills and resources (HelpAge International 2006; Cited in ActionAid and VSO 2008)

<sup>xvi</sup> The continuum contains a range of comprehensive services, including counseling and testing, clinical management, nursing care and community-based social support. The provision of care extends from the individual/home to the hospital, through various levels of care linked with discharge planning and referral networks, and back to the individual/home. (Osborne C. 1996. HIV/AIDS in resource-poor settings: comprehensive care across a continuum. AIDS 10 (Suppl. 3): S61–7)

Policies and programmes must look further than formal hospital-based care and community home-based care programmes which are but two aspects of a truly comprehensive AIDS care agenda. Many national AIDS strategies are sectoral and in some instances civil society is relied on to implement them.<sup>98</sup> In seeking a broader response, civil society will not be able to advance such an agenda alone. Home-based care provisions need to be supported as a part of development expenditure, acknowledging the interface with poverty reduction, health, education and sustainable development.<sup>99</sup> Although a multi-sectoral response is necessary, it is likely that the health sector will need to take the lead in initiation and coordination. The process to develop a more linked up agenda should expand the scope of HIV and AIDS policies, incorporating a wider set of public and private sector domains, e.g. social protection, employment practices and policies, key public health infrastructure (e.g. water, sanitation, and primary health care), agriculture, nutrition and housing. This expansion will have budgetary implications at international, national and local levels in terms of allocation of spending and revenues to include consideration of the needs of informal caregivers.<sup>100</sup> International donors have a role to play, making way for real progress through a range of measures, including meeting their commitments to increasing development assistance to 0.7% of GNP, granting debt relief, and reforming their own macroeconomic and trade policies to enable developing countries to achieve sustainable economic development.<sup>101</sup>

#### *4. Support carers and reduce poverty through social protection*

Distributing the burden of care is important to reduce care burden inequities on women and girls but social protection is increasingly being seen as a key element of social development policy in developing countries in supporting women of all ages and households affected by HIV and AIDS. Both cash and non-cash mechanisms can protect the most vulnerable, raise people above the poverty line, and give them a chance to support themselves.<sup>102 103 104</sup> Social protection should include employment creation and facilitate an enabling environment for entrepreneurship development. Multi-level interventions aimed at capacitating local institutional intermediary organizations can build the capacity of the project beneficiaries and their dependents.

#### *5. Increase household access to HIV related services and resources*

Access to HIV-related services (including anti-retroviral therapy, food and palliative care) and information must remain a key strategy for alleviating the burden of care on women, and for facilitating equal participation of men in caregiving. Carers still require adequate and appropriate HIV related services and information to operate effectively. This must include:

- a. strategies to promote access to services include reducing barriers to health care by removing official and unofficial charges, reducing distances to seek services, improving social service infrastructure, and rehabilitation of health facilities; and
- b. bringing into better focus the “Care” part of *Treatment and Care*. Expanding access to ART is essential; however, the emphasis on treatment has displaced some of the limited interest that previously existed in home care, while the need has yet diminished. The displacement is exacerbated by the fact that anti-retroviral therapy is perceived as keeping people healthy, and thus obviating the need for care, when there are care needs which remain and must not be neglected.<sup>105</sup> Many care giving groups report that the needs of their clients has shifted; those living longer due to ART need access to food and income generating activities.
- c. Carers at household level and in volunteer programmes need health related information and basic supplies in order to effectively care for those in need.<sup>106</sup> And care givers also need recognition of the valuable role they play in the continuum of care. Access to anti-retroviral therapy and treatment literacy must be incorporated

into the broader continuum of care so that carers also access information and support to facilitate adherence<sup>107</sup> including access to adequate food to ensure its efficacy.

- d. carers and people living with HIV must also be targeted with HIV prevention information and resources: carers so that they can protect themselves and their dependents (especially children) from future transmission, and people living with HIV so they can protect themselves and their partners from sexually transmitted infections, HIV transmission (in the case of discordant couples), re-infection (where both partners are living with HIV), and treatment-resistant HIV transmission (where one or both partners are on anti-retroviral therapy).

*6. Facilitate the greater involvement of men in caregiving roles and the equal sharing of care work between women and men*

Men's greater involvement in providing care, whether in the home or through home-based care programmes, could not only reduce the pressure on women and girls, but may also raise the numbers of men who gain help from support groups of people living with HIV (which women currently dominate in terms of numbers)<sup>108</sup> and may have spillover effects into men's accessing HIV testing and other health services. It is also a valuable part of broader gender equality strategies. Programmes and local governments are demonstrating that it is possible to increase men's involvement, while at the same time showing consideration towards women who may fear their decision making power in programmes will be forfeited.<sup>109</sup> To increase men's participation in caregiving activities, more work must be undertaken to address the concept and practice of masculinity and to influence social norms in ways that fit new socioeconomic realities.<sup>110</sup>

*7. Promote women's rights and address broader gender inequalities including employment*

It remains important to focus on empowering women to attain equality in the family,<sup>111</sup> the workplace and the community by ensuring that existing policies and commitments supporting women's rights are implemented.<sup>112</sup> Policies and programmes must address the structural causes of inequality between women and men, and focus on empowering women and girls socially and economically to help reduce their vulnerability and to attain equality<sup>113</sup> including in areas like land and inheritance rights. At national level, employment programmes can target unemployed and/or underemployed parents and caregivers. For example, South Africa's Extended Public Works Programme's social sector plan<sup>114</sup> has the potential to be scaled up with significant benefits for women.<sup>115</sup> In a wider context women must participate equally in political and formal economic spheres in addition to their work in the care economy being counted and valued.<sup>116</sup> Because unpaid care work falls outside the boundary of the formal labour market since is not recognized as having direct market value, analysis of the economy is required to understand its impact on and relevance to women.

*8. Develop policies and programmes which are informed by a full gender and ageing analysis AND*

*integrate programmes which address caregiving into National AIDS Strategies:* National AIDS plans need to incorporate a gender analysis to assess the extent to which women – as unlinked family carers and/or as volunteers in formal community home-based care programmes – have access to the resources they need to undertake their caring tasks appropriately, and to assess whether the well-being of households in which these women live is being undermined.<sup>117</sup> In addition to understanding the impact of care on women, such analyses must also pay close attention to men's motivations and vulnerabilities when designing policies.<sup>118</sup> Most countries have some mention of gender and/or women in most of their documents but in a majority of cases, the discussion of gender does not extend to care

nor to specific budgeted actions to address care needs.<sup>119</sup> The UNAIDS Inter Agency Task Team on HIV/AIDS' 2005 guidelines on gender sensitive programming in the context of HIV includes tools to inform a gender-sensitive and rights-based approach to HIV and AIDS and to enhance analysis and understanding of the gender dimensions of HIV.<sup>120</sup> These and other tools which seek to integrate gender perspectives into programming should be used to strengthen national AIDS programmes. These efforts should take a lifecycle or aging analysis as it is vital to include carers of all ages. Programme designers and policy makers must carefully consider whether interventions reinforce existing gender roles without reducing immediate needs, such as those that increase the burden on women by focusing solely on their domestic roles.<sup>121</sup> At the same time programmes and policy that focuses only on women risk emphasizing their subordinate roles instead of seeking to address gender relations and empower women, adding to the burden on women and marginalizing men.<sup>122</sup>

Little is said about the involvement in men in care work in either international or national AIDS frameworks but there are a number of notable exceptions. In at least four cases (Botswana, Tanzania, Uganda<sup>123</sup> and Swaziland<sup>124</sup>), national HIV documents suggest that men should play a greater part in care. Changes can also be seen at local government level. In Malawi, Chitipa District AIDS Coordinating Committee requires that community home-based care programmes should ensure a minimum of 40% male volunteers.<sup>125</sup> At international level documents like WHO's *Policy Framework for Community Home-Based Care in Resource-Limited Settings* need to incorporate a gender analysis to assess the extent to which women – as unlinked family carers and/or as volunteers in formal community home-based care programmes – have access to the resources they need to undertake their caring tasks appropriately, and to assess whether the well-being of households in which these women live is being undermined.<sup>126</sup>

#### *8. Promote the participation and involvement of home-based care networks and caregivers in shaping national policies and solutions*

For health systems strengthening and reform, cash transfers, greater integration of a continuum of care and national AIDS strategies to be maximally effective, networks of caregivers must participate in recommending solutions and shaping policies and programmes to ease their burdens. A formal recognition and valorization of the role caregivers play in the community and the country is a first step, along with ensuring that caregiving networks participate in and inform national AIDS strategies and programmes.

#### *10. Invest in operational research to better understand caregiving in the context of HIV and AIDS and to generate strategic information to inform programming*

As care-giving, unpaid care work, and the care economy in the context of HIV and AIDS are issues that have not been exhaustively examined, and evidence has not been systematically gathered, there are a number of areas that require further research and investigation, 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 and AIDS pandemic.
- Understanding how decentralization and privatisation within the health sector and of HIV/AIDS funding and services has affected access to care and its provision;
- Analyzing impact and trade-offs of transferring the costs of care to households, especially to the poorest households
- Assessing the potential of public works and employment programmes which focus on care-giving to reduce poverty;

- Analyzing the impact of anti-retroviral therapy provision on caregiving.

### Conclusion

In conclusion, while the burden of care in the context of AIDS and the serious gender inequalities in the delivery of care are often acknowledged, a much more systematic and multi-sectoral approach to dealing with these challenges is required. Facilitating the equal sharing of care work between women and men of all ages would have a number of benefits. At the same time equalising the burden of care will not address the fundamental impact of care on poor and vulnerable households. The impact of AIDS on women and the impact of caregiving on households must become part of global and national AIDS agendas. But to fully meet the needs of women and households affected by AIDS and poverty, a multi-sectoral approach is required which encompasses a range of support from health, social protection, material, education and rights perspectives.

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