



**REDUCING THE BURDEN  
OF HIV & AIDS CARE  
ON WOMEN AND GIRLS**

**VSO POLICY BRIEF**



**AIDS**  **gender**

# CONTENTS

---

EXECUTIVE SUMMARY	3
BACKGROUND	4
WHO ARE THE COMMUNITY CAREGIVERS?	7
THE IMPACT ON WOMEN AND GIRLS IS UNSUSTAINABLE	9
POLICY AND PRACTICE MUST CHANGE TO REDUCE THE BURDEN ON WOMEN AND GIRLS	11
POLICY ACCOUNTABILITY: HOLDING GOVERNMENTS AND INTERNATIONAL INSTITUTIONS TO ACCOUNT	12
VSO BELIEVES THE BURDEN OF CARE ON WOMEN AND GIRLS CAN BE REDUCED THROUGH THREE KEY CHANGES	14
VSO'S RESPONSE TO THE NEED TO REDUCE THE BURDEN OF CARE	18
ACT NOW! ALL STAKEHOLDERS HAVE A ROLE TO PLAY	20

**“THE BURDEN OF HIV & AIDS CARE HAS DEHUMANISED WOMEN, IT HAS FEMINISED POVERTY AND TURNED WOMEN INTO WORK HORSES IN THE NAME OF VOLUNTEERING AND CARING FOR THE COMMUNITY.”<sup>1</sup>**

**AUGUSTINE CHELLA**  
VSO Programme  
Manager, Zambia



Lomanzi Phiri, a community caregiver at VK Home-Based Care in Zambia, with community members. See page 18 for more information about Lomanzi Phiri.

1 Interview at the VSO Panel Discussion, Reducing the Burden of HIV & AIDS Care on Women and Girls, March 2006, London.

## EXECUTIVE SUMMARY

---

This policy brief builds on VSO's earlier work, *Gendering AIDS: women, men, empowerment, mobilisation*,<sup>2</sup> and highlights the crisis in delivering equitable health care for people living with HIV & AIDS, and the overwhelming burden it places on women and girls; it identifies changes that VSO is advocating for and provides recommendations to key stakeholders for policy and programme change.

VSO believes that community and home based care<sup>3</sup> is an important and appropriate patient supported approach to care, indeed, many people prefer to be cared for in their home and communities. However, VSO believes that the caregiver has a right to be **valued, supported and receive appropriate compensation** and the patient has a right to **care of a high quality**.

Currently community and home based care, delivered with little support from the public health system, is the key response to the HIV & AIDS pandemic globally. A report in 2004 showed that 90% of care for people living with AIDS takes place in the home.<sup>4</sup> This care is provided by community caregivers who are predominantly women and girls, and are usually **unpaid, unsupported and unrecognised**.

VSO recognises that the increasing demands on communities, overwhelmingly women and girls, to provide community and home based care is as a result of a complex interaction of factors including: gender inequality; traditionally gendered roles; weak public health systems; health care worker shortages and migration; insufficient national and donor funds; weak social security systems; poverty and structural adjustment policies of earlier decades that reduced the public sector mandate and capacity. We are calling for a comprehensive response to the pandemic that recognises the impact of HIV & AIDS on women and girls.

We believe that a comprehensive, sustainable response must include: **good standards of care for patients; recognising the role of community caregivers; appropriate standards of support for caregivers; providing the necessary equipment** e.g. home based care kits and medicines; **fair financial support**; and **on-going training**.

VSO further believes that delivering this comprehensive, sustainable response in an equitable manner **requires reducing the burden of HIV & AIDS care on women and girls**. To this end VSO is calling on the international community, national governments and civil society to deliver policy and programme changes that:

- Recognise and support female community caregivers;
- Ensure the greater involvement of males in delivering community and home based care;
- Strengthen the public health systems; and
- Meaningfully involve people living with HIV & AIDS as caregivers, patients and key stakeholders.

2 VSO, 2003, *Gendering AIDS: women, men, empowerment, mobilisation*.

3 The World Health Organisation (WHO) defines community and home based care as any form of care given to sick people within their homes and includes physical, psychosocial, palliative and spiritual interventions.

4 UNAIDS, 2004, 4th Global AIDS Report, p118.

## BACKGROUND

---

While HIV & AIDS prevalence levels continue to grow globally, with 40.3 million people living with HIV & AIDS in 2005, so the need for care and support escalates. 6.5 million people living with AIDS currently need antiretroviral treatment<sup>5</sup>, and many more need treatment for opportunistic infections, palliative care, general nursing care and emotional support. As public health systems in most developing countries do not have the capacity to provide the necessary care and support, most people living with HIV & AIDS turn through necessity to family, neighbours and friends for care.

These family members, neighbours and friends are overwhelmingly women and girls (who are often children and grandmothers), and they undertake this role again through necessity. VSO believes that placing this burden of care on women and girls without recognition or support is both unacceptable and unsustainable. This policy brief will outline why women and girls carry the burden of care, the impact of this burden on them and the policy and programme changes that VSO believes are needed to reduce this burden.

### GENDER INEQUALITY DRIVES THE HIV & AIDS PANDEMIC

It is the inequalities between women and men that are driving the global HIV & AIDS pandemic, and in turn, this pandemic is exacerbating existing gender inequalities. It is **women who are particularly vulnerable**, 57% of people living with HIV & AIDS in Sub-Saharan Africa are female.<sup>6</sup> This is due to a number of factors including: low socio-economic status; gender based violence; unequal access to property and inheritance rights; lack of basic rights; unequal access to prevention and health care and higher biological risk. As Stephen Lewis<sup>7</sup> illustrates, HIV & AIDS in Africa has a Female Face, and this female face will be eradicated from Africa if we do not respond adequately.<sup>8</sup> But it is not only Africa where women are increasingly vulnerable, globally the number of women living with HIV & AIDS is growing rapidly, in South and South East Asia 26% of infections (1.9 million) are among women.<sup>9</sup>

At the same time it is **women and girls who carry the burden of caring for those living with HIV & AIDS**, again as a result of gender inequalities. HIV & AIDS has brought an increased need for community and home based care. Due to 'traditional gender norms' and unequal relations it is the women and girls in the communities who have become caregivers, whilst often needing care themselves, and possibly being HIV positive. These 'traditional gender norms' also provide social barriers to men and boys becoming caregivers, exacerbating the burden for women and girls. Many women and girls have left work (both formal and informal) and school to provide this care, and most have taken on this role in addition to their existing reproductive and productive roles.

Furthermore, while there is growing commitment to the greater involvement of people living with HIV & AIDS (GIPA), meaningful involvement of people living with HIV & AIDS is still far from a reality. This means that women living with HIV & AIDS, as both patients and caregivers, are further excluded from involvement in formulating and implementing policies and programmes.

5 Avert <http://www.avert.org/aidstarget.htm>, this figure is valid as at the end of 2005.

6 UNAIDS, 2005, AIDS Epidemic Update 2005, p4.

7 Stephen Lewis is the UN Special Envoy for HIV & AIDS in Africa.

8 Text of a speech delivered at the University of Pennsylvania's Summit on Global Issues in Women's Health, 2005.

9 UNAIDS, 2005, AIDS Epidemic Update 2005, p4.

## WEAK PUBLIC HEALTH SYSTEMS

Many public health systems in developing countries are weak and the HIV & AIDS pandemic has brought an already simmering crisis to the boil. One study showed that less than 14% of home based care services for people sick with AIDS-related illness were supported by the public health system.<sup>10</sup>

We are seeing a decline in numbers of health care workers (through illness, migration, career changes and fewer choosing to enter the health profession), and poor conditions and opportunities for remaining health care workers. Inadequate supply and distribution of medicines; weak management systems and insufficient infrastructure of clinics, hospices, laboratories and hospitals are also commonplace. Globally we need 4 million new health care workers, 1 million of whom are needed in Africa alone,<sup>11</sup> however we are not training enough to meet this need. Furthermore, user fees create barriers to available health care.

Public health systems are failing to deliver citizens' right to health, and as a result women and girls are responding to this need, and filling the vacuum.

## COMMUNITY AND HOME BASED CARE IN RESPONSE TO HIV & AIDS

Community and home based care is defined by the World Health Organisation (WHO) as any form of care given to sick people within their homes and includes physical, psychosocial, palliative and spiritual interventions. As already noted, community and home based care has become the key response to the pandemic, and many people report that they prefer to be cared for in their home and communities, indeed a study in Zambia showed that 90% of interviewees prefer home based care.<sup>12</sup> However, this level of unrecognised and unsupported community and home based care is unsustainable.

Although this burden is currently more significant in Africa, this trend is growing across the developing world, as can be seen by figures that show that "...in Thailand two-thirds of all adults with AIDS related illnesses are nursed at home by parents."<sup>13</sup> If gender inequalities and the burden of community and home based care are not addressed comprehensively in Asia now, women and girls are likely to carry the unsustainable burden of care as the pandemic escalates. VSO's Policy Paper, *Gendering AIDS* notes that as the pandemic grows, so will the need for community and home based care, and this will continue to fall on women and girls. Therefore even where the burden of caregiving is **not yet overwhelming** we are **advocating for addressing the crisis of inadequate public health care, and gender inequalities now to avoid women and girls carrying this unacceptable and unsustainable burden in all regions in the future.** *Gendering AIDS* states that: "VSO partner organisations in India and Cambodia warn that policy-makers in their countries need to deal with this now as the epidemic progresses to the stage where people are becoming ill."<sup>14</sup>

Among many governments and communities today home based care is perceived as 'a cost effective response' to the crisis because it is based on the unrecognised, under-valued and frequently unpaid work of women and girls. This is **not cost effective - this is exploitation of unpaid labour.** This exploitation is possible as care work is seen as women's work, and globally women's labour has less recognition and value.

"There is very little that is natural about women's work in general or their caring work in particular...Women's caring can be understood only within unequal relationships, structures and the processes that help create women as carers

10 USAID/UNAIDS/WHO/UNICEF/ Policy Project study, 2003, in International HIV/AIDS Alliance, 2006, Universal Access to Treatment, Care and Prevention by 2010: What does it mean for civil society?

11 Hilary Benn, Secretary of State for International Development, 2006, Speech at London School of Hygiene and Tropical Medicine.

12 Action Aid, 2001, Under the Mupundu Tree, p11.

13 Paul, Godfred, 2006, Cost of Care, HelpAge International Presentation.

14 VSO, 2003, Gendering AIDS: women, men, empowerment, mobilisation p34 .

and undervalue this caring work. Many women who do provide care...may not even see this as care because it is so much a part of their daily lives."<sup>15</sup>

It is important to note that while women and girls undertake the vast majority of care, men and boys are beginning to take on some of these responsibilities; we are slowly seeing an increasing number of men and boys who are providing care. VSO acknowledges and commends these boys and men, however, there is still a significant number who do not engage in caregiving roles. We need to encourage more male involvement through developing strategies that create an enabling environment generating opportunities for men and boys to provide care.

Furthermore, a lot of the unspoken choices about **who** provides care and **where** it is provided, in terms of the state versus the community, has been driven by the impacts over the last few decades of structural adjustment policies. These policies limited public sector spending, thereby placing more expectations and demands on communities. These policies forced communities to provide services that states were no longer able to provide, and as these were 'traditionally' female roles, they fell to women and girls. The HIV & AIDS crisis has bought this underlying problem to an unmanageable point.

It is important to acknowledge that these female community caregivers often receive no or inadequate training, and minimal support which significantly affects the standard of care that the sick receive. Not only does this burden have an impact on the community caregivers, but also on those receiving care.

### LACK OF APPROPRIATE ACTION BY THE GLOBAL COMMUNITY AND GOVERNMENTS

The global community and most national governments have failed to respond appropriately to this crisis. The global community has not provided sufficient funding to address either the health care crisis or inequalities between men and women. Furthermore, they have failed to generate an important debate and discussion on these issues, or to develop appropriate policy and programme responses. Indeed many of the conditionalities introduced by donors in the last few decades have fuelled the health care crisis by reducing public sector mandate and capacity. Furthermore, in some instances, they may have unwittingly increased the burden on female community caregivers. They have also failed to meaningfully involve people living with HIV & AIDS as caregivers and patients, and as key stakeholders when developing policy and programmes.

The Alma Ata Declaration (1978)<sup>16</sup> affirms health as a basic human right, and yet many governments in developing countries are not meeting this obligation and are failing to provide adequate health care. Furthermore, African Heads of State agreed in 2001 to allocate 15% of national budgets to health<sup>17</sup> and this target has not been met either. In some cases this is as a result of factors such as external conditionalities limiting public sector spending and expansion, and the burden of debt repayments. VSO recognises that some governments are genuinely committed to providing universal access to free health care. However, VSO also believes that many governments have failed to take adequate action that was within their means. It appears that many governments have been content to shift the burden of care to communities, particularly women and girls, essentially reneging on their roles as duty bearers in providing citizens' rights to health care. As a result the women and girls who provide community and home based care are subsidising the state, while being denied their right to health and appropriate compensation.

15 Zoll, Miriam, 2005, Securing Orphan Access to Education, p29.

16 The Alma Ata Declaration (1978) was a ground-breaking declaration sponsored by WHO and UNICEF and arose from observations of failings in health care systems. It affirms health as a basic right.

17 Agreed at the African Heads of State meeting in Abuja, 2001.

## WHO ARE THE COMMUNITY CAREGIVERS?

---

Community caregivers include **all people in the homes and communities who are responding to the health crisis and caring for the sick and dying**. Many terms are used to describe community caregivers, and they tend to be very context specific. Commonly they include: female primary caregivers (a patient's primary caregiver, usually family – grandmother, mother, sister, wife or community members), community nurses and health workers.

Some are referred to as 'community volunteers' as they are volunteering, and are not in paid employment, however, others are working through organisations or the government. Some are formally recognised and perhaps supported, compensated or remunerated by an organisation or the state, while many others are simply caring for family and neighbours with no organisational support, compensation or remuneration. UNAIDS refers to 'informal volunteers' as friends and neighbours who care for sick people they know out of a sense of love or duty. 'Formal volunteers' are recognised as those who have been recruited, and supervised by an organisation.<sup>18</sup> At VSO, we use community caregiver as a term that reflects all of the above.

A significant number of caregivers are grandparents. Research by HelpAge International shows that among older caregivers, it is the grandmothers, rather than the grandfathers, who tend to provide the care. At the opposite end of the spectrum we are seeing a significant number of children providing care. A UNAIDS report estimated that the least recognised caregivers were the children, when one parent dies there is frequently no one else to care for siblings and the second parent (where there were two parents).<sup>19</sup> Both groups of caregivers are especially vulnerable as they are not in the traditional income earning age bracket, and are frequently not protected by policies or support programmes, as they are often 'invisible' to authorities. In addition, while they can be excellent providers of love and support, they are often frail or simply young and inexperienced; and usually cannot provide adequate medical care. Furthermore, these groups are often not the targets of information sharing, further disempowering them. This burden means that many grandmothers and children are caregivers without the necessary skills and support, and at the same time they are having their 'retirement' years and their childhood stolen from them.

---

"Women don't only bear the burden of HIV infection, they also bear the burden of HIV care. Grandmothers are looking after their children. Women are caring for their dying husbands. Children are looking after dying parents and surviving siblings." NELSON MANDELA<sup>20</sup>

---

18 UNAIDS, 2000, Caring for Carers, Case Study.

19 ibid.

20 Nelson Mandela, 46664 HIV & AIDS Awareness Concert, 2005.

### THE COMMUNITY CAREGIVERS ARE WOMEN AND GIRLS

- Two thirds of primary caregivers in households surveyed in Southern Africa are female, one quarter of these are over 60 years of age.<sup>21</sup>
- A South African national evaluation of home based care found 91% of caregivers were women.<sup>22</sup>
- In another South African study only 1 out of 21 of the primary caregivers was male.<sup>23</sup>
- 36 of 38 volunteers working for a home based care programme in the Midlands Province of Zimbabwe were women.<sup>24</sup>
- In Thailand elderly mothers serve as the primary caregivers for a large proportion of people living with HIV & AIDS.<sup>25</sup>

However, we are beginning to see an increase in male involvement in some communities. For example, Padare, Men's Forum on Gender, a VSO partner in Zimbabwe, offers an excellent example of a community based organisation that supports men to provide home based care, in 2005 they trained 80 male community caregivers.

21 UNAIDS, 2004, Facing the Future Together, p38.

22 Southern Africa Partnership Programme, 2005, Impact of Home Based Care on Women & Girls in Southern Africa, p6.

23 Ibid.

24 Ibid.

25 <http://www.eldis.org/ct/search/disp/docdisplay.cfm?doc=DOC9680&resource=f1>



## THE IMPACT ON WOMEN AND GIRLS IS UNSUSTAINABLE

---

### LOST OPPORTUNITIES AND INCOME

Women and girls pay a high price in lost opportunities, they will never have equal choices in the family, community or workplace as long as they are carrying almost complete responsibility for caring for people living with HIV & AIDS.

Their caring role means many women have to leave or regularly stay away from the **workplace** (a study in South Africa showed that of 312 households 40% had to take time off from work to care for the ill),<sup>26</sup> and many of their **income generating activities** suffer, resulting in families being pushed further into poverty. It is important to remember that women are often the agricultural producers in the family and this productive capacity is often lost when women and girls become community caregivers. They have less time **available to care for their own family**. Girls often **leave school** to care for parents and siblings. A study in Zimbabwe showed that 'volunteer caregivers' provided between 2.5-3.5 hours of care per day, highlighting a significant impact on caregivers.<sup>27</sup>

### PHYSICAL AND PSYCHOSOCIAL EFFECTS

In addition to lost opportunities, many of the caregivers experience physical and psychosocial effects including stress, burnout and exhaustion, which affect the individual and her family's well-being. Many caregivers suffer from the stressful nature of the work - which includes caring for dying people and orphans - with little, if any equipment, supplies or support mechanisms. In addition, the frequent lack of training means patients often receive a poor standard of care, and this exacerbates the caregivers' stress. Studies show that "home based carers experience considerably more stress and distress than medical carers, in the absence of adequate training, mentoring and support."<sup>28</sup> Inadequate training also places caregivers at greater risk of becoming infected themselves.

Furthermore, many community caregivers experience stigma as a result of working with people living with HIV & AIDS and this adds to their stress and burden. As Jennifer Gatsi Mallet from the International Community of Women Living with HIV/AIDS states:

---

"...much of the stress experienced by caregivers is in the nature of the work itself - the fact that they are working with largely incurable conditions that kills mainly young people and is heavily stigmatised causes terrible suffering."<sup>29</sup>

---

Occasionally, because of this stigma the patient is cared for 'secretly' and this adds to the caregiver's burden as s/he cannot be identified, trained or supported. Furthermore, when men provide care, due to the stigma associated with HIV & AIDS and the perception that caregiving is a female role, they are sometimes assumed to be HIV positive themselves.

26 Southern Africa Partnership Programme, 2005, Impact of Home Based Care on women & Girls in Southern Africa, p 26.

27 Ibid.

28 Campbell, Cathy, 2004, Creating Contexts for Effective Home Based Care of People Living with HIV/AIDS p4.

29 Jennifer Gatsi Mallet, at the VSO Panel Discussion, Reducing the Burden of HIV & AIDS Care on Women and Girls, London.

## UNIVERSAL ACCESS TO PREVENTION, CARE, SUPPORT AND TREATMENT BY 2010

In the current climate of growing global commitment to achieve universal access to prevention, care, support and treatment, we need to reflect on what this might mean for the burden on women and girls, especially in terms of the roll out of treatment, and the substantive health care worker needs associated with this. Will this roll out be a key factor in addressing their burden or will it increase the burden? VSO believes that unless we tackle the existing burden of care, treatment roll out **will increase the burden of care on women and girls**; as people on treatment will need care, treatment management, support to ensure adherence, peer support etc - all of which are 'traditionally female roles'. VSO believes it is imperative that all stakeholders are mindful of the existing burden on women and girls, we must ensure that our strategies to reach universal access do not exacerbate this burden. In developing policy and designing programmes we must recognise the impact of gender inequality and consciously address it. We must recognise that it is unsustainable to try to achieve universal access through continuing to exploit women's unpaid labour.

## POLICY AND PRACTICE MUST CHANGE TO REDUCE THE BURDEN ON WOMEN AND GIRLS

---

VSO believes that to effectively address the HIV & AIDS pandemic and the burden of care on women and girls, gender inequalities must be placed at the heart of all our policy and programme responses. Failure to meaningfully address these inequalities will result in inadequate responses to HIV & AIDS.

In order to meet the global commitment of universal access to prevention, care, support and treatment by 2010, while ensuring the burden of care on women and girls is reduced, VSO believes we need to provide comprehensive community and home based care that is based on:

- Good standards of care for patients;
- Recognising the role of community caregivers;
- Appropriate standards of support for community caregivers;
- Providing necessary equipment e.g. home based care kits and medicines;
- Fair financial support; and
- On-going training.

VSO further believes that a gendered approach to mitigating the impact of HIV & AIDS requires that policy and programme interventions tackle reducing the burden of care in a comprehensive way. We call on the international community, governments and civil society to:

- Address the **immediate burden facing women and girls** as community caregivers within homes and communities;
- 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;
- Increase the constructive **involvement of men and boys** in delivering community and home based care; and
- **Meaningfully involve people living with HIV & AIDS** as caregivers, patients and key stakeholders when developing policies and programmes.

## POLICY ACCOUNTABILITY: HOLDING GOVERNMENTS AND INTERNATIONAL INSTITUTIONS TO ACCOUNT

---

Meaningfully redressing the unequal burden on women and girls requires policy change, and where strong policies exist governments, as duty bearers, and international institutions must be held to account for ensuring meaningful implementation. Key policies operate at multiple levels, from local to international, and may be in the form of: declarations, commitments, conventions, charters, guidelines, National HIV & AIDS Plans or Ministerial Plans.

Many existing policies could be effectively used to realise a reduction of this burden and change women's lives positively, but most are not being implemented and are therefore meaningless. At the same time, there are also many significant policy gaps where reform and change is needed. Nonetheless, we do have significant opportunities to hold governments and international institutions to account. The Africa Common Position to The United Nations General Assembly Special Session on HIV & AIDS (UNGASS) (2006), the G8 Communiqué (2005), the UNGASS Declaration of Commitment (2001) and the (UNGASS Review) Political Declaration (2006) all provide **clear targets against which governments and international institutions must deliver and be accountable**. Below we highlight the key targets that were set. In addition there are many other commitments in each document that are strong and demand accountability:

### AFRICA'S COMMON POSITION TO UNGASS, ABUJA (2006)

Commits to "adopting gender-centered approaches (in their HIV & AIDS responses) in order to address the needs of women and girls" and by 2010 "at least 80% of those in need...will have access to HIV/AIDS treatment...as well as care and support."<sup>30</sup>

### G8 - GLENEAGLES COMMUNIQUÉ (2005)

Commits to "develop and implement a package for HIV prevention, treatment and care" and to "as close as possible provide universal access for all who need it by 2010" (paragraph 18d).

### UNGASS DECLARATION OF COMMITMENT (2001) AND THE POLITICAL DECLARATION (2006)

Commits to "By 2005, develop and make significant progress in implementing comprehensive care strategies to: strengthen family and community-based care, including that provided by the informal sector, and health-care systems (2001, paragraph 56)." And "By 2003...review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers, and in families affected by HIV/AIDS, and address their special needs; and adjust and adapt economic and social development policies, including social protection policies, to address the impact of HIV/AIDS...(2001, paragraph 68)."

The Political Declaration (2006) committed to expanding the coverage of universal access "...towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010."

<sup>30</sup> African Union, June 2006, Africa's Common Position to the UNGASS on HIV/AIDS, Abuja.

## ADDRESSING THE POLICY GAPS - ADOPT AND IMPLEMENT A CHARTER TO RECOGNISE COMMUNITY CAREGIVERS

Despite these commitments and targets, a review of existing policies reveals a significant policy gap at international and national levels, in terms of recognising and supporting the rights of female community caregivers. The UN Global Coalition on Women and HIV & AIDS report in 2004 was the first call for a Volunteer Charter to address the burden of care on the community, and in particular on women. The report called for a charter that not only respects community caregivers, but also standardises working hours, and introduces remuneration, psychosocial support and other tangible protections.<sup>31</sup> In September 2004 a survey was undertaken with 54 organisations, surveying approximately 20,000 'volunteers', the key findings were that 'volunteers' were over-worked, and under-recognised.

Two years later we have still not seen any meaningful progress in recognising the rights of this unpaid, unrecognised female labour. VSO believes that a charter of such a nature, whether adopted internationally or at national level, could be **key in providing a policy framework** that recognises and addresses the crisis, and creates a policy environment that can be used to mobilise resources and interest and to deliver change on the ground.

31 UNAIDS, 2004, Facing the Future Together, p19.

## VSO BELIEVES THE BURDEN OF CARE ON WOMEN AND GIRLS CAN BE REDUCED THROUGH THREE KEY CHANGES

---

As outlined earlier VSO believes that comprehensive change, based on addressing gender inequalities, is needed to reduce the burden of HIV & AIDS care on women and girls, below we outline the three changes that must occur immediately. These are:

- 1) Recognise and support community caregivers;
- 2) Greater involvement of men and boys in delivering home and community based care; and
- 3) Strengthening public health systems.

### 1 RECOGNISE AND SUPPORT COMMUNITY CAREGIVERS

VSO is calling for the **rights of community caregivers to be recognised and supported**. Many declarations, National AIDS Plans, standards of care guidelines and the WHO do not fully recognise these key health care workers. Full recognition of community caregivers is vital to ensuring their rights are enshrined and then protected. We are calling on the international community and governments to adopt and implement a Charter for Community Caregivers that will recognise and then realise their rights. As mentioned above, the UN Global Coalition on Women and HIV & AIDS report has supported this call in 2004, but it has not been taken forward.<sup>32</sup>

We are calling for **financial support and/or compensation for their labour**, this could be through reimbursements, stipends, salaries or improved social protection mechanisms such as: pensions, child support grants, or cash transfers. This should particularly target women, and older and child caregivers. Many developed countries have social protection mechanisms and these should be available to developing countries. We are also calling for **improved support** for community caregivers, including support in the form of: psychosocial support (care for the caregivers); ongoing training; supervision and managerial support; appropriate equipment e.g. home-based care kits and medicines; compensation for expenses e.g. travel costs; incentives e.g. food parcels, uniforms, bicycles; and small grants.

In addition, we need to support female community caregivers holistically through **strengthening and protecting the rights of women to land, property, water, credit and incomes**. Most community caregivers undertake some form of agricultural work as a way to gain income and support their families. However, when their husbands or partners die they are often unable to attain ownership or continue using the land. VSO is also calling for increased access to land, inheritance rights, credit and income generating activities for community caregivers.

It is important that these responses **recognise the particular needs of older and child caregivers**. In addition to the above calls, grandmothers and child caregivers must be explicitly acknowledged in policies and standard of care guidelines, and their particular needs must be recognised. For older caregivers this includes: reduced energy and stamina, poverty levels, literacy challenges, and poorer health.<sup>33</sup> For child caregivers education systems need to offer flexible schooling options that recognise their additional burden, and they need psychosocial support that recognises their particular needs as child caregivers. For both older and child care givers there must be improved access to pensions and child support grants.

Finally, we recognise that there are a few policies that address these concerns, but as discussed above, in many instances these are not translating into meaningful

<sup>32</sup> UNAIDS, 2004, Facing the Future Together, p19.

<sup>33</sup> HelpAge International, 2005, Valuing Older Women Carers.

change on the ground. Therefore where policies that recognise and support community caregivers already exist e.g. the South African social assistance system, **we must build awareness** amongst community caregivers of their **rights to access such support**, and ensure people are enabled to access them.

### WHAT IS FAIR FINANCIAL SUPPORT?

VSO believes that fair financial support could be realised through a number of different mechanisms. These could include compensation for expenses incurred in being a caregiver, stipends or allowances, social protection or salaries/remuneration. Decisions by governments, civil society and the international community, about what financial support to offer, are likely to be influenced by a number of factors including: affordability; and ideological considerations (including whether care giving work should be paid as work, or merely compensated for expenses incurred).

As VSO we call for fair and just financial support to community caregivers. We recognise that financial support can be applied differently in different contexts, however, we call on all stakeholders to **adopt a minimum standard that no one should be poorer as a result of being a caregiver** (as many female caregivers currently are), and **no one should be exploited by the work they do**. We support the growing interest in social protection mechanisms e.g. pensions and cash transfers, as a key poverty reduction strategy that has shown, if applied properly, can have significant benefits for women and can be a key intervention to support community caregivers. We urge policy makers to adopt and implement policies to ensure that all community caregivers receive fair financial support.

### SOCIAL PROTECTION

The term 'social protection' can be used to describe a range of public, private or informal interventions to reduce vulnerability and risk faced by the poor. These interventions can be described under terms such as social security, social assistance, safety nets and social policy. Such interventions include, but are not limited to: cash transfers, social pensions, and cash or food for work.

Social protection as a poverty reduction strategy has been gaining more attention and support in the last few years, the Commission for Africa Report (2005) the UNAIDS Report on the Global AIDS Epidemic (2006), DfID, and the International Labor Organisation are increasingly supporting this call. A recent DfID Briefing on a project in Zambia noted: "Social transfers can have an immediate impact on hunger and poverty, and a wider impact on the poor accessing health and education services... They should be considered alongside a range of policy options for tackling poverty...It is often assumed that national social transfer programmes in very poor countries are unaffordable but, increasingly this view is being challenged."<sup>34</sup>

When there are limited formal social protection mechanisms, or when the state withdraws from provision, more of the responsibility for the provision of social protection and care falls on the family and community - and this means primarily on women. Therefore, a gender analysis of social protection is needed to ensure not only that women and men benefit from social policy, but also to maximise its efficiency. The design of social protection must include the needs of women and men for support and

<sup>34</sup> DfID Briefing, November 2005, Can low-income countries in Africa afford social transfers? p1.

control over their lives and to recognise how changing patterns of work and employment affect women's and men's access to social protection. Social protection needs to understand how state withdrawal from health, welfare and education services differentially affects the responsibilities of women and men, in both paid and unpaid work, and realise the intersection of gender with issues such as class, race and ethnicity.

**Unconditional cash transfers have been shown to address women's empowerment and economic needs.** When older women receive the money directly, it increases their self-esteem and empowerment; the money which goes to women is spent 'better' than that which goes to men; with positive overspill effects on household nutrition, and children's school attendance.

Extracted from Eldis

[http://www.eldis.org/gender/socialprotection\\_genderdimensions.htm](http://www.eldis.org/gender/socialprotection_genderdimensions.htm)

## 2 THE BURDEN SHOULD BE SHARED WITH MEN AND BOYS, THROUGH THEIR GREATER INVOLVEMENT AND BY CHALLENGING SOCIAL BARRIERS TO MEN BEING COMMUNITY CAREGIVERS

The **greater involvement of men and boys** in delivering community and home based care is a crucial response in alleviating the burden on women and girls. The increased involvement of men will mean 'more hands to do the work' and will challenge gender norms that are fuelling inequalities. Additionally, a number of male patients report anecdotally that they prefer being cared for by someone of the same sex, this is largely driven by the personal nature of the care e.g. bathing and discussions about sexual practices, condom use etc. Many males enthusiastically welcome the idea of male community caregivers.

VSO recognises that there are challenges to creating an enabling environment where significant numbers of men can share the burden, but we believe that while the change may be slow, it is possible. The work must begin with political leadership and programmes that lead to **attitude and behaviour change about male caregivers**. We need to **challenge social norms**, by encouraging community and traditional leaders to role-model 'different behaviour' and support programmes that challenge stereotypes about male and female behaviour. In addition we need to work with men and boys in their everyday lives to challenge gender norms that inhibit them from being caregivers. It is also important to **work with young children to support behaviour change**, we need to empower girls and we need to raise awareness and responsibility among boys.

We recognise that a small proportion of **men are involved in caregiving**, sometimes through necessity, and sometimes through a sense of commitment, and this number is growing. While some remain committed and become excellent caregivers, others do not continue in this role for long ...most times they get tired of the job, or have to go back to work, so then they'll call their mothers from the farm. But that's only when things get bad - otherwise they just get on with it."<sup>35</sup> Furthermore, it is important to recognise that there may be **risks in engaging men** as they may dominate leadership positions, or perpetuate gender stereotypes by only performing traditionally male roles e.g. driving patients to health facilities or lifting them. However, such potential risks do not always play out, and are not a reason to avoid involving men, we need to be aware of the risks and set mechanisms in place to manage them.



Challenging behaviour and attitudes is key in **addressing the structural inequalities between women and men** - this will create an **enabling environment** for behaviour change. But this needs to be mirrored and/or lead by policy change. Many of the current policies, standard of care and support guidelines and National AIDS Plans do not actively support the involvement of men, and these need to be reformed. Standards of care and support guidelines should include **the right of a male patient to be cared for by a male caregiver**, and **address the specific needs of male caregivers**. This would contribute to creating an expectation among patients for male caregivers, and by addressing male caregivers' specific needs would also help to unblock constraints to male involvement. In addition **core indicators for progress** as set by UNAIDS, WHO etc must include the number of male caregivers, thereby setting benchmarks to drive change.

### 3 STRENGTHEN PUBLIC HEALTH SYSTEMS TO INCREASE GOVERNMENTS' CAPACITY TO DELIVER COMMUNITY AND HOME BASED CARE

A comprehensive response to HIV & AIDS needs to include **strengthening public health systems to increase the capacity of governments** to better respond to the communities' care needs. This must include strengthening patient centered health systems with: increased training for all health care workers including community caregivers; recognition of all cadres of community caregivers; improved conditions of service and promotion opportunities; improved supply and distribution of medicines; improved management systems and better infrastructure including clinics, hospices, laboratories and hospitals. These changes would result in improved retention of existing health care workers particularly in the context of the large-scale migration of health care workers.

As mentioned under the first call for changes, recognition of community caregivers is crucial for strengthening health systems, and as such **WHO must immediately change its current method of identifying and counting health workers**. The WHO 2006 Report states that: "current methods of identifying health workers does not allow unpaid carers of sick people or volunteers who provide other critical services to be counted."<sup>36</sup> This policy exacerbates the **invisible nature** of many of the caregivers, contributes to the burden on women and girl caregivers and means that improved benefits for health care workers will not necessarily benefit all community caregivers. WHO recognition and counting of all community caregivers will be key to addressing the health care worker crisis and reducing the burden of care. We also call for support for the UNAIDS recommendation that where appropriate **"alternative and simplified delivery models** (should be adopted) to strengthen the community-level provision of prevention, treatment, care and support."<sup>37</sup>

Improved health systems require **increased, predictable, long-term funding**, and donors need to make this available. Donors must move away from primarily allocating direct budget support, where appropriate they should provide funds to support civil society responses. Recognising that the bulk of care for people living with HIV & AIDS occurs in the communities, donors should support mechanisms that provide direct support to this community response. In addition, **more funds should be allocated to health budgets from national budgets**, governments should meet the target set in Abuja in 2001 to allocate 15% of the national budget to health. In order for improvements in health systems to be meaningful, **barriers to accessing available health care need to be removed and user fees must be abolished**.

36 WHO, 2006, Working Together for Health, p2.

37 UNAIDS, 2006, Report on the Global AIDS Epidemic, p21.

## VSO'S RESPONSE TO THE NEED TO REDUCE THE BURDEN OF CARE

---

In response to this crisis, VSO has incorporated the three key changes outlined above into our programme and policy work on a number of levels. VSO sends international volunteers to build local capacity where requested by communities or governments. These volunteers are recruited from Kenya, Uganda, India, the Philippines, the Netherlands, Canada and the UK. VSO also builds the capacity of national volunteering partners to improve the support given to local volunteers, formal and informal, for volunteering; and we work with partners on the ground to support community caregivers in community and home based care work.

In order to ensure that the response to HIV & AIDS is sustainable and the burden of HIV & AIDS care on women and girls is reduced, VSO works programmatically as well as undertaking advocacy at local and international level. Our work is driven by our experience with partners in developing countries and our analysis and demands as outlined in this brief. Below we give a few examples of this work.

VSO works with partners who are **challenging social norms** to create a space where men can be involved as caregivers without being stigmatised. In Namibia, VSO is currently supporting partners on the Caring Namibian Man photo project. This project is using images, taken by community members, to challenge traditional notions about care work not being masculine. The project has been enthusiastically welcomed by community members and leaders, and has significantly contributed to raising debates within the community and among policy makers about who provides community and home based care. In Zimbabwe, VSO provided a small grant to Loving Hand, an organisation which provides home based care to people living with HIV & AIDS. This grant helped Loving Hand to train community caregivers, with a specific focus on increasing the number of male caregivers. They adapted the training to make it 'mainly male focused'. Loving Hand now has 20 male community caregivers out of a total of 125. This has challenged attitudes in the community about the role of men as caregivers.

In a similar vein, **VSO supports work with young children on behaviour change.** In order to challenge the gender norms that underlie the burden of care falling on women and girls, we need to empower girls and to raise awareness and responsibility among boys. In Zambia VSO has been working with the Ministry of Education to influence education policy and introduce new courses to the curriculum that focus on empowering girls, and raising awareness among boys. These changes will contribute to changing attitudes and breaking down inequalities between women and men.<sup>38</sup>

In Malawi VSO is working with the Ministry of Health to **support the Malawian Government to strengthen their health system**, in particular assisting in developing the Human Resources for Health Sector Wide Approach programme (SWAp). Key targets include: increased training capacity; improved retention and short-term gap-filling of critical posts until more Malawians have been trained. VSO was requested by the Ministry of Health and the UK Department for International Development (DfID), to support the implementation of the SWAp, primarily through the provision of health professionals. The main requests were for doctors in district hospitals, nurse trainers and lecturers in a range of health disciplines to train Malawian health care workers. VSO is participating beyond the provision of health professionals as a stakeholder in the policy reform

<sup>38</sup> Two Training Manuals were produced by VSO in collaboration with the Ministry of Education, "Kanyike Walunga – Boys' Gender Awareness Programme" and "Knyike Wapwevo, The Girl Child – Girls' Empowerment Programme."

process. This intervention is key, as it is aimed at **addressing the cause of the weak public health system** through developing policy changes at the ministerial level and ensuring these changes lead to sustainable improvements in the public health system including better conditions, retention and infrastructure.

### VK HOME BASED CARE, ZAMBIA

VK Home Based Care, a small community based organisation in Lusaka, Zambia, provides training and support to community caregivers.

Lomanzi Phiri is a caregiver supported by VK Home Based Care. When Lomanzi's son and husband both became ill with TB she had nowhere to turn and cared for them by herself before they died. Lomanzi received no support, recognition, training or remuneration. She knew there were many people in Garden Compound where she lived in the same situation. She had heard about VK Home Based Care and after her husband died she became a caregiver with them.

Lomanzi now has three regular patients whom she visits in their homes. She visits them most days and helps them with any basic medical ailments they might have. She also helps them to access and take their TB medications and anti retrovirals. Lomanzi received training from VK and they have also helped her to send her two daughters to secondary school and her oldest remaining son on a carpentry course. Lomanzi looks after her six remaining children, six grandchildren and six orphans.

Lomanzi recognises that she is one of the fortunate caregivers because, unlike most, she receives support from VK. She says of her care giving role:

"It is hard to do this and look after my family. I have a small shop and I sell some things from here when I have money to buy stock. Sometimes I have to borrow the money to do this and when I can't pay it back the company comes here and takes things from the house. The shop isn't open at the moment and last week they came and took our TV, as I couldn't afford to pay them back, but this is just a part of life."

VSO is supporting training of VK's community caregivers on HIV prevention and care and proposal writing skills through placing an international volunteer with VK. VSO is calling for support and recognition for community caregivers such as Lomanzi who are shouldering the burden of HIV & AIDS care.

## ACT NOW! ALL STAKEHOLDERS HAVE A ROLE TO PLAY

---

VSO has a series of recommendations requiring action from a broad range of actors at national and international levels. Advocacy work is necessary to secure the political will, funding and prioritisation of these issues alongside other needs. These recommendations for action are based on our analysis of the problem as outlined in this policy brief and our policy paper *Gendering AIDS*.

### ALL STAKEHOLDERS SHOULD:

These demands apply to all stakeholders below, and are not repeated under each section, they should be read as implicit for **all stakeholders**.

- **Recognise and support the rights of community caregivers**, particularly women and girls, and older and child caregivers.
- Ensure that HIV & AIDS programmes **do not increase the burden on women and girls**.
- Deliver **social protection** schemes as a key intervention in reducing the burden of care on women and girls.
- Support initiatives to **strengthen public health systems**, and address the **health care worker crisis** in developing countries.
- Support the development of an **enabling environment for income generating activities** for female caregivers.
- Meaningfully involve **women and men living with HIV & AIDS**, as caregivers and patients, and also as key stakeholders when developing policies and programmes.
- Address the **inequalities between women and men** that are driving the pandemic.
- **Women's voices** must be taken into account when formulating policy, budgeting, planning and implementing programmes.
- Create an **enabling environment** such that men can become caregivers.
- **Develop better data collection** mechanisms (including gender disaggregated data, numbers of male caregivers and the cost of community and home based care - both social and economic); and adopt good practice **systems for sharing data**.

### THE UNITED NATIONS SHOULD:

UNAIDS SHOULD:

- Establish policies to **recognise and protect community caregivers**, in particular **adopt and implement a Volunteer Charter** (per its own recommendations in 2004).
- Develop a **more comprehensive analysis of care, support and treatment** that addresses the burden of care on women and girls and **recognises gender inequalities as a key driver** of the pandemic.<sup>39</sup>
- Update, implement and give more profile to the **UNAIDS Case Study, Caring for Carers** (2000).

THE WORLD HEALTH ORGANISATION SHOULD:

- **Revise its current method of identifying health workers** to recognise and count community caregivers, and ensure they receive support.
- **Revise the Care Guidelines**, to address the needs of community caregivers and the particular needs of female, child and older caregivers.

### DONORS AND DONOR GOVERNMENTS SHOULD:

- **"Do no harm"** - ensure their funds, monitoring and evaluation systems and reporting requirements do not exacerbate the burden on women and girls.

<sup>39</sup> The Executive Summary of the 2006 Report on the Global AIDS Epidemic fails to reflect gender inequalities as a key driver of the epidemic, and neglects to recognise the burden of care on women and girls.

- Adhere to the **Paris Declaration on Aid Effectiveness** that calls for more aligned and harmonised aid practices.
- Actively seek to fund programmes that a) **reduce the burden of care**, b) **involve men in delivering community and home based care**, c) **strengthen health systems** and d) **support social protection schemes**.
- **Move beyond direct budget support**, they must provide support to multilateral institutions, government and civil society, ensuring the funds reach community caregivers.
- Provide **more aid that is predictable and long-term**, in accordance with the 0.7% pledge made at the Monterrey Financing for Development Conference.
- By 2010 donors should be delivering **US\$20-23 billion per annum**- this is the figure that UNAIDS estimate is **needed to deliver universal access to treatment by 2010**, this delivery must start now.
- **International financial initiatives**, such as the Global Fund, must be **fully funded**.
- The Global Fund must prioritise **supporting the delivery of community and home based care** in a way that decreases the burden on women and girls.

#### NATIONAL GOVERNMENTS SHOULD:

- **Establish policies to recognise and protect community caregivers**, in particular consider adopting and implementing a Charter for Community Caregivers.
- Meet their **commitment of allocating 15% of national budgets** to health, as agreed by African Heads of State (Abuja, 2001). These must be gender responsive, and strengthen the health system.
- **Abolish user fees** for all public services.
- **Fully implement the commitments** to deliver comprehensive prevention, care and treatment, as agreed by Africa's Common Position to UNGASS (Abuja, May 2006).
- Revise **Standard of Care Guidelines** within National Health Plans to reduce the burden of care.
- Demonstrate **leadership**, at all levels, around the need to address gender inequalities and HIV & AIDS, and to challenge gender norms about men's involvement in caregiving.
- **Meet domestic and international commitments** with a priority on policies impacting on gender inequality and caregiving.

#### CIVIL SOCIETY AND NON-GOVERNMENTAL ORGANISATIONS SHOULD:

- All community and home based care organisations must **develop comprehensive policies** that recognise and protect community caregivers' rights and responsibilities, and ensure appropriate compensation. The NGO Code of Good Practice<sup>40</sup> provides clear guidelines on developing such policies.
- Create, and/or, strengthen local, national and regional **community and home based care alliances**, to share knowledge, skills and resources.
- Work with **community and traditional leaders** to challenge gender norms, and encourage them to role model 'caring male behavior'.
- **Educate citizens, especially women, about their rights** as enshrined in gender equity laws, national laws and policies, including any available social protection schemes and inheritance and property rights. And assist citizens, especially women, to **access these rights**.
- **Health care professionals** must recognise and support the important contribution of community caregivers.
- **Support, monitor, and, where necessary, challenge governments** to undertake their responsibilities in relation to healthcare delivery and support to community caregivers.

<sup>40</sup> Code of Good Practice for NGO's Responding to HIV/AIDS, 2004, p45.

## FOR MORE INFORMATION PLEASE CONTACT:

Nina O'Farrell, VSO Advocacy Officer HIV & AIDS, [nina.ofarrell@vso.org.uk](mailto:nina.ofarrell@vso.org.uk)  
 Samantha Willan, VSO Policy Adviser HIV & AIDS, [samantha.willan@vso.org.uk](mailto:samantha.willan@vso.org.uk)  
 Mike Podmore, VSO Campaigns Officer, [mike.podmore@vso.org.uk](mailto:mike.podmore@vso.org.uk)

## BIBLIOGRAPHY:

- **Action Aid, 2001**, Under the Mupundu Tree
- **African Union, 2006**, Africa's Common Position to the UN General Assembly Special Session on HIV/AIDS, June 2006, Abuja
- **Akintola, Olagoke, 2004**, A Gendered Analysis of the burden of Care on Family and Volunteer Caregivers in Uganda and South Africa
- **Benn, Hilary, Secretary of State for International Development, 15th June 2006**, Speech at London School of Hygiene and Tropical Medicine, London
- **Campbell, Cathy, 2004**, Creating Contexts for Effective Home Based Care of People Living with HIV/AIDS
- **Code of Good Practice for NGO's Responding to HIV/AIDS, 2004**
- **Concern, 2006**, Positive Lives International Responses to HIV & AIDS
- **DfID Briefing, November 2005**, Can low-income countries in Africa afford social transfers?
- **HelpAge International, 2005**, Valuing Older Women Carers
- **G8 Communiqué, Gleneagles, 2005**
- **International AIDS Alliance, 2006**, Universal Access to HIV Treatment, care and prevention by 2010: What does it mean for civil society?
- **Lewis, Stephen, UN Special Envoy for HIV/AIDS in Africa, April 26, 2005**, Text of a speech delivered at the University of Pennsylvania's Summit on Global Issues in Women's Health, Philadelphia
- **Paul, Godfred, 2006**, Cost of Care, HelpAge International Presentation at UNGASS, New York
- **Protocol to the African Union Charter on Human and Peoples Rights on the Rights of Women in Africa, 2003**
- **Southern Africa Partnership Programme, 2005**, Impact of Home Based Care on Women and Girls in Southern Africa
- **UNAIDS, 2000**, Caring for Carers Case Study
- **UNAIDS, 2004**, 4th Global AIDS Report
- **UNAIDS, 2004**, Facing the Future Together: Report of the Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa
- **UNAIDS, 2005**, AIDS Epidemic Update
- **UNAIDS, 2006**, Report on the Global AIDS Epidemic
- **UNGASS Declaration of Commitment (2001) and Political Declaration (2006)**
- **USAID/UNAIDS/WHO/UNICEF/Policy Project study, 2003**, in **International HIV/AIDS Alliance, 2006**, Universal Access to Treatment, Care and Prevention by 2010: What does it mean for civil society?
- **VSO, 2003**, Gendering AIDS: women, men, empowerment, mobilisation
- **WHO, 2002**, Community and Home Based Care in Resource Limited Settings
- **WHO, 2006**, Working Together for Health

