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

# Men, the care economy and HIV-AIDS: structure, political will and gender equality

# **Dean Peacock and Mark Weston\***

Division for the Advancement of Women Department of Economic and Social Affairs United Nations, New York Fax: (212) 963-3463 daw@un.org http://www.un.org/womenwatch/daw

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

# Men and the Care Economy in the Context of HIV and AIDS: Structure, political will and gender equality

# Dean Peacock and Mark Weston<sup>1</sup>

## **Introduction:** The problem

Over 33 million people worldwide are living with HIV/AIDS. In low and middle-income countries, nearly 10 million are in immediate need of treatment yet only 3 million are receiving it. This leaves 7 million people sick with AIDS and in need of intensive and long-term care.<sup>1</sup>

AIDS is a long and debilitating illness that renders patients unable to fend for themselves and often unable to cope with the mental stress of knowing that death, in the absence of treatment, is inevitable. Caring for those with the virus therefore involves both physical care – feeding, cleaning and providing medicine to cure opportunistic infections – and emotional support. Many of those caring for AIDS patients find that it is a full-time occupation, which imposes great stresses on the carer's body, mind and finances.

In wealthy countries, health systems provide much of this care – sick people are taken into hospital or visited by health staff in their homes. Professional psychological support is also available. But in the developing world – and especially in the areas hardest hit by HIV/AIDS – a lethal mix of inadequate political will, failure by governments to fulfil commitments and the impact of structural adjustment policies have left health systems without the capacity to undertake such care. Instead of the state assuming its responsibility to provide the care needed, the burden is taken up by family and community members, who look after the sick person at home.

A large majority of home-based carers are women. In most countries, society expects wives, daughters, mothers, sisters and grandmothers, rather than men and boys, to care for sick family members. In South Africa, for example, a national time-use survey found that women carry out eight times more care work (for all illnesses) than men.<sup>2</sup> In the case of HIV/AIDS, a Kaiser Foundation survey found that over two-thirds of primary caregivers are women.<sup>3</sup> Women are also the principal carers of children who have lost parents to HIV/AIDS. A South African study by Desmond and Desmond (2006) found that in households where the mother has died, only 30 per cent of surviving fathers are present, whereas in those where the father has died, 71 per cent of surviving mothers are present.<sup>4</sup>

The disproportionate burden on women matters for several reasons. First, it can have a crushing impact on women and girls. Caring for people with such a debilitating illness is extremely tiring. Fatigue renders carers more vulnerable to illness themselves, including to

<sup>&</sup>lt;sup>1</sup> Dean Peacock is Co-Director of the Sonke Gender Justice Network (<u>www.genderjustice.org.za</u>) and a research analyst with the UCLA Program for Global Health (<u>http://globalhealth.med.ucla.edu/</u>). Mark Weston is a public health consultant with Riverpath Consulting (<u>www.riverpath.com</u>) and works regularly with Sonke. This article draws on a paper submitted at the 2003 expert group meeting on involving men and boys in achieving gender equality held in Brasilia and on Sonke's recently finalised literature review and policy scan on men, gender, health and HIV and AIDS in South Africa. The authors acknowledge the contributions made by Alan Greig, Jean Redpath, Michael Flood, Rachel Jewkes, Robert Morrell and Gary Barker to other Sonke documents upon which this chapter draws and are grateful to the Ford Foundation, the South Africa Development Fund, and the International Women's Health Coalition for partial funding contributed. The authors are solely responsible for the content of this paper.

the opportunistic infections that plague those with the virus. The stress of caring for someone who is dying increases susceptibility to mental problems; carers of those sick with AIDS in Botswana, for example, report being emotionally drained by their roles.<sup>5</sup> Because caring for AIDS patients is a full-time occupation, moreover, women can become disconnected from their communities (and the stigma associated with the infection can exacerbate this), which heightens the risks to their health. Putnam (2000) has found that social capital helps people fight off illnesses; those who have close links to their families and communities have half the risk of dying from any cause compared to those who are socially disconnected.<sup>6</sup> Social capital also relieves emotional stress, with self-help groups proven to improve mental health – such support is often not available to full-time carers of people living with AIDS.<sup>7</sup>

Girls orphaned as a result of AIDS are particularly vulnerable. In South Africa, for example, as communities across the country are denuded of productive adults, more and more households are headed by children. As of 2005, 1.2 million children under 18 had lost one or both parents to AIDS in South Africa, and millions more have been made vulnerable.<sup>8</sup> In most child-headed households, it is girls that take on the responsibility of caring for their siblings. Children orphaned or made vulnerable by AIDS often struggle with food insecurity and malnutrition, and they are often excluded from society.<sup>9</sup> Their plight is made worse when illness or overwhelm prevents their parents or guardians from registering them for child grants, and they are also more vulnerable to HIV infection themselves. Among sexually active youth in a study in KwaZulu-Natal, South Africa, orphans reported younger age of sexual intercourse with 23% of orphans having had sex by age 13 or younger compared to 15% of non-orphans.<sup>10</sup> Studies in neighbouring Zimbabwe have shown that adolescent orphaned girls are significantly more likely to become infected with HIV than their non-orphaned (or male) peers.<sup>11</sup> This creates a vicious cycle of poverty, violence and HIV infection.

Caring also places an economic burden on women and girls. Many girls have been withdrawn from school to care for relatives sick with AIDS. In Swaziland, enrolment in school has fallen by 36 per cent since the epidemic hit the country, and enrolment among girls has fallen more precipitously than among boys.<sup>12</sup> Being removed from school diminishes girls' chances of obtaining a job in adulthood and therefore harms their economic prospects. Adult women, too, often have to leave work in order to care for the sick – this weakens them economically and leaves them more dependent upon their husbands, thereby strengthening gender inequality in the household and, because wealth makes it easier to access health services and obtain better nutrition, potentially imperilling women's health.

Women whose husbands die as a result of AIDS can face particularly severe economic hardship. In many parts of Africa, women are denied the right to own or inherit land, so they often lose their homes and possessions when their husbands pass away. They are therefore left without the resources to care for themselves and their remaining family members, much less to help their families climb out of poverty. In Uganda, women's lack of property and inheritance rights has left female-headed households more vulnerable to the impacts of HIV/AIDS.<sup>13</sup>

The quadruple burden placed by AIDS care on women – weaker health, social exclusion, lack of education and reduced economic power - makes it more difficult for them to advocate for change and engage in efforts to transform their lives and communities. Women's engagement in advocacy and activism is crucial to achieving gender equality, yet those who are fully occupied caring for relatives who are sick with AIDS are unable to

participate in such activism. Their isolation also makes it hard for them to articulate their needs to activists.

Although the harmful effects of the gender imbalance in AIDS care are primarily felt by women and girls, they are not limited to them. Men and boys also suffer, as do societies as a whole. For example, if women fall sick due to the stress of caring, they will be less able to help attend to the health and other needs of their families; with men unwilling or lacking the knowledge to perform duties previously carried out by women, entire households will suffer. Women's disproportionate burden of care is also bad for a society's health as stress and fatigue exacerbate women's vulnerability to infectious diseases (including HIV) and thereby increase the amount of illness prevalent in a society, with potential risks for all its members.

There are economic effects on societies too. If women have to withdraw from the workplace to care for relatives, whole families will be poorer and thus more vulnerable to illness. These effects extend to society as a whole: if women are unable to participate in the economy, the economy's productive potential is reduced. Men's involvement in care can have positive impacts on their families. Children are keen for men to play a more active caring role in their lives. A survey of young children in KwaZulu-Natal, South Africa, found that they wish for more interaction with their fathers and for their fathers to be more involved in family tasks.<sup>14</sup> Richter (2005) has found that men's engagement can improve family health, since their status in the community and their financial resources enable them to protect their children. Women who live with their male partners in healthy relationships, meanwhile, report being less stressed by childcare.<sup>15</sup>

The imbalance in AIDS care, then, can have harmful consequences for women, men and societies as a whole. In the next section of this paper, we outline some of the causes of this imbalance, and in the final section we make recommendations for governments as they attempt to address the problem.

## **One: Causes of the problem**

The disproportionate burden of care borne by women and girls in the context of high HIV and AIDS prevalence undermines efforts to achieve gender equality and requires urgent attention. In this section, we examine the structural forces driving this phenomenon. Rather than focusing simply on ways to increase men's participation in shouldering a more equitable share of the current burden, we look first at the causes of the enormous burden of informal care and identify ways to reduce it. We start by analysing the ways in which global economic policies and forces affect how AIDS care is provided and then discuss the relationship between these policies and the lack of health systems capacity available in most high HIV prevalence settings. We then focus on what currently prevents men and boys from being more fully involved and identify strategies for increasing their involvement.

## Government inaction and the burden of AIDS care

Government inaction on HIV prevention and treatment has increased the burden for carers of those sick with AIDS. If fewer people fell ill, both women and men would have reduced caring responsibilities, but the failure by governments in the developing world in particular to provide prevention services has allowed infection rates to soar; their failure to provide treatment to those infected has inflated the number of people needing care; and their failure to take on the responsibility for providing that care has added enormously to the difficulties of households that already have to deal with the emotional and often financial shock of having a member infected with the deadly virus. There are two main reasons for government inaction: a lack of capacity and a lack of political will. In wealthy countries, governments, aided by civil society, have taken on much of the responsibility of HIV prevention, treatment and care. Their capacity for doing so is, of course, greater than that of poorer countries as they generally have quite well-functioning health systems and the money to expand those systems to address new threats. Many developing country governments lack this capacity.

Over the last two to three decades, most developing countries have been pressured by the World Bank, the International Monetary Fund and other financial institutions to pursue neoliberal development policies characterized by a reduction in public spending, privatisation of public services, flexible labour laws, and an emphasis on attracting foreign investment. These policies have had an enormous impact on the health of those living with HIV/AIDS and subsequently on the lives of those who provide care and support to them<sup>16</sup>.

The strictures of the international financial institutions led to steep declines in spending on health care and reductions in both health services and other services that are important to those caring for the sick, including electricity, water and sanitation. Currently in South Africa, for example, there are 74 doctors per 100,000 people and in Lesotho there are just five; in the UK there are 222 doctors per 100,000. There is a similar discrepancy in the number of nurses, with South African and Lesotho having 393 and 62 per 100,000 respectively, compared to 1,170 in the UK.<sup>17</sup>

The second reason for government inaction is that governments failed to invest sufficiently in health care in general and AIDS care in particular. Even when prevalence rates had become shockingly high, many authorities delayed – still delay - in making antiretroviral treatment available. Globally, millions of adults with advanced AIDS are dying or posing a heavy burden on their families and, later on in the illness trajectory, often to public health systems because they are not receiving antiretroviral drugs.<sup>18</sup> Few pregnant women infected with HIV in Africa, moreover, receive the antiretroviral treatment that can stop them passing the virus to their unborn child – in low and middle-income countries, just 11% of pregnant women infected with HIV received such treatment in 2005.<sup>19</sup>

They have been even slower to provide care, and poor families have been unable to force them to take on more responsibility. A large proportion of those infected with HIV are poor and, as we have seen, most of those caring for them are women. The poor in general and poor women in particular have a muted voice in national decision-making in most of the developing world, so since the vast majority of policy-makers are men, who often have little idea of or little interest in the problems faced by female carers, the latter's needs are rarely attended to.

#### Harmful gender norms and the care economy

Gender norms are a further key cause of the excessive care burden on women. Gender norms across the world expect women to bear the burden of caring for the ill, even when they also work. It was therefore predictable that when the AIDS epidemic emerged, it would be women who played the role of carers. Many men believe that caring is "women's work" and that it is beneath them, that their traditional role as breadwinners is more important and should exclude them from having to carry out domestic chores. In a survey carried out in Soweto, South Africa, men said they did not participate in caring activities because of traditional gender norms and the fear that they would lose respect among their peers if they did so.<sup>20</sup>

Government policies often underpin these harmful gender norms. In most countries, for example, mothers are expected to take maternity leave to look after their newborn babies, but paternity leave is nearly always much shorter if it exists at all. This entrenches an image of women, and not men, as carers. Even in places where child care grants are supposed to go to the carer irrespective of whether they are a man or a woman, many men report difficulties in accessing the grant.

It is important to note that some men are keen to engage in caring. The Kaiser Foundation report cited above suggests that in the one-third of households where women are not the main carers, men are playing a significant role. A further study by Montgomery et al in KwaZulu-Natal found that some men are involved in caring for their families but that this often goes unacknowledged. Montgomery et al argue that whilst there is a "linguistic and conceptual locus for the discussion of 'deficient' men, no such language appears to exist to talk about men who are positively involved in their families". They point out, though, that their study revealed that men were involved in care giving activities, and that they "care for patients and children, financially support immediate and extended family members and are present at home, thereby enabling women to work or support other households". However, they write that these activities were seldom acknowledged by community members or by the field workers conducting research who continue to hold the perception that "men are not caring for their families because they are irresponsible and profligate". They conclude by calling for more research on men's roles in the family and argue that this has the potential to "inform the development of new programmatic approaches that might feasibly engage men's concerns and needs, and more effectively involve men as actors in community coping strategies"<sup>21</sup>.

Similarly, a study on the impact on caring provided by teachers to their students due to AIDS indicates that "teachers in schools with the least resources are frequently those required to provide the most demanding forms of support and care to learners" and points out that in the schools they studies, "the work of caring does not seem to be confined to women teachers. Male teachers, in our study, do emotional work". They argue, "…the state provides neither adequate staff to deal with the challenge of care, nor the training necessary to support teachers who find themselves at the frontline". The authors insist that "much more recognition must be given to teachers for providing care…in schools" and call for "professional counsellors to be employed in each school"<sup>22</sup>.

Many men would like to become more involved in supporting their families but are deterred by gender norms and more practical constraints. A study in Tanzania found that some male heads of households wanted to do more when their partners fell ill with AIDS but were prevented from doing so by "cultural definitions of maleness and the defined roles which determine masculinity."<sup>23</sup> A survey in Soweto, meanwhile, found that men lacked the knowledge and skills to take part in caring activities, and that they worried that their consequent inadequacy might expose them to ridicule.<sup>24</sup> A further study in South Africa reported that some men were willing to attend antenatal care with their partners but did not have the knowledge and skills they believed were necessary.<sup>25</sup> It is important, therefore, not just to shift the attitudes of individual men but also to instil in those whose attitudes are already more gender-equitable the confidence to participate in care.

Although the imbalance in caring duties is a real problem and needs to be addressed, however, still more important is the overall burden of AIDS care on households. Gender norms act to increase this overall burden by encouraging many men to disregard their health and to engage in sexual behaviour that places them at high risk for HIV infection or for becoming sick with AIDS. Worldwide, men are expected to take more risks than women, including with their health. Men often neglect to access health care, in the belief that it is unmanly and that they are invulnerable. In South Africa, only 21 per cent of those presenting to be tested for HIV are men, and there are similar gender gaps in Namibia, Swaziland and Zambia (in Uganda testing rates are more even).<sup>26</sup> Despite more or less equal infection rates, moreover, South African women are twice as likely as men to be on antiretroviral therapy and their CD4 counts are much higher than men's when they start treatment.<sup>27</sup> Men's failure to access testing and treatment increases the number of people who need care for AIDS. Women, as the primary caregivers, bear the brunt of this extra burden.

# Two: What strategies might reduce the burden on women?

## Reducing the overall AIDS burden

The best way for states to relieve the burden of AIDS care is by reducing the overall level of HIV in a population. In countries threatened by deadly epidemics such as HIV/AIDS, the historic underinvestment in health should be reversed; good health is a vital spur to poverty reduction and economic development, as well as a worthwhile goal in itself. Governments' sluggishness in responding to AIDS means large investments are now needed to recover lost ground. It is mostly men that make the macroeconomic decisions that determine the allocation of resources related to the care economy, whether at the national level or in institutions like the World Bank, the IMF or pharmaceutical companies and others in the private sector. To reduce the tremendous burden borne by women and girls who take care of the sick, men in positions of power in governments should be called to honour their commitments to aid and debt relief, to functioning heath services and to clean running water. When these commitments are not met, this inaction should be named as evidence of disregard for women's lives.

Government inaction is not inevitable. Activism by civil society or by prominent figures in global agencies such as the United Nations can make a big difference. South Africa's Treatment Action Campaign, for example, successfully took its government to court to force it to provide antiretroviral drugs to those living with AIDS<sup>28</sup>. The former United Nations special envoy for AIDS in Africa, Stephen Lewis, lent further weight to this campaign by publicly criticising the South African government's stance on treatment.<sup>29</sup> Together with on-the-ground advocacy and activism as well as growing frustration within government at the inaction emanating from the Presidency and the Minister of Health, his comments helped pressure the government into rolling out a more effective national strategic plan for AIDS treatment in 2007.

Measures specific to HIV/AIDS must also be more widely implemented. Effective prevention technologies such as male circumcision and the prevention of mother-to-child transmission of HIV need to be rolled out more widely, while government efforts to educate people about how to prevent infection must be unrelenting. Antiretroviral drug treatment is no longer costly, meanwhile - the main barrier to its widespread use is a lack of political will. Expansion of testing and treatment services should make special efforts to target men, who are currently underserved by them.

## Reducing the burden on women

Even if prevention and treatment efforts are greatly expanded, however, there will still be patients who require care and support, at least in the short- and medium-term. Not only women but entire societies will benefit if governments shoulder more of the burden. AIDS care is a public good in that its benefits are not limited just to those who receive it (patients' children, partners, communities and economies also benefit if they are kept healthy for longer and if they do not pose great emotional, physical and financial strains on those close to them). Public health systems, which have the knowledge, equipment and skills needed to provide care and benefit from economies of scale in procurement and delivery of drugs and other supplies, are better placed than families to provide care efficiently and cheaply.

Where health systems are unable to take on the full burden of care, financial support should be considered to compensate women for easing the demands on state resources. Professional carers in the West, such as nursing homes for the elderly or private hospitals for the sick, are well paid by their patients or by governments who contract the work out, but home-based individuals caring for family members are rarely rewarded either in rich or poor countries. This entrenches the notion that care work is somehow not a valuable activity and discourages men who see their role as breadwinners from engaging in it. It also maintains women's position of inferiority by keeping them financially dependent on the men of the household. Compensation for care work not only helps relieve the economic strain on women; it is also likely to strengthen their status relative to men and persuade more men to share caring duties.

In addition, to make life easier for carers, health systems must become more responsive to their needs. Participation by women in the design of public AIDS care services is crucial if their needs are to be attended to.

Further, work through health systems should assist home carers by providing the training and supplies needed to look after those sick with AIDS. Special efforts should be made to reach households isolated from communities by the stigma of the epidemic or by their poverty. Psychological counselling to both carers and their sick family members and advice for carers on how to deal with their relatives' emotional difficulties are also important in relieving the strain of caring.

### Involving men as part of the solution

Governments and civil society organisations working to reduce gender inequality in AIDS care should start by approaching men differently - as potential partners and not just probable perpetrators of violence or inevitable obstacles to women's health and wellbeing. Over the last four decades, women's rights advocates, including those working more recently to address the growing feminization of AIDS, have worked tirelessly and effectively to draw attention to the damage done to women by gender inequalities. Much of this work has historically posited men as beneficiaries of the gender order and necessarily resistant to gender transformation. This is perhaps especially true in the literature on gender and AIDS. Efforts to draw attention to the many ways in which AIDS maps onto and reinforces women's subordination have been relatively successful - at least in terms of raising awareness of the issues and securing national and international commitments. However, too often, to create a sense of urgency, these efforts have described men in broad brushstrokes as inevitably violent, irresponsible and uncaring and in the process often traded on stereotypes common in the global north about men in the global south.

There is a perception among many women in Africa, for example, that disclosing their HIVpositive status to their male partners will likely provoke a violent response. In studies from Tanzania, South Africa and Kenya, between 16 and 51 per cent of women who do not disclose their status cite fear of men's violence as a major reason.<sup>30</sup> In reality, however, such violence is the exception rather than the rule; a ten-country World Health Organisation study in 2004 found that between 4% and 15% of women reported violence after disclosure – unacceptably high figures but a small minority nevertheless.<sup>31</sup>

As discussed in part one, many men are willing to engage in caring if given the skills and knowledge to do so, with some already playing an active role in AIDS care. Messages which convey to women that men will be violent – even when the data suggests the reality is more complicated and includes an invisible majority of supportive men – may prevent women from disclosing their status or from bringing in their partners in for testing and education. This is a lost opportunity given that studies show that interventions that encourage women to invite their male partners to test can significantly increase men's uptake of services and their support for their partners participation in prevention of mother to child transmission programmes. <sup>32</sup> For instance, in a pilot PMTCT program implemented by the Horizons project in Kenya that sought to increase partner involvement in PMTCT, the proportion of male partners who used VCT services as a result of being involved in the program doubled in one site and increased by 50 per cent at another site.<sup>33</sup>

Models also exist that indicate that men can be supported to play a more active role in meeting the care needs of children made vulnerable by HIV and AIDS. Sonke Gender Justice, the organisation for which the authors work, has developed a model for working with men to increase their involvement in meeting the needs of orphans and children affected by HIV and AIDS. The model is unique, not only in that it aims to support men to play a more active role in the lives of children, but also in that it gives voice to vulnerable children through training and engaging them in using multi-media approaches to bring the realities of their daily lives to the attention of the leaders in their communities. The One Man Can Campaign's Fatherhood Initiative has two primary objectives. The first objective is to increase men's involvement, not only in the lives of their own children, but also in ensuring that children in general, and orphans and vulnerable children in particular, have access to essential social services. As such, men of all walks of life-traditional and religious leaders, representatives of local government, teachers and coaches, fathers and social fathers--are supported to play an active role in making sure that children are able to access child grants, attend school, benefit from school feeding schemes and have their psycho-social and educational needs met. The second objective is to develop men's capacity to be advocates and activists in efforts to eliminate violence against women and children, prevent the spread of HIV and AIDS and promote health, care and support for orphans and vulnerable children. The success of the project is then measured against very concrete impact indicators that determine whether men are in fact playing a more active role in meeting the care related needs of orphans and vulnerable children. These indicators include: men spend more time actively parenting their children; men assist their children with homework; men decrease their use of physical punishment of children and report increased understanding of alternatives to corporal punishment; men decrease their use of violence against children and their mothers; men demonstrate improved understanding of their children's nutritional needs and report doing more to ensure that children's nutritional needs are me and men become more actively involved in local childcare forums. This in turn should lead to an increased number of orphans and vulnerable children accessing social grants, attending school, and demonstrating improved nutrition.

To achieve further involvement by men in the care economy, states can take steps to improve health systems to make them more friendly to men who either want to or are already involved in care and support activities. Nurses and clinics that provide care to the sick are not always set up to deal with male carers – like society as a whole, health systems expect women to do care work and are therefore sometimes unfriendly to men who wish to become involved<sup>34</sup>. Health ministries should train their employees to be more supportive of

men's involvement in care. As discussed above, many men believe they lack the skills to participate, and health systems can play a valuable role in providing training and counselling to potential male carers. Outsourcing such training to civil society organisations that work with men should also be considered, with governments providing the funding and materials needed and monitoring programs' effectiveness. Significant evidence shows that working with men and boys to promote gender equality and engage them in household responsibilities can be effective, and governments should encourage and support such work.<sup>35</sup>

# Legal and policy approaches

Governments can also use policy levers to increase men's involvement in the care economy. Legislation is important for improving gender equality. Legislation governing maternity and paternity leave in South Africa allows mothers four months leave from work and fathers just three days. This conveys a message that women are responsible for caring duties and helps turn this message into reality. In Norway and Sweden, parental leave is not allocated to one parent in particular but can be shared by mother and father. After this law was passed, few fathers took up their leave so their governments made it obligatory for them to take at least a month off work. Over seventy per cent of fathers in both countries now use this month.<sup>36</sup> Smith (2001) has shown that the Scandinavian measures have helped increase the time spent by fathers performing caring duties,<sup>37</sup> while Aldous and co-authors (1998) found that fathers' early engagement in child care makes them more likely to continue to provide care later.<sup>38</sup>Similar interventions are possible in poorer countries, and they could help ease the burden on women. For instance, in Brazil, a number of states offer one month parenting leave for fathers and discussions are being held to make this national policy. It is important to note, however, that in some instances having men at home during the postnatal period simply increases the burden of care on the new mother who can end up taking care of both the child and the stay-at-home father<sup>39</sup>. To address this, it is critical that policy changes are accompanied by efforts to shift social norms.

Broader workplace measures can also help address the gender imbalance in care. Rules that prohibit gender discrimination in recruitment, pay and promotion can open up economic opportunities to women and thereby strengthen their position within households. Economic clout can give women more control over family affairs and more leverage to insist that men participate in caring duties. Governments' own employment policies should also proscribe such discrimination.

Legislative and policy change that strengthens women's rights to own property and land and allows them to inherit possessions is a further important step. Empowering women economically can render them and their families less vulnerable to HIV infection as well as helping them if they have to care for the sick and mitigating the impact on them of the death of a husband.

Education, too, is important to promoting gender equality in caring. In schools, the importance of men's involvement in care should be emphasised to boys and girls, not least through increasing the number of male pre-school, primary and secondary school teachers who serve as role models in this regard. Communication messages to adult men and women, perhaps delivered by non-governmental organisations, should highlight the importance of keeping girls in school rather than removing them to care for sick relatives. Messages should also attempt to reduce the stigma of caring through peer education by existing male carers, demonstrating positive role models at the same time as teaching caring skills.

Government interventions not directly related to health can also make carers' lives easier. Carers of those sick with AIDS generally need plentiful supplies of water for cleaning and laundry as well as sanitation facilities. In communities affected by the virus, governments can help ease the burden by halting and rolling back the privatisation of electricity, water and sanitation services. Day care centres that look after patients for short periods or look after children will provide some relief to carers and possibly allow them time to partake in economic activities. In schools, psychosocial support should be provided to orphans. And microfinance programs can provide invaluable financial support. In many countries hard hit by AIDS, jobs in the formal sector are scarce and non-discrimination legislation will have no effect on women working informally. Women in many developing countries have gained greater independence, confidence and negotiating power as a result of the small loans provided by microfinance programs.<sup>40</sup> A recent study of the IMAGE program in South Africa found that women who received loans were more likely than a control group to engage in collective action and felt that they had greater support from their communities in a crisis. They were also less likely to be affected by intimate-partner violence.<sup>41</sup> This indicates that the program helped improve women's status and, possibly, their relationship with their male partners. These are crucial first steps on the road to enhanced gender equality in the home, including around caring duties.

Governments, then, can take steps to improve gender equality among those caring for patients with AIDS, and they can also alleviate many of the difficulties facing carers of both sexes. These steps involve health ministries as well as other parts of government. In countries where HIV/AIDS is already crippling societies and in those where it still poses a potential future threat, a multi-sectoral response is required. Greater government action on HIV/AIDS not only helps mitigate the problem – by relieving the heavy burden on women carers, it can promote gender equality and thereby trigger broad benefits for all members of society.

<sup>&</sup>lt;sup>1</sup> Avert (2008): Worldwide AIDS Statistics. Available at: http://www.avert.org/worldstats.htm. Last accessed 29 September 2008.

<sup>&</sup>lt;sup>2</sup> D Budlender, N Chobokoane, Y Mpetsheni (2001): A survey of time use: How South African men and women spend their time. Statistics South Africa, Pretoria.

<sup>&</sup>lt;sup>3</sup> Henry Kaiser Family Foundation (2002): Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic. A Survey of Households Affected by HIV/AIDS in South Africa. The Henry Kaiser Family Foundation, Social Surveys, Memory Box Project.

<sup>&</sup>lt;sup>4</sup> C Desmond, C Desmond (2006): HIV/AIDS and the crisis of care for our children. In Morrell and Richter (Eds.) Baba: Men and Fatherhood in South Africa. HSRC Press, Cape Town: 229.

<sup>&</sup>lt;sup>5</sup> R Ndaba-Mbata, E Seloilwe (2000): Home-based care of the terminally ill in Botswana: knowledge and perceptions. Int. Nurs. Rev. 47: 218-223.

<sup>&</sup>lt;sup>6</sup> R Putnam (2000): Bowling Alone, Simon & Schuster. New York: 19.

<sup>&</sup>lt;sup>7</sup> M Lieberman, L Snowden (1994): Problems in assessing prevalence and membership characteristics of selfhelp group participants. In TJ Powell (Ed.): Understanding the self-help organization: Framework and findings. Thousand Oaks, CA: Sage Publications.

<sup>&</sup>lt;sup>8</sup> Children and AIDS: A stocktaking report. Action and progress during the first year of Unite for Children, Unite against AIDS. UNAIDS/UNICEF/WHO January 2007.

<sup>&</sup>lt;sup>9</sup> HIV/AIDS: Crisis causes increased vulnerability to HIV infection retrieved on May 6<sup>th</sup> from http://www.unicef.org/emerg/southernafrica/index\_hiv\_aids.html

<sup>&</sup>lt;sup>10</sup> Thurman TR, Brown L, Richter L, Maharaj P, Magnani R. Sexual risk behavior among South African adolescents: is orphan status a factor? AIDS Behav 2006; 10:627–635.

<sup>&</sup>lt;sup>11</sup> Birdthistle I,Floyd S, Machingura A, Mudziwapasi N, Gregson S, and Glynn R, "From affected to infected? Orphanhood and HIV risk among female adolescents in urban Zimbabwe", AIDS 2008, 22:759–766; Gregson

S, Nyamukapa CA, Garnett GP, Wambe M, Lewis JJ, Mason PR, et al. HIV infection and reproductive health in teenage women orphaned and made vulnerable by AIDS in Zimbabwe. AIDS Care 2005; 17:785–794.

<sup>12</sup> Desmond, C. Michael, K. and Gow, G. (2000): 'The hidden battle: HIV/AIDS in the household and community', South African Journal of International Affairs, Vol. 7 No. 2

<sup>13</sup> Kanyamurwa JM, Ampek GT. Gender differentiation in community responses to AIDS in rural Uganda. AIDS Care 2007; 19 Suppl 1:S64-72.

<sup>14</sup> G Clacherty (2008): The role of men in our lives. Participatory research with children in Nkandla and Mhlontlo Districts conducted for Sonke Gender Justice. August.

<sup>15</sup> L Richter (2005): The importance of fathering for children. In Morrell and Richter (Eds.) Baba: Men and Fatherhood in South Africa. HSRC Press, Cape Town: 55-56.

<sup>16</sup> For a discussion of the impact and response to privatization in South Africa, including on the care economy, see, for instance, Bond, P. (2000) Cities of Gold, Townships of Coal: Essays on South Africa's New Urban Crisis. Africa World Press, Asmara. & Desai, A (2002). We are the Poors: Community Struggles in Post Apartheid South Africa. Monthly Review Press. New York, NY and Marais, M (2006, May 19) A plague of inequality. Mail and Guardian, Johannesburg

<sup>17</sup> Medecins Sans Frontieres (May 2007): Help Wanted: Confronting the health care worker crisis to expand access to HIV/AIDS treatment: MSF experience in Southern Africa.

<sup>18</sup> Avert (2008) op cit

<sup>19</sup> UNICEF (2008): Preventing mother to child transmission of HIV. UNICEF website. Available at: http://www.unicef.org/aids/index\_preventionyoung.html. Last accessed 2 October 2008.

<sup>20</sup> V Kruger (2003): Being willing to love and support them. An EngenderHealth report on focus group discussions held in Soweto by the HOPE Worldwide Men as Partners staff.

<sup>21</sup> Montgomery, CM, V Hosegood, J Busza, & IM Timaeus. (2006). "Men's involvement in the South African family: Engendering change in the AIDS era." Social Science and Medicine, 62, p.2415.

<sup>22</sup> Bhana D, Morrell R, Epstein D and Moletsane. The hidden work of caring: teachers and maturing AIDS epidemic in diverse secondary schools in Durban. Journal of Education, No.38, 2006.

<sup>23</sup> Aggleton, P. and Warwick, I. (1998) A Comparative Analysis of Findings from Multi-Site Studies of Household and Community Responses to HIV and AIDS in Developing Countries. Geneva: UNAIDS
 <sup>24</sup> Kruger (2003) op cit

<sup>25</sup> Aggleton and Warwick (1998) op cit

<sup>26</sup> Magongo B, Magwaza S, Mathambo V, Makhanya N. (2002): National Report on the Assessment of the Public Sector's Voluntary Counselling and Testing program. Durban: Health Systems Trust; Carla Makhlouf Obermeyer (2008): Gender and HIV in high- and low-prevalence countries: evidence, determinants and implications. Paper presented at American University in Cairo for World Health Organisation, April 13-16. <sup>27</sup> Sonke Gender Justice Project (2006): Working with Men: Essential to Reducing the Spread and Impact of HIV and AIDS in Southern Africa. Cape Town, South Africa, April.

<sup>28</sup> See, for instance, Peacock, D; Budaza T and Greig, A (2008) "Justice for Lorna Mlofana": The Treatment Action Campaign's AIDS and Gender Activism in\_AIDS and Society in South Africa ed by Angela Ndinga-Muvumba. UKZN Press.Mandisa Mbali, The Treatment Action Campaign and the history of rights-based, patient-driven HIV/AIDS activism in South Africa, Research report no. 29, University of KwaZulu-Natal, Centre for Civil Society, 2005 and Steven Robins "Long live Zackie, Long Live: AIDS Activism, Science and Citizenship after Apartheid, Journal of Southern African Studies, 30, 3 page numbers (September 2004).
<sup>29</sup> BBC News Online (2006): South Africa AIDS Policy Attacked. Available at:

http://news.bbc.co.uk/1/hi/world/africa/5265432.stm

<sup>30</sup> Medley A, Garcia-Moreno C, McGill S and Maman S. 2004. Rates, barriers and outcomes of HIV serodisclosure among women in developing countries: Implications for prevention of mother-to-child transmission programmes. Bulletin of the World Health Organization. 82 (4): 299-307.

<sup>31</sup> Maman S, and Medley A, (2004) Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes. World Health Organisation: Geneva.

<sup>32</sup> UNICEF. Evaluation of United Nations-supported pilot projects for the prevention of mother-to-child transmission of HIV. New York: United Nations Children's Fund, August 2003.

<sup>33</sup> Rutenberg, Naomi et al. Evidence of Success in Increasing Male Participation and Support for the Prevention of Mother to Child Transmission of HIV in Kenya

<sup>34</sup> Mullick, S, B Kunene, & M Wanjiru. (2005), "Involving men in maternity care: health service delivery issues." Agenda Special Focus, p.126.

<sup>35</sup> See, for example, Sonke Gender Justice (2008): WHO Men and Gender Policy Brief: Policy Approaches to Involving Men and Boys in Achieving Gender Equality. Paper prepared for the Department of Gender Women and Health, World Health Organization. March.

<sup>36</sup> D Cohen (2000): Father Work in Europe: Phase One of a Report of Fathers Direct to Bernard Van Leer Foundation. Unpublished.

<sup>37</sup> Smith, Alison J. (2001) Parental leave: supporting male parenting? A study using longitudinal data of policy variation across the European Union. Paper given at the EURESCO Second Demographic Transition in Europe, Bad Herrenalb, Germany 23-28 June, pp. 4-5.

<sup>38</sup> Aldous, J., Mulligan, G.M., and Bjarnason, T. (1998) Fathering over time:

What makes the difference? Journal of Marriage and the Family, 60, November, 809-820, p. 818.

<sup>39</sup> Gary Barker, presentation at Working Group Meeting on Men and Policy Approaches, Cape Town, March 26-28, 2008

<sup>40</sup> N Goldberg (2005): Microfinance systems: taking stock of what we know. Washington DC. Grameen Foundation.

<sup>41</sup> PM Pronyk, JR Hargreaves, JC Kim, LA Morison, G Phetla, C Watts, J Busza, JDH Porter (2006): Effect of a structural intervention for the prevention of intimate-partner violence and HIV in rural South Africa: a cluster randomised trial. Lancet; 368: 1973-83.