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including care-giving in the context of HIV/AIDS”

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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.*

HIV and AIDS related care generally refers to care for people living with HIV and AIDS who fall ill as well as care provide

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.^{17 ii}

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.^{18 iii} 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.¹⁹

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.²⁰

The impact of care work is far-reaching. The physical labour of fetching water,^{iv} 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.²¹ The physical and psycho-social impacts of caring on women's well-being are rarely acknowledged, as women often ignore their own health concerns.^{22, 23} Without proper

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 research³⁰ and at international level,^v 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,

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^{vii}
- 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.*"⁴²

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.^{viii} As well as being more likely to provide financial support⁴³ men

of carers, the physical and psycho-social impact of providing care or its costs or on the impact of care giving on households.⁴⁸ For example, there are no UNGASS indicators for tracking progress of commitments in the implementation of the United Nations Declaration of

governmental and non-governmental efforts to mitigate the impact of the disease.⁶³ 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.^{64 65}

Accessing existing external financial support is also a challenge to carers. Many households in South Africa rely on pensions as unemployment is so high.⁶⁶ 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.⁶⁷ 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.^{68 69}

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

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.^{90 91} 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.⁹² 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.⁹³ 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.^{94 xv} 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^{xvi} is being prioritised across sectors in countries like Cambodia,⁹⁵ 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.⁹⁶ 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.⁹⁷ 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*

^{xv} 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

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.⁹⁸ 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.⁹⁹ 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.¹⁰⁰ International donors have a role to play, making way for real progress through a range of

into the broader continuum of care so that carers also access information and support to facilitate adherence¹⁰⁷ 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)¹⁰⁸ and may have spillover effects into men's accessing HIV testing and other health services. It is also a valuable part of broader gender

nor to specific budgeted actions to address care needs.¹¹⁹ 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.¹²⁰ 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.¹²¹ 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.¹²²

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, Uganda¹²³ and Swaziland¹²⁴), 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.¹²⁵ At international level documents like WHO's *Policy Framework for Community Home-Based Care in Resource-Limited Settings*

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- ⁸⁶ Horizons 2007: Changes in Stigma among a Cohort of People on ART: Findings from Mombasa, Kenya
⁸⁷ Ogden et al 2006
⁸⁸ UNDESA 2004: Policy Workshop on HIV/AIDS and Family Well-being, Namibia
⁸⁹ UNDESA 2005b: Policy Workshop on HIV/AIDS and Family Well-being in South and Southeast Asia, Thailand
⁹⁰ HelpAge International 2007e: Key advocacy messages: Supporting the role of older women caregivers of OVC and PLWHA
⁹¹ UNAIDS 2005a
⁹² Ogden et al 2006
⁹³ Global Coalition on Women and AIDS 2004: Reference Group Meeting *Impact of AIDS on Women's unpaid work within the household and community*
⁹⁴ Ogden et al 2006
⁹⁵ Maher 2008
⁹⁶ Budlender 2007
⁹⁷ Budlender 2007
⁹⁸ UNDESA 2004
⁹⁹ HelpAge International 2003, cited in Ogden et al 2006
¹⁰⁰ Ogden et al 2006
¹⁰¹ Ogden et al 2006

The referenced documents can be accessed via <http://plurpol.invisionzone.com/>

¹⁰² Horizons 2005b

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