

# 4. CARING FOR THE CARERS

## REALISING THE RIGHTS OF WOMEN AND GIRLS PROVIDING HIV AND AIDS CARE

**Community and home-based care is a key response to the HIV and AIDS pandemic. But efforts must be made to reduce the impact on women and girls who provide the bulk of care globally. Appropriate compensation and support must be made available to carers, and the burden of care shared with men and boys.**

### WHY IS IT IMPORTANT?

Community and home-based care is a key response to the HIV and AIDS pandemic, with around 90 percent of care taking place in the home.<sup>1</sup> It is usually delivered with little support from the public health system, most of which are failing because of health worker shortages, insufficient funding and investment. Care is provided by community care providers who are predominantly women and girls, and are usually unpaid, unsupported and unrecognised. Care providing responsibilities mean women and girls often have to leave or regularly stay away from their workplace or school, their income-generating activities suffer and they have less time available to care for their own families. Care providers may experience physical and psychosocial effects, including stress, burnout and exhaustion, and many also face stigma and discrimination as a result of caring for people living with HIV and AIDS.

### KEY DEBATES

The key question is how to reduce the heavy costs of providing care on women and girls and there are several key debates around how to achieve this. The first revolves around how we ensure governments take more responsibility for providing care for people living with HIV and AIDS rather than leaving it solely to communities. The second centres on gender inequalities and traditional gender roles that define caring as a female role and how we can challenge these to greater involve men and boys. The third asks how we can most effectively ensure female care providers receive recognition, training and financial support from their communities and the government. This is compounded by a fourth debate that questions how we balance the value of voluntarism (as a response to the HIV and AIDS pandemic) with the importance of recognising care providers as workers with rights to pay, training and psychological support.

### VSO'S POSITION

Caring for the carers is one of two international advocacy themes for VSO (the other is HIV prevention – see Position 7). VSO believes community and home-based care is important and appropriate, but that efforts must be made to realise the rights of female care providers. VSO believes care providers have a right to be valued, supported and receive appropriate compensation. The patient also has a right to high-quality care.

A comprehensive and sustainable response must include:

- good standards of care for patients
- recognising the rights of community care providers
- appropriate standards of support for care providers, including supervision and managerial support
- providing the necessary equipment, for example, home-based care kits and medicines
- fair financial support and/or compensation for labour, expenses and incentives
- on-going training
- care for the care providers, including psychosocial support.



<sup>1</sup> UNAIDS (2004) 4th Global AIDS Report, p118

The burden of HIV and AIDS care should be shared with men and boys, through their greater involvement and by challenging social barriers to men being community care providers. This will mean more hands to do the work and will challenge gender norms that fuel inequalities. Anecdotally, some male patients report they prefer being cared for by someone of the same sex, largely due to the personal nature of the care.

## KEY PRINCIPLES

- Community care providers must be recognised and remunerated for the work they do: where possible, regular pay or stipends should be provided. At a minimum, no-one should be poorer as a result of being a care provider and no-one should be exploited by the work they do.
- All community and home-based care organisations must develop policies that recognise and protect community care providers' rights, and ensure appropriate compensation. The NGO Code of Good Practice provides guidelines on developing policies.<sup>2</sup> VSO programmes should support partners working with community care providers to do this.
- Awareness must be built among community care providers of their rights to support.
- Social protection mechanisms such as pensions and cash transfers are a key poverty reduction strategy for care providers.
- The work of community care providers must be linked into services provided by the health system.
- Support must be given to initiatives to strengthen public health systems, and to address the health-worker crisis.
- The particular needs of older and child care providers must be recognised.
- The burden of HIV and AIDS care should be shared with men and boys.
- Community and home-based care alliances should be created and/or strengthened to share knowledge, skills and resources.
- Work must take place with traditional and community leaders to challenge gender norms, and to encourage them to role model caring male behaviour.
- HIV and AIDS programmes must not increase the burden of HIV and AIDS care on women and girls.
- Income-generating activities for care providers should be developed.
- Women and men living with HIV and AIDS, as care providers and patients, must be meaningfully involved when developing policies and programmes.

## RESOURCES

- NGO HIV/AIDS Code of Good Practice Project (2004) *Renewing our Voice: Code of Good Practice for NGOs Responding to HIV and AIDS*
- VSO (2006) *Policy brief: Reducing the Burden of HIV and AIDS Care on Women and Girls*
- UNAIDS (2004) *Facing the Future Together. Report of the Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa*

## LANGUAGE

- **'Community care providers'** include all people who are responding to the health crisis and caring for those who are sick. Many terms are used to describe community care providers, and they tend to be context specific. They include: primary care providers (a patient's primary carer, usually family), community nurses, health workers, community volunteers, formal and informal volunteers. VSO uses 'community care provider' as a term that reflects all of the above.
- **'Social protection'** can be used to describe a range of public, private or informal interventions to reduce the vulnerability and risk faced by poor people. These interventions can be described under terms such as social security, social assistance, safety nets and social policy.



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<sup>2</sup> NGO HIV/AIDS Code of Good Practice Project (2004) *Renewing our Voice: Code of Good Practice for NGOs Responding to HIV and AIDS*, p45