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Walking the talk

Putting women's rights at the heart of the HIV and AIDS response

Cover Photo: Gideon Mendel/Corbis/ActionAid

Ruth Nkuya, who is living with HIV and AIDS and taking antiretroviral medication, talks to a participant in an HIV and AIDS education drama at the market place in Ngwenya Location, Lilongwe, Malawi.

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Glossary

ABC	‘Abstinence, Be faithful, Condom use’ approach
ACHR	American Convention on Human Rights (1968)
ACHPR protocol	Protocol of the African Charter on Human and People’s Rights on the Rights of Women in Africa (2003)
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARVs	Antiretrovirals
CAAP	Confidential Approach to AIDS Prevention
CBO	Community-based organisation
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women (1981)
CHBC	Community home-based care
CRC	Convention on the Rights of the Child
CSO	Civil society organisation
DFID	Department for International Development UK
FBO	Faith-based organisation
FGM	Female genital mutilation
GBV	Gender-based violence
HIV	Human Immunodeficiency Virus
ICPD	International Conference on Population and Development (1994)
ICCPR	International Covenant on Civil and Political Rights (1966)
ICESCR	International Covenant on Economic, Social and Cultural Rights (1966)
ICW	International Community of Women Living with HIV/AIDS
INGO	International non-governmental organisation
LGBTQI	Lesbian, gay, bisexual, transsexual, queer, intersex
MDGs	Millennium Development Goals
NGO	Non-governmental organisation
PEP	Post-exposure prophylaxis
PEPFAR	President’s Emergency Plan for AIDS Relief
PITC	Provider initiated testing and counselling
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission
PPTCT	Prevention of parent-to-child transmission
PWN+	Positive Women’s Network, India
SIDA	Swedish International Development Agency
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
UDHR	Universal Declaration of Human Rights (1948)
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNIFEM	United Nations Fund for Women
VAW/G	Violence against women and girls
VCT	Voluntary counselling and testing
WHO	World Health Organization

Definitions

Universal access ‘continuum’	Universal access is the most recent and comprehensive commitment made by the international community in response to HIV and AIDS. The ‘continuum’ is composed of prevention, treatment, care and support – four indivisible pillars of an effective response to HIV and AIDS.
Civil society	Civil society is composed of diverse actors and institutions such as charities, non-governmental organisations, community-based organisations and groups, women's organisations, faith-based organisations, professional associations, self-help groups, networks of people living with HIV and AIDS, social movements, coalitions, advocacy groups etc.
International human rights instruments	A body of treaties, charters, covenants, bills of rights, declarations and other international legal instruments that governments have agreed or signed.
Rights holders	Individuals and groups with rights as defined in International Human Rights Instruments.
Duty bearers	State or non-state actors responsible and accountable for ensuring rights, as defined in International Human Rights Instruments, are respected, protected and fulfilled.
Empowerment	The process through which women and girls come to see themselves as having entitlements and rights and identify the power they and others have to claim those entitlements.
Women’s agency	The capacity of women to act individually or within a group, to start an empowerment process and to then regain control and make choices in their life.
Sex	The characteristics of human biology and anatomy that define males and females; sexual intercourse.
Gender	Socially constructed characteristics, qualities and behaviours, assigned to human beings according to their sex, against which women and men are measured.
Sexuality	Encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Includes thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.[1]
Gender equality	The right of both sexes to equal rights and opportunities, and to be free from discrimination established through gender norms.
PMTCT-Plus	Unlike simple prevention of mother-to-child transmission programmes (PMTCT) that put the burden of prevention of transmission to the newborn exclusively on women, PMTCT-Plus involves every family member infected or affected by HIV and AIDS. It is a more holistic set of services for pregnant women living with HIV and AIDS, providing preventative therapy, treatment and care for women in their own right (including treatment options beyond pregnancy). PMTCT-Plus encourages the participation of men at all stages of pregnancy, delivery and care as well as on issues around stigma and positive status disclosure.

Positive-living	A term used to describe a way of living a full and healthy life with HIV and AIDS including mental, physical and emotional health. Positive living can include good nutrition, accessing treatment including for opportunistic infections, and with psychosocial, spiritual, emotional and community support.
Primary care provider	Family members or close friends who provide care and support in the home.
Secondary care provider	Visiting nurses, health workers or community care providers from NGOS or community groups. They provide a range of services for people living with HIV and AIDS.
Sero-discordant	A term used to describe a couple in which one partner is living with HIV and AIDS and the other is not.
Vertical transmission	Vertical transmission, also known as mother-to-child transmission refers to transmission of an infection, such as HIV, hepatitis B, or hepatitis C, from mother to child during the perinatal period, the period immediately before and after birth.

Gideon Mendel/Corbis/ActionAid

Aderonke Afolabi, founder of the support organisation Potter Cares in Nigeria, is one of the few people in the country living openly with HIV and AIDS.

Executive summary

It is time to walk the talk on women, human rights and universal access to HIV and AIDS services. We call on decision-makers to take urgent and practical action to ensure that women and girls' rights are recognised as an essential foundation for achieving universal access to prevention, treatment, care and support.

Rights violations drive the pandemic

Using research from 13 countries, this report demonstrates that gender inequalities and the persistent and systematic violation of their rights are leaving women and girls disproportionately vulnerable to HIV and AIDS. Poverty and limited access to education and information, discriminatory laws and ingrained gender inequalities all deny women and girls their rights. Gender-based violence, health systems that serve the needs of women poorly and limited participation in decision-making processes all fuel the feminisation of the HIV and AIDS epidemic.

Globally the percentage of women and girls living with HIV and AIDS has risen from 41% in 1997, to just below 50% today, while in sub-Saharan Africa, 75% of 15 to 24-year-olds living with HIV and AIDS are female. This report shows that it is poor, rural women who are among those hit hardest by the profound health, economic and social impacts of the HIV and AIDS epidemic.

We have known for some time that while women and girls are disproportionately affected by HIV and AIDS, they still provide the backbone of community support and play critical roles as agents of change, activists and leaders. However, responses to HIV and AIDS still do not reflect these realities.

Universal access and women's rights: the framework for action

There are only two years left to meet the commitment by governments and donors to 'universal access to prevention, treatment, care and support by 2010' for those affected by HIV and AIDS. The only effective way to realise this commitment is to promote a women's rights-based and gender-sensitive approach.

Our call to action

Our report lays responsibility for making these changes firmly with those who hold power and bear the duty to respect, protect, promote and fulfil rights – national governments, donors and multilateral organisations and, to some extent, civil society. Our report balances this with the essential promotion of women and girls as rights holders, activists and leaders of change.

Prevention, treatment and care and support

In every aspect of prevention, treatment and care and support, women and girls are regularly unable to exercise their rights to access HIV and AIDS services. In this report we detail the barriers for women and girls in terms of prevention, treatment and care and support, and suggest recommendations. We summarise these recommendations below.

Prevention

> *"…my husband tested positive before me, but my aunties, together with my late husband, disapproved of condom use, arguing that he had paid up all the bride wealth and therefore [I] was supposed not to deny him sex, unprotected or not… they accused condom use with lack of love for my late husband… everyone was against me and [I] had no option…"*
>
> Zimbabwean woman living with HIV and AIDS

Strategies to prevent HIV infection often fail to take into account the real lives of women and girls. Prevention strategies based on abstinence, being faithful and using a condom ignore the lack of control most women have over their sexuality and the violence women face, particularly within marriage. The development of prevention methods that women can control (female condoms and microbicides) will help, as will education and public awareness campaigns that promote women's rights.

National and donor governments must only fund evidence-based, gender-sensitive prevention programmes that take a rights-based approach, including contributing their fair share to the development of microbicides and increasing access to the female condom and other female-initiated HIV-prevention methods.

Treatment

> *"How can I get up at 3am then travel alone during the night to make sure I get antiretrovirals? But a man can easily walk during the night."*
>
> Rwandan woman living with HIV and AIDS

Women are more likely to receive treatment than men, but our research suggests they may be less likely to adhere to it. Reasons given are the lack of privacy and the fear of violence or abandonment if their positive status is discovered. Women also have less access to adequate nutrition, which they need to support their treatment. If access to treatment is to be increased, the particular barriers for women will also have to be addressed.

National governments must develop, fund and implement their national treatment plans and budgets with a strong emphasis on the access and adherence of women and girls to treatment, particularly those in poor and rural communities.

Care and support

> *"We walk for miles and miles in order to reach clients in other homesteads. Once we are there clients expect a lot from us, like food and even money. This puts pressure on our personal resources."*
>
> Namibian care provider

Women living with HIV and AIDS face significant barriers in getting the care and support they need. Leadership of support groups is often dominated by men, with women and girls unable to raise their concerns. The problem is particularly difficult for women living in poverty, who don't have access to the income generation opportunities or state services they need to provide for themselves or their families. Furthermore, women and girls are the major care providers, yet they are seldom paid and the value of this work is rarely recognised.

Donors, multilateral organisations and governments should recognise non-volunteer secondary care providers as workers with a right to a fair wage, training and support.

Cross-cutting recommendations

- **National and donor governments** should base national AIDS plans on a rights-based analysis of the barriers faced by women and girls in regard to HIV and AIDS prevention, treatment, care and support services. UNAIDS and the World Health Organization must develop clear targets, guidelines and a single strategy to support country governments to do this.

- **National and donor governments** should consult with women's movements, local networks and movements of women living with HIV and AIDS to ensure funding reflects local priorities. They should also ensure that their policies and programmes do not reinforce inequalities and have the participation of women and girls living with (and affected by) HIV and AIDS at their heart.

- **National and donor governments** should ensure long-term, predictable funding for the strengthening of health systems, in particular to ensure women-friendly and pro-poor health systems that integrate HIV and AIDS and sexual and reproductive health rights services with HIV and AIDS prevention, treatment, care and support services. This should include adequate staffing, diagnostics, medicines and other provisions to treat opportunistic infections that particularly affect women and girls, such as cervical cancer.

- **The Global Fund to Fight AIDS, Tuberculosis and Malaria** should improve expertise on women's rights at all levels of the decision-making process, and develop adequate indicators to monitor that country coordinating mechanisms are reflecting the priorities and rights of women and girls.

- **Civil society** should undertake advocacy and raise awareness around women's rights to HIV and AIDS prevention, treatment, care and support, as well as hold governments to account for the realisation of these rights. They should also increase meaningful involvement of women in leadership and decision-making positions in their organisations to ensure issues related to women and girls' rights are prioritised in their work.

Worldwide commitment to the universal access goal – and the universal access process itself – provides an opportunity to strengthen advocacy for women's rights. Moving from recognition of the feminisation of HIV and AIDS to action is a major challenge. To date, this challenge has been met by devastating inaction. The solution requires both political commitment and resources. Those with power must listen to women's priorities, uphold their right to participation, support their empowerment and challenge those who violate their rights.

> *"When my husband was ill I went with my husband for medication, but when I'm ill I talk to the NGO staff."*
>
> Woman living with HIV and AIDS, Pakistan

Gideon Mendel/Corbis/ActionAid

Street vendors trained as HIV and AIDS educators perform an educational song in Bobole in Mozambique. They aim their message at truck drivers who buy their produce.

1. Introduction

> *"The HIV/AIDS epidemic has put the spotlight on deep-rooted constraints that hold women back in many areas of life. Traditional attitudes and behaviours change gradually, sometimes over several generations. This epidemic gives us no such luxury of time."*[2]
>
> Dr Margaret Chan
> Director-General of the World Health Organization

Most governments have committed to ensuring the rights of women and girls through the legal frameworks of international human rights. However, growing feminisation of the HIV and AIDS pandemic is damning proof of the failure by governments to deliver on their commitments. Gender inequality, violence against women and other violations of women's rights are critical drivers of the HIV and AIDS pandemic. Studies have affirmed gender norms to be among the strongest underlying social factors influencing sexual behaviour and HIV risk. Similarly, women and girls living with HIV and AIDS may experience particular stigma, discrimination and increased violence if their HIV status is disclosed. Despite the overwhelming evidence of the importance of discrimination against women, it has not become an integral aspect of the global AIDS response. By failing to acknowledge and respond to gendered aspects of the pandemic, not only are governments falling short on their commitments, their efforts to stem the spread of HIV and AIDS are destined to fail.

This report argues that only a rights-based approach can redress the current failures and support women in the response to HIV and AIDS. While firmly anchored in the treaties, declarations and commitments that make up international law, a rights-based approach places people squarely at the centre of the agenda. It empowers women and girls to claim their rights, and take control of their bodies and lives. It puts women and girls at the heart of policies and programmes, ensuring their meaningful participation by making governments and institutions accountable to them. It also places responsibilities on men and boys for respecting and promoting women's rights. It is our hope that this report will contribute to international advocacy efforts that go beyond mere rhetoric and make a tangible difference in the lives of the people we serve.

1.1. Structure of the report

> *"We will not be able to stop this epidemic if we don't address its drivers in the first place – gender inequality and its consequences for women. This will require that we go well beyond the gender rhetoric and be more operational in what we promote."*[3]
>
> Dr Peter Piot
> UNAIDS Executive Director

This report explores obstacles to universal access to prevention, treatment, care and support for all women and girls. It illustrates the ongoing violations of women's rights by the actions and inactions of those setting policies, providing funding, offering services and implementing programmes. It further provides working solutions and best practices for overcoming those obstacles. Such strategies were gathered through research studies conducted in 13 countries in which ActionAid and VSO work. While not an exhaustive review of women's rights, it incorporates the voices of our constituents to bring to life the particular challenges for women living in the era of HIV and AIDS. By weaving such everyday stories throughout the text, we hope to illustrate that rights are not just abstract principles, but rather tangible tools that fundamentally affect the wellbeing of women and girls around the world.

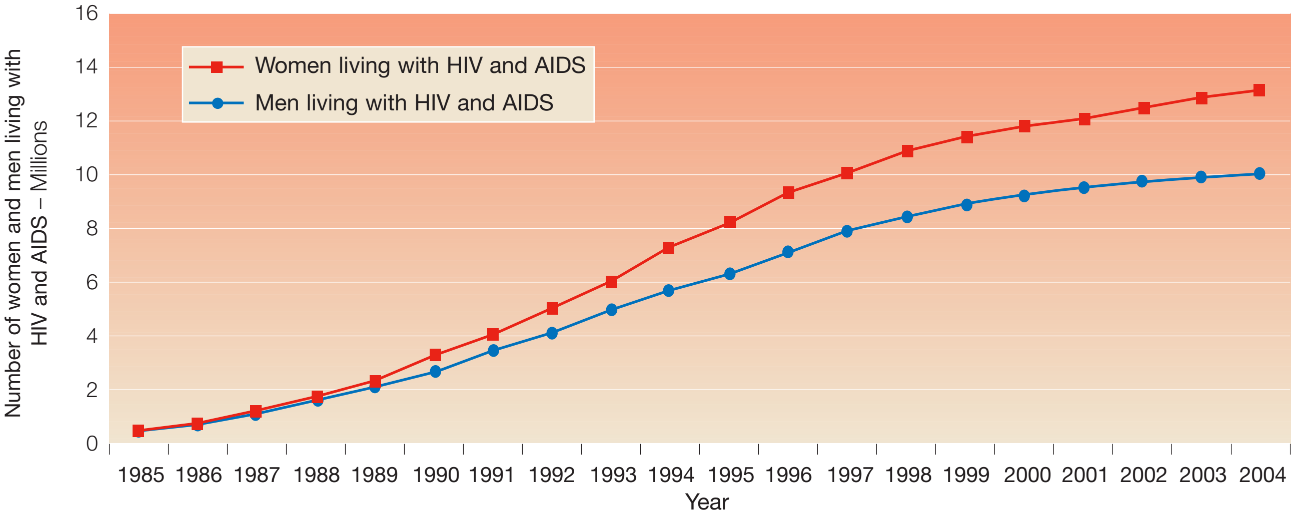
The report presents an overview of the ways in which women's rights affect every aspect of HIV and AIDS prevention, treatment, care and support. We begin in Chapter 2 with an overview of cross-cutting women's rights issues relevant to HIV and AIDS. Chapters 3 to 5 then examine the many barriers women face in accessing HIV and AIDS prevention (Chapter 3), treatment (Chapter 4), care and support, as well as the challenges faced by women care providers (Chapter 5). Finally, the report concludes by calling upon governments in rich and poor countries, as well as donors, multilateral organisations and civil society, to take specific steps to place women's rights at the heart of their response to HIV and AIDS. Throughout the report we have included recommendations for incorporating the rights of women and girls in the scale up to universal access.

Lastly, we use the term 'women and girls' throughout the report, while acknowledging that this does not represent a homogeneous category. However, we recognise that some women and girls are particularly vulnerable or marginalised, whether as a result of income, ethnicity, class, caste, religion, sexual orientation, age, disability, profession or other factors. There are specific challenges to realising the rights of each of these groups, made more complex and pressing by the many ways in which they are marginalised. While this report does not cover every kind of marginalisation, stories integrated into the report highlight some of the challenges faced by specific groups in the developing world, where ActionAid and VSO's work is focused.

1.2. Methodology

This report is a joint project between ActionAid and VSO, conducted between May and November 2007. It draws together desk-based research at international level and short participatory research projects commissioned from Bangladesh, Ethiopia, Guatemala, India, Mozambique, Namibia, Nepal, Nigeria, Pakistan, Rwanda, South Africa, Vanuatu and Zimbabwe. ActionAid and VSO programme staff and national partner organisations conducted the country level participatory research over a two-month period. They used a range of research methods including: focus groups of women living with HIV and AIDS, as well as specific vulnerable groups such as sex workers, in addition to focus groups of community care providers in both urban and rural settings; semi-structured and in-depth interviews with key policy makers in government, international non-governmental organisations (INGOs) and national coordinating institutions; and desk-based surveys of national research and policy to assess the legal and social context affecting women in those countries. Quantitative data was gathered through desk-based research. The information and stories gathered from focus group participants have both guided the content of the report as well as provided its most personal testimony.

Figure 1: Number of women and men living with HIV and AIDS in sub-Saharan Africa 1985-2004



(Source: UNAIDS/WHO estimates 2004)

1.3. Overview: the feminisation of HIV and AIDS

The 'feminisation of HIV and AIDS' is an often quoted recognition by governments and international organisations that women and girls are increasingly infected by HIV and AIDS, and carry many of the burdens related to the pandemic. Globally, the percentage of people living with HIV and AIDS who are women and girls has risen sharply from 41% in 1997[4] to just below 50% today.[5]

The vulnerability of women and girls to HIV and AIDS is particularly marked in sub-Saharan Africa. As the above graph shows, the difference in the number of women living with HIV and AIDS in sub-Saharan Africa now significantly outstrips the number of men. Women and girls in this region now represent nearly 60% of all those living with HIV and AIDS,[6] and as much as 75% amongst 15 to 24 year olds. In other regions, an increasing proportion of people living with HIV and AIDS are women and girls.[7] The reasons for the feminisation of HIV and AIDS are complex. As we discuss more extensively in Chapter 2, women and girls' rights violations leave them more vulnerable to HIV and AIDS and with limited access to HIV prevention, treatment, care and support services. Understanding the role of women and girls' rights in respect to achieving universal access to prevention, treatment, care and support is therefore crucial.

1.4. Universal access: what is it and why are we using it as a framework?

Providing universal access to prevention, treatment, care and support is the most recent and comprehensive commitment made in response to HIV and AIDS by the international community. These four pillars are now recognised as the indivisible elements of an effective HIV and AIDS response. First proclaimed by the G8 countries in 2005 at the Gleneagles Summit, and reiterated by other UN member nations in 2006 at the UN High-Level Meeting on AIDS, universal access sets the framework for both the UN system and, by extension, country-level response. As part of their commitment, countries promised to set national level targets to work towards the goal of "universal access to comprehensive prevention programs, treatment, care and support by 2010".[8]

There are two important limitations to using universal access as a framework for scaling up women and girls' access to prevention, treatment, care and support. The first refers to the actual definition of 'universal'. While we at ActionAid and VSO define 'universal' as access for everyone, UNAIDS has set specific targets for prevention, treatment, care and support. For example, the 2010 target for the 'treatment' goal has been set at 80% coverage of those who would die within one year without such treatment.[9] It is important that these targets are seen as a milestone towards reaching the ultimate goal of genuinely accessible services everywhere, for everyone.

The second limitation refers to the importance of (or lack of) gender as a factor in the universal access process. Governments ratcheted-up the significance of gender during the 2007 G8 summit, the first G8 meeting both to acknowledge the importance of women's rights in addressing the pandemic as well as to expressly make the link between HIV and AIDS and sexual and reproductive health.[10] And yet the lack of an explicit mandate to include gender issues on country-level targets is worrying. Lack of global targets to hold governments accountable means that attention to gender may be patchy and inconsistent. Indeed, because gender inequalities are deeply embedded in the social and cultural traditions of many societies, governments may be reluctant to take the bold steps required to create real change.

Nevertheless, as an internationally agreed goal, universal access represents an important framework on which to base our advocacy efforts. The term 'universal' indicates equality and equity between and for all people, and makes a strong link to the concept and realisation of human rights. 'Access' has two important meanings, both of which have to be recognised in this context. The first is that it recognises progress towards making services *available* everywhere and to everyone; the crucial second meaning is that people are empowered to *use* these services. In the absence of specified goals and targets, women's rights advocates are themselves in the position to influence country-level processes to ensure the goal of access is realised. This report, then, is part of a concerted advocacy effort to persuade policy makers of the importance of women's rights in the scale-up to universal access efforts.

1.5. Why take a rights-based approach to universal access?

> *"Understanding how rights can shift power relations is essential to realising the potential of rights to contribute to change."*[11]

A rights-based approach to HIV and AIDS uses the values of – and respect for – human rights and human dignity as a fundamental basis for realising universal access to HIV and AIDS prevention, treatment, care and support services. Conversely, the approach recognises that abuses of women and girls' rights sustain the spread of the virus and undermine attempts to contain it. Rights-based approaches identify rights-holders (and their entitlements) and corresponding duty bearers (and their obligations). Duty bearers, for example, have 'positive' obligations to respect, protect, promote and fulfil particular rights. In the context of HIV and AIDS, this promotional approach might include, for example, the provision of comprehensive sexuality education or protection of a woman's right to privacy in choosing whether or not to disclose her HIV status. Human rights approaches to HIV and AIDS also include 'negative' obligations, such as abstaining from rights violations. A government, for example, must not discriminate against women (or men) living with HIV and AIDS, must punish those who commit violence against women, and should provide redress for those making claims of abuse.

While historically governments have been considered the main 'duty bearers', there is increasing support for the idea of a moral, and perhaps a legal obligation on the part of donor governments to help realise human rights outside their borders.

Girls' forum, Pelelaza primary school, Likoni, Kenya.

ActionAid

International aid donors can play an important role in influencing the degree to which women's rights are prioritised at the national level. Donor influence gives them a responsibility to encourage and support recipient countries in incorporating rights into their HIV and AIDS policies and programmes. And yet this opportunity may present challenges for the donors themselves, who don't always have sufficient capacity and expertise on women's rights within their own organisations. Furthermore, tensions may exist between country ownership of the national HIV and AIDS response and conditions imposed by 'outsiders'. Whereas national ownership and building country capacity is of paramount importance for donors, women's rights often remain low priority at country level.

Duty bearers are responsible to rights-holders – individual citizens who can claim their rights and entitlements. These rights, explored throughout the course of this report, are our birthright as human beings, and they cannot be voluntarily given up or taken away. However, they are seldom defended and are all too often abused. HIV and AIDS and women's rights activists have used varied approaches to claim their rights.

One well-known example of the political participation of women living with HIV and AIDS has been the important presence and activism of women in the Treatment Action Campaign (TAC) in South Africa since 2001, although tensions regarding women's leadership of the organisation remain. The vast majority of volunteers who provided TAC with a critical grassroots mobilisation to challenge the pharmaceutical companies and the South African government were women living with HIV and AIDS. The women achieved this despite the hostility and rejection they experienced from their communities, friends and families, and at a time where their government did not recognise their rights as citizens. TAC very quickly became a struggle for new spaces of political participation, changing forever the concepts and notions of citizens' rights, from the local to the global level.

The legal status of universal human rights instruments varies. **Declarations (with the exception of the Universal Declaration of Human Rights), principles, guidelines, standard rules and recommendations** have no binding legal effect, but such instruments have an undeniable moral force and provide practical guidance to states in their conduct. On the other hand, **treaties, covenants, statutes, protocols and conventions** are legally binding for states that ratify or accede to them. For example, governments that have acceded to international human rights treaties are held accountable for fulfilling those rights. Each of the core human rights treaties has established a committee of experts to monitor implementation of the treaty provisions by states' parties. While governments are periodically required to submit reports detailing their progress towards realising those rights, civil society organisations can supplement the information available to the committee through the submission of shadow reports.

1.6. Achieving a rights-based approach to universal access

However, as this report illustrates, despite stated commitments, governments are failing to meet their obligations on HIV and AIDS and are reneging on their duties to protect women's rights. Many women and girls are denied adequate information and methods to prevent HIV. They are also subsequently denied the supportive environment necessary to adhere to treatment and to access care and support services. Furthermore, in the absence of state-run care and support services, women and girls are also expected to step in and care for others affected by HIV and AIDS. National AIDS strategies are currently providing very little hope for positive change (see Chapter 2). Furthermore, donors need to provide more and better funding for the delivery of HIV prevention, treatment, and care and support services, based on an assessment of women's rights. Multilateral organisations like WHO, UNAIDS and the Global Fund to Fight AIDS, Tuberculosis and Malaria need to lead the way by proactively promoting good practice.

1.7. Gender, poverty and HIV and AIDS

Poverty interacts closely with discrimination against women as a driver of HIV and AIDS. Poor people – the majority of them are women and girls[13] – are vulnerable to the effects of HIV and AIDS in particular ways, because of their lack of income, assets, education and low social status.[14] Poverty also limits people's ability to cope with HIV and AIDS, and can deepen that poverty by taking economically active adults out of work, either because of illness or as carers, and by forcing 'distress' sales of assets. Poor people, who in most low income countries live disproportionately in rural areas, are also less likely to be able to get access to publicly funded prevention, treatment, care and support services. Health expenditure in most high-prevalence countries is strongly biased in favour of urban areas, while both the direct costs of paying for treatment and the opportunity costs of reaching healthcare services make essential medicines an unaffordable luxury for millions of people. As a result, it is crucial that policies designed to achieve universal access not only realise women's rights, but also are expressly designed to meet the needs of people living in poverty.

A woman comforts her sister who has malaria, in the female general medical ward of Kamazu Central hospital, the second largest in Malawi.

2. Gender inequality, women's rights and HIV and AIDS

> *"Violence against women is a fact of life in India. A woman has the duty of pleasing her husband; if she refuses sex, she risks violence, abuse and abandonment. These women tolerate their husband's infidelity and abuse and submit to their demands to avoid further abuse, remaining in these relationships for fear of abandonment. The culture of silence is maintained and many view this violent relationship as 'normal'."*[15]
>
> *Walking the talk* research, India, 2007

Gender bias undermines the universal access effort at every step – from prevention to treatment, to care and support. This chapter explores some of the rights of women and girls that cut across the universal access continuum. We have grouped the rights under broader categories of sexual and reproductive rights, right to the highest attainable standard of health, and economic rights. As HIV and AIDS is not just a health issue, but an issue of social, cultural and economic inequalities, we focus on the interplay of abuses of these rights in hindering the universal access process for women and girls.

2.1. Sexual and reproductive rights and violence against women

All people have the right to control what happens to their bodies and to make personal decisions regarding when, how, and with whom they have sex. 'Sexual rights' refers to sexuality and human rights associated with physical and mental integrity, including the right to a safe sex life, the right to choose an intimate or life partner, and the right to sexual health information and services. Yet the prevalence of violence against women means that countless women around the world are denied that basic right. Whether forced into sex through expressly violent means, or coerced through early marriage, harassment or other societal pressure, women are often at great risk of contracting HIV.

Indeed, there is widespread recognition that HIV and AIDS cannot be addressed effectively without specifically addressing violence against women, particularly sexual violence.[16] The two issues are inextricably linked. HIV and AIDS are recognised as both a cause of violence (eg following a positive test) and a consequence of it (eg through rape or domestic violence). Domestic violence, rape and harmful traditional practices such as female genital mutilation (FGM) all increase women's risk of infection. Young women and girls are at particular risk of infection since they are more biologically vulnerable and may have less control over their sexuality.

Gender-based violence strips women of their physical autonomy and is explicitly or implicitly used by men as a means of control, enforcing many of the gender inequalities that we shall explore in this chapter. Recent research by the World Health Organization shows that sexual violence, particularly by an intimate partner, is a leading factor in the increasing 'feminisation' of the global AIDS pandemic.[17] However, recent research by the *Women won't wait* campaign has confirmed that this recognition is not yet reflected consistently (or, sometimes, at all) in the policies, programming and funding priorities of governments and donors at the national, regional and international level.[18]

The right to enter into marriage freely and to equality in marriage also affects women's – and in particular young girls' – likelihood of contracting HIV, as well as their ability to seek treatment, care and support. Worldwide trends show that married women may in fact be at greater risk than unmarried women for contracting the disease. In Bangladesh, for example, one focus group with women belonging to the self-help group MUKHTO AKASH, stressed that the majority of women living with HIV and AIDS are married women infected by their husbands, who are often migrant workers, or in monogamous relationships.[19] Indeed, the executive director of the Confidential Approach to AIDS Prevention (CAAP), argued that in Bangladesh it is widely considered a *"man's innate right to indulge in unsafe sex with their wives. These women are infected by their husbands and then are blamed by society for infecting their husbands."*[20] In Rwanda, members of a focus group reported how their husbands had beaten them because they once refused to have sex if no condom was used.[21] Sexual rights are often abridged in the case of an 'early' or child marriage, especially where a dowry has been paid. Dowries are often considered 'an outright purchase of a wife'.[22] As a result, wives who do not 'measure up' may be denied information or control over their lives and in some cases are victims of violence.[23]

Reproductive health and rights are also critical for stemming the spread of HIV and AIDS. A majority of HIV infections worldwide are sexually transmitted or are associated with pregnancy, childbirth or breastfeeding. Women who become pregnant after sex with an infected partner face particular challenges. These women are more likely to be aware of their HIV status, because of the prevalence of pre-natal testing. However, women living with HIV and AIDS may be advised against continuing their pregnancy. In cultures where women's value is strongly linked to their maternal abilities and where childbearing brings social status and economic support, stigmas arise around a woman's real or perceived infertility. (See Chapter 3 for more discussion on sexual and reproductive health and rights in relation to HIV prevention).

Choices around childbearing may be most acute for young, married women living with HIV and AIDS. On the one hand, women who choose not to have children or to stop childbearing before having the socially expected number of children, may be stigmatised for breaking social and gender norms. On the other hand, communities frown upon women living with HIV and AIDS having children, and tend to blame them for infecting their children. *"In India, motherhood is perceived as the ultimate validation of womanhood. With the increasing risk of married, monogamous women contracting HIV… women [are commonly] stigmatised and blamed for passing the infection to her unborn child. Blame is accentuated if a male baby becomes infected, due to the high value already awarded male children."*[24]

HIV-positive mothers also may need to take precautions to prevent mother-to-child transmission, such as using breast milk substitutes. However, in cultures where breastfeeding is commonplace, women who don't breastfeed may be condemned by relatives or other members of the community. Failure to breastfeed is often seen as tantamount to an admission of HIV-positive status. Even women aware of the risks of breastfeeding may continue the practice because of the fear of being stigmatised or because of economic dependence on husbands who can't or won't give them money for formula. Stuck between contradictory cultural expectations, these young women can be said to face 'multiple, simultaneous stigma'[25] (see Chapter 3 for more on prevention of mother-to-child transmission plus).

2.2. Right to the highest attainable standard of health

> *"When my husband was ill I went with my husband for medication, but when I'm ill I talk to the NGO staff."*[26]
>
> Woman respondent, *Walking the talk* research, Pakistan, 2007

Many women and girls living with HIV and AIDS, especially those who live in poor, rural communities, find it difficult to take care of their health. In some cases they face discrimination from health professionals that further violates their rights. As one woman in Nepal reported, *"When I visited Teku Hospital for getting my quota of ARV for that month, there was a new nurse there. When I asked her for ARV, she looked at me from top to bottom and made a comment 'you look so pretty, you must have been involved in some immoral behaviour, that's why you got this virus'."*[27] Such discrimination and stigma, coupled with inadequate training around HIV and AIDS, has resulted in some women receiving poor treatment or inaccurate information from health professionals in comparison to that given to men:

> *"A man gets priority treatment with politeness from the nurses while a woman in pain screams in the background. A woman is also most of the time shouted at and dismissed easily when they are late for medication. If the medication is not available they are told to go home, not considering the distance that they have travelled to get there."*[28]

The International Community of Women Living with HIV and AIDS (ICW) has highlighted many incidents of women living with HIV and AIDS who have been advised to have terminations or sterilisations, have been given misinformation about child-bearing options, prevention of parent-to-child transmission and breastfeeding, or encountered fear or judgement from healthcare workers.[29] In research for this report in China, for example, one focus group participant reported that she had been forced by healthcare professionals to have a termination of her pregnancy because she was living with HIV and AIDS.[30] Research in Namibia has found that healthcare workers do not make medical information accessible to their clients, thus denying their right to information. Women in Namibia reported that they often do not understand what healthcare workers are telling them about their health or treatment.[31]

As a result, many women and girls are reluctant to access or return to healthcare facilities. All participants in one focus group in India, for example, agreed that women and girls find it difficult to visit clinics compared to men, mainly because of stigma and discrimination, and the fear of being branded as sex workers.[32] Furthermore, many cases exist of health professionals violating women's right to privacy by notifying others of their HIV status. For example, one woman interviewed by ICW reported the following:

> *"I got pregnant and was happy about that. But, after the delivery, I got ill. They did a test without my knowledge. And then the staff didn't treat me so well. And then, instead of telling me the result, they announced it to my husband! No one said anything about it to me. I had no idea what was going on. People began to treat me strangely, but I didn't know why. It was only four months later that my husband told me I was HIV-positive."*[33]

According to the Positive Women's Network (PWN+) in India, some health systems also fail to provide adequate treatment for opportunistic infections commonly affecting women living with HIV and AIDS. PWN+ found that a lack of trained medical staff specialising in these areas has resulted in a dire shortage of medical diagnostics, treatment and care for many opportunistic infections experienced by women.[34] Similarly, despite growing evidence that HIV and AIDS predisposes women to cervical cancer regardless of age, ICW found that many health professionals in South Africa and Swaziland refused to screen women living with HIV and AIDS for cervical cancer,[35] thus violating their sexual and reproductive rights. As one woman in Sibasa, South Africa reported, *"I tested HIV-positive in 2003. To date I have not been asked about a pap smear or anything like that at my clinic."*[36]

There are also more practical concerns that women have. In Bangladesh, for example, one focus group expressed concerns that, at one state-owned hospital, women were placed in mixed-sex general wards regardless of their ailment, while men with certain ailments were placed in men only wards.[37] One focus group in India also expressed a wish for health services to provide a separate section for women in clinics and hospitals as well as a good attitude to patients, female doctors, provision of house visits and provision of childcare facilities.[38]

The burden of unrecognised domestic and informal work, including caring for others (see Chapter 5) means that many women are simply not able to find time to realise their own right to health. The need to make childcare arrangements or to take time off work may prevent many women from accessing health clinics, particularly those who work in the informal sector where sick leave and other employment rights may not exist. Finally, because of costs such as transport to health facilities or user fees for accessing medical services, formal medical care may simply not be an option for many women and girls, even for those with a regular income. Richard Bauer, Chief Executive of Catholic AIDS Action in Namibia, highlighted this tension:

> *"People need to make a decision on either buying food for their family or spending money on transport to access a medical facility. Most people decide to go for the short-term solution and provide food to their family."*[39]

Restrictions on freedom of movement further mean that some women are not allowed to go to the doctor alone or without permission from a male relative. In Malawi, Nigeria, Mali and Burkina Faso, 70% of women surveyed said their husbands made the decisions regarding their healthcare.[40] In rural areas of Limpopo province in South Africa, some women we spoke to regard men as the head of the family and every family member is expected to follow his words. Women told researchers that they find it difficult to seek help because this action alone might lead their husbands and their husbands' families to suspect she is doing something against her husband's will. Even leaving the house of their own accord may place a woman's motives under suspicion. In such a situation, it is hard for women to realise their health rights by going to a clinic or to seek support for fear of being diagnosed as sick and being blamed for her illness.[41]

The stress and impact of restricted mobility, of the financial cost of healthcare, and of the time spent travelling to healthcare facilities is well articulated by one woman from Nepal, who feared seeking the permission of her parents-in-law to travel to a treatment centre:

> *"This time I said I am going for some check up but in future when I need to travel repeatedly, I don't know what I should say to seek their permission. Kathmandu is very far from my home and I can't bear the repeated travelling cost."*[42]

Indeed, costs and financial considerations are a significant impediment to universal access, as we explore in the next section.

2.3. Poverty and economic rights

> *"If you want me to have sex with a condom, I won't give you any money for food."*[43]
>
> Partner of member of Women against Women Abuse, South Africa

Poverty is a major driver of HIV and AIDS. It is also inextricably tied to women's rights, as women make up a majority of the world's poor population. Globally, women are more likely than men to work in the informal sector with low earnings, little financial security and few or no social benefits such as free or subsidised anti-retroviral treatment, or food supplements. Furthermore, a woman's earned income is on average approximately half that of a man's in sub-Saharan Africa, falling to 40% in Latin America and South Asia, and 30% in the Middle East and North Africa.[44]

Feminised poverty is also linked to women's lack of ability to administer and own property. Some women and girls also have limited control over household income and assets, despite their right to own and administer property. In sub-Saharan Africa, for example, title deeds to land are normally issued to male heads of household.[45] In Kenya, women hold only 1% of registered land titles and around 5-6% of registered titles are held jointly with others.[46] Even upon inheritance, many women and girls face eviction from family property because of disputes with members of their husband's or father's extended family.[47] Such property grabbing is common as women and girls are thrown off their land by husbands/partners and their relatives.

Furthermore, legislation, where adopted, may not give women equal protection under the law. The Indian Hindu Succession Act 1956, for example, recognised the right of women to inherit the property of their father. However, this Act does not apply to women belonging to non-Hindu religious communities and is rarely implemented even in the case of Hindu women.[48] Without property and inheritance rights, women and girls living with HIV and AIDS, widowed or abandoned by their husbands or families, may be left penniless and destitute.

Poverty and the resulting economic dependency of many women and girls often means that they are forced to rely on, and stay with, their male partners, even in violent or abusive relationships. Furthermore, it gives them little power to negotiate safe sex, even when they know that their partners are HIV-positive or have multiple sexual relations. In Zimbabwe, for example, *"although women knew their sexual rights, they fear* *imprisonment of their husbands and the consequent loss of income if they reported sexual violence by their partners."*[49] Early marriage and relationships with 'sugar daddies' often represent a form of economic exchange which leave women and girls with little power. In situations of extreme poverty, sex serves as a survival strategy, where women balance immediate needs of food or shelter with the more distant and abstract prospect of contracting a disease.

This same economic dependency forces many women and girls to disclose their HIV status and ask their male partners or guardians for money for medication or transport.[50] According to the Zimbabwe study, "*some women living with HIV and AIDS had been deserted by their husbands,"* and *"many were facing problems in raising funds for AIDS treatment, including CD4 cell counting services".* Even when her partner stands by her, such dependency can leave women more vulnerable to interruptions in their treatment. In Uganda, for example, *"if the husband dies, most of the widows are dependent and their lives change so abruptly".*[51]

In fact, socio-economic barriers are a major reason women are unable to access treatment, care and support. In many countries, prohibitively high hospital fees combined with other expenses are a major barrier to access. According to research in Nepal undertaken for this report, *"The major obstacles faced by these women… are associated with regular cost to Kathmandu, and to clinics for CD4 count and ART coupled with the time lost due to long travel time and few days stay in Kathmandu and thus time lost from regular income generation work and childcare."*[52]

The burden of HIV and AIDS care places a heavy toll on women and girls, affecting their financial productivity, among other things. Up to 90% of care is provided in the home, and the principal givers of physical and psychosocial support are women and girls.[53] In one region in Ethiopia, for example, about 85% of care providers (the majority of whom are women) spend their time providing care and support to home-based patients and have no other sources of income to support their families.[54] It is often taken for granted that such women will continue to provide unremunerated care and support to infected and affected family and community members. Lesser known is the cost of this care, how it affects economic, societal and familial relations, and – last but not least – the women and girls themselves (see Chapter 5).

2.4. Recommendations

Donor governments

1) Donor governments should consult with women's movements, local networks and movements of women living with HIV and AIDS to ensure donor funding reflects local priorities of the people living with and affected by HIV and AIDS. They should also ensure that their policies and programmes do not reinforce inequalities.

2) Donor governments should fund civil society and legal aid organisations to support women living with HIV and AIDS to establish test cases, research, monitor and report women's rights violations, and to lobby and advocate for reform of laws and policies that discriminate against women.

3) Donor governments should ensure long-term, predictable funding for the strengthening of health systems, in particular to ensure women-friendly health systems that integrate HIV and sexual and reproductive health rights (SRHR) services.

Multilateral organisations

1) The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization should develop clear guidelines and a strategy to support country governments to develop a human rights-based analysis of the barriers faced by women and girls for scaling up HIV and AIDS action. This can be done in conjunction with local Human Rights Commissions.

2) The Global Fund to Fight AIDS, Tuberculosis and Malaria should improve expertise on women's rights at all levels of the decision-making process and develop adequate indicators to ensure that country coordinating mechanisms are reflecting the priorities and rights of women and girls.

3) The second independent evaluation of UNAIDS must analyse the degree to which women's rights in relation to HIV and AIDS are addressed by UNAIDS and its co-sponsors. It must make clear recommendations around women's rights to improve UNAIDS' effectiveness.

Developing country governments

1) National governments should base national HIV and AIDS strategies on a human rights-based analysis of the barriers faced by women and girls in regard to HIV prevention, treatment, care and support services. This should have the participation of women and girls, living with and affected by HIV and AIDS, at its heart.

2) National governments should tackle stigma and discrimination head on by establishing and enforcing anti-discrimination laws, investing in national stigma reduction campaigns and by providing training for doctors and healthcare workers on the rights of women and girls living with HIV and AIDS. Governments, donors and civil society should also be careful about how public information campaigns transmit messages in order to avoid stigmatising messages.

3) National governments should provide training and funding and put systems in place to ensure that adequate staffing, diagnostics, medicines and other provisions are made to treat opportunistic infections that particularly affect women and girls, such as cervical cancer. Governments must invest in training female healthcare workers and other medical professionals.

Civil society organisations

1) Civil society should prioritise capacity building in women's rights-based programming in their HIV and AIDS responses.

2) Civil society organisations in developed and developing countries should prioritise women's rights advocacy and campaigns at all levels.

3) Civil society should ensure that a human rights approach to the barriers faced by women and girls is at the heart of their programmatic interventions.

Young people march in a street protest against an alleged child abuser in the poor Lagos neighbourhood of Ajeromi, Nigeria.

3. Women's rights and universal access to HIV prevention

The political declaration on HIV/AIDS adopted by the UN General Assembly in 2006 reaffirmed the centrality of women's rights in HIV prevention.[55] Governments pledged *"to eliminate gender inequalities, gender-based abuse and violence; increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection."*[56]

Such ambitious goals necessitate multi-pronged strategies. Whereas critical areas of HIV prevention have already been explored in Chapter 2, including issues around sexual and reproductive rights and violence against women, this chapter examines a variety of complementary strategies to empower women (and men) to protect themselves against contracting HIV. These strategies can be roughly divided into the categories of 'information', including formal and informal education and awareness-raising to promote behaviour change; 'technologies' and medical interventions, including condoms, microbicides, circumcision, and post-exposure prophylaxis; and services such as voluntary counselling and testing. A few of the strategies, such as prevention of mother-to-child transmission plus, can be considered cross-cutting, as they involve elements of all of these strategies. No strategy will succeed if tackling gender inequality and women's lack of power to use HIV prevention is not at its heart.

3.1. Women's right to education and information

Sexuality education in schools

In the absence of a cure for HIV and AIDS, education has been called a 'social vaccine' for preventing HIV. Research in a variety of settings asserts that educated girls are more likely to know the basic facts about HIV and AIDS, more empowered to negotiate safe sex, may be more likely to delay sexual activity, and are less likely to suffer from sexual and gender-based violence.[57] Women with at least a primary education are three times more likely than uneducated women to know that HIV can be transmitted from mother to child.[58]

Schools play a crucial role in providing vital information on HIV prevention. They are often the only method for delivering information on HIV prevention, especially in remote places, or where access to family planning information only exists for married couples, such as in Vanuatu. Recent statistics make it clear that young people need better access to accurate information on safer sex. According to UNAIDS, *"though the Declaration of Commitment on HIV/AIDS aimed for 90% of young people to be knowledgeable about HIV by 2005, surveys indicate that fewer than 50% of young people achieved comprehensive knowledge levels."*[59] In Zimbabwe, adolescents associated with this study *"showed ignorance of sexual and reproductive rights"* as well as negative perceptions about condoms which they associate with lack of trust among partners.[60] In Vanuatu, girls openly said that they were afraid to ask to use condoms *"in case they were accused of being promiscuous"* and showed a clear lack of knowledge and familiarity with their bodies when acknowledging their anxiety to use condoms for fear that *"they would get stuck"*.[61]

Education also plays a second, crucial role in *"empowering young women to take control of their sexual lives."*[62] Studies have shown, for example, that "completion of secondary education was related to lower HIV risk, more condom use and fewer sexual partners, compared to completion of primary education".[63] We also know young people are more likely to delay sexual activity if they receive correct and unbiased information, allowing them to make informed decisions.[64] For example, highly educated girls and women are better able to negotiate safer sex, having an impact on HIV rates.[65] Given the predominance of pressure to enter into high-risk sex, this is especially important. In research completed in Nigeria, South Africa and Vanuatu, boys were generally quoted as wanting to have 'skin to skin' sex.[66] In South Africa, for example, HIV prevention strategies involving life-skills programmes focusing on HIV and AIDS in schools were found to be *"not appropriate for women who are poor and vulnerable to violence"* because they do not *"dig deep into the dynamics of gender inequality and arm young women and men to transform the cycle of inequality and gender-based violence in society."*[67]

Taught properly, sexuality education can begin to change harmful gender stereotypes and empower boys and girls to make choices about healthy sexual behaviours, including protecting themselves from HIV. Information given must be comprehensive and evidence based, and lessons must go beyond presenting biological facts to providing a space for girls and boys to discuss, challenge and analyse gender relations. This should include gender equality, girls' empowerment, mutual respect, gender-awareness education for boys and girls, and empowerment training for girls. Information should be fully integrated in school curricula in consultation with the community, local leaders and gatekeepers. An example of good practice is the new curriculum developed last year in Nigeria for comprehensive sex education targeting 10-18 year olds. It aims to increase their knowledge and change their attitudes to sexual health and reduce risky behaviours. In the past such measures would have faced strong opposition on religious and cultural grounds, but this time the curriculum was developed in consultation with religious and community leaders, showing promising signs for long-term implementation.[68]

To enable effective sexuality education, governments must invest in girls' education to send the strong signal that their education is just as important as that of boys. Although, worldwide, girls' enrolment has gone up, gender inequality in accessing education remains an important issue,[69] in particular in sub-Saharan Africa.[70] The efforts must be sustained at all levels of education since gender inequality in accessing secondary education stems from disparities in primary education.[71] In Vanuatu, as in many countries surveyed, *"boys in the family get priority if resources are limited."* Educating girls was seen as a *"waste of resources if you just want her to stay home,"* since *"educating women might encourage them to look outside the home"*.[73] This shows that family and marriage are still often wrongly perceived as safe havens for girls whose worth is still exclusively tied to their roles as mother and care provider.

In order to maximise the educational benefit of schooling and to promote girls' safety and empowerment, girls must be free from violence in the school setting.[74] Growing evidence of sexual violence and exploitation in schools shows that girls (and less often boys) experience rape, assault and sexual harassment both by teachers and male students. In some countries, it is considered an inevitable part of the school environment.[75] Research in Ghana, Malawi and Zimbabwe demonstrates the role of schools themselves in sanctioning sexual and gender-based violence.[76] According to the study, this includes male teachers and pupils propositioning girls for sex, teachers and students using language sexually explicit and degrading for girls; and teachers dismissing boys' intimidating behaviour as a normal part of 'growing up'. Violence and fear of violence are important reasons for girls not attending school. In fact, many cases go unreported because of fear of stigmatisation by the family or broader community.[77] As long as the state, officials, the police and prosecutors pass the responsibility to each other, leaving perpetrators unpunished, girls' right to bodily integrity will keep being violated.[78]

Women's rights and awareness-raising: from awareness to behaviour change

In some rural areas, state-sponsored health or education services are not available. The existence of accessible, reliable information in these areas is especially important because of high levels of ignorance and misinformation about HIV and AIDS. In Nepal, for example, *"the rural female, though classified as a low risk population, is in fact at extreme high risk due to a deeply rooted traditional discrimination belief system that regards the discussion of HIV and AIDS as being taboo, their traditionally lower, unequal social status and limited access to means of protection rendering them vulnerable to infection."*[80]

In such circumstances it is often civil society that provides information about how to prevent HIV and AIDS. In other rural areas where health and education services are available but limited, civil society plays a crucial role in disseminating information on HIV prevention. For example, one woman in the rural province of Limpopo, one of the poorest regions in South Africa, said:

> *"Without the NGOs, we would have very little information. Indeed, many of us would just die of ignorance."*[81]

Efforts to raise awareness in rural areas about HIV prevention must therefore be increased through national and local campaigns. A rights-based approach to public awareness-raising campaigns on HIV prevention requires key messages to be tailored for women and girls. As one focus group participant in Nigeria said:

> *"Women and girls need prevention messages tailored peculiarly to the needs of women, the use of such messages on men worked for family planning and the same can be used to tell women that using [a] condom is also their right."*[82]

For example, information must be available in local languages in order to ensure that women have access to the information they need to make informed HIV-prevention choices. Local clinics should have up-to-date materials displayed on the walls or available for patients to take away. Information must also be made available through multiple means in order to increase its accessibility, for example to illiterate women and girls. One focus group in India suggested street theatre should be used to target unique locations frequented by women, such as markets, places of worship and primary schools.[83] In Nigeria, women and girls cited radio campaigns and the engagement of celebrities and

Box 1. Female guardians *(mlezi)*, Tanzania

A good practice in this area comes from Tanzania, which instituted a 'female guardian' programme in primary schools. This initiative trains guardians or *mlezi*, one per primary school, to give advice in cases of sexual violence or harassment and other issues related to sexual health and HIV and AIDS. The programme began as an HIV-prevention effort when girls identified sexual coercion as a major issue affecting prevention efforts. Mlezi are teachers chosen by their colleagues and trained to give advice and advocate for girls in cases of wrongdoing. An evaluation of the programme has shown that the establishment of mlezi has significantly increased the reporting of sexual harassment or violence in the schools.[79]

Box 2. The Climbing to Manhood Project, Chogoria hospital, Kenya

In Kenya, the Climbing to Manhood Project of Chogoria hospital uses the practice of circumcision, a traditional rite of passage, to address issues around young men's sense of manhood and masculinity. During the time of circumcision around the age of 15, boys are expected to undergo physical, psychological and behavioural changes associated with manhood, and may be encouraged to begin having sexual relations. Chogoria hospital recognised the time around this ceremony as an opportunity to inform boys about sexual health. Incorporating the seclusion and bonding that occur as part of traditional circumcision rites, groups of boys participating in the project spend a week together in a special ward following hospital circumcision. Men from the community including healthcare workers, pastors and teachers explore a range of topics with them including STIs and HIV and AIDS, community expectations of men, and issues surrounding violence.[92]

musicians as good sources of HIV-prevention messages.[84] In South Africa, women mentioned *Soul City* and *Lovelife*, TV programmes that have been targeting youth with HIV-prevention information. *Soul City* has in fact been very successful in its outreach and replication in other countries of the region, including the creation of school clubs. International donors, including DFID, fund the project and it provides a clear case of good practice. Governments and donors should fund additional and large-scale programmes that raise awareness of HIV prevention with the participation of women and girls. These campaigns must go hand in hand with programmes challenging gender norms so that women and girls' knowledge about HIV and AIDS is accompanied by the necessary power to negotiate safer sex.

Public campaigns must also reflect women's rights, the need for women's empowerment and women's leadership in order to be effective. The ABHAYA project in India, for example, raises awareness among vulnerable and excluded groups of their rights and entitlements. The project has had substantial success basing HIV-prevention messages on women's rights. As one sex worker explained:

> *"Here I learnt that if we sex workers unite, we will be able to get our rights. We talked about violence and how we can protect ourselves from violence, and that we have the right to ask questions. I come to ABHAYA for the monthly support group meetings and visit the STI clinic regularly. I have also learnt about safe sex and HIV and AIDS after coming here and have started insisting on using condoms ever since."*[85]

However, among the women interviewed for this research, this experience seems to be the exception rather than the rule. Many women and girls remain unaware of their rights. Some members of a focus group of women living with HIV and AIDS in Bangladesh, for example, argued that women are *"usually unaware of their basic rights"*.[86] For other respondents, women seemed to be *"programmed from an early age to think of themselves as unequal and thus they are not aware of their rights as individuals"*.[87]

Finally, women and girls' access to HIV prevention information and services often lies in the hands of husbands, fathers, community leaders and service providers who play the role of gatekeepers. For example, women and girls are often deliberately left in the dark regarding their husband's HIV status as well as their own. One focus group in Bangladesh reported cases of women whose husbands had infected them knowingly and subsequently refused them or their children an HIV test.[88]

> *"When a male is identified as positive, it often takes considerable convincing and coercing for them to get their families tested"* [and the husband] *"always makes that decision."*[89]

To resolve this, one focus group participant in Nigeria emphasised that:

> *"Messages should be made in such a way that they give power to women to freely make choice[s] and take decisions on usage of prevention tools like condom[s]."*[90]

In particular, community awareness-raising initiatives need to be long-term, strategic and sustainable.[91] They need to enable women to increase their participation, power and equality in the community and family spheres, lead men to act responsibly and respect their wives' rights, and enable women and girls to share their positive status publicly without violence, stigma and discrimination.

Abstinence, Be Faithful, Use a Condom (ABC)

> *"A lot is being done on the preventive aspect; however these activities are limited to what the government considers 'high-risk' groups. HIV/AIDS can strike anyone at any time; it does not discriminate between age, gender or race. The preventive measures should be directed towards everybody, not just those who are considered to be under threat of infection."*[93]
>
> *Walking the talk* research, Bangladesh, 2007

ABC has become the most common HIV-prevention approach for many governments and NGOs around the world. However, ABC fails to consider the need to put HIV prevention directly into the hands of women and the influence of powerful conservative lobbies, many of them faith based, has often detrimentally skewed the ABC strategy further. According to numerous studies, abstinence-only approaches have little proven benefit. For example, a recent study in the United States of HIV 'abstinence only' and 'abstinence plus' programmes (promoting comprehensive safe sex strategies including condom use) indicated that the former do not decrease sexual risk among youths and *"do not encourage abstinent behaviour but instead are ineffective for preventing or decreasing sexual activity among participants"*. 'Abstinence plus' participants generally knew more about HIV and AIDS.[94] The emphasis upon 'being faithful' also risks presenting marriage as a risk-free environment for women and girls who are not living with HIV and AIDS. As we have seen throughout the course of this report, marriage in fact is a main risk factor for women in contracting HIV.

This shift in emphasis is in large part the result of US policies initiated through the President's Emergency Program for AIDS Relief (PEPFAR), the largest global health grant ever announced by any donor government. The original $15 billion (now proposed to increase to $30 billion) HIV and AIDS grant provides a huge influx of new resources to countries with the greatest need, primarily those in sub-Saharan Africa. PEPFAR thus has the potential to change not only the course of the pandemic, but the politics and priorities around condom-based prevention.

PEPFAR stipulates that one-third of HIV prevention monies must be spent on abstinence-only interventions. It advocates condom promotion only for so called high-risk groups such as sex workers and truck drivers, and couples where only one partner is infected.[95] According to ActionAid research in Nigeria, *"PEPFAR funds focus on abstinence and fidelity education, mother-to-child transmission and blood safety… Condom marketing will be improved, but only for those thought to be at high risk of being infected, such as prostitutes and truck drivers. Condoms will not be marketed to young people or married couples."*[96] Such an emphasis ignores the local context in Nigeria and similar high-prevalence countries. Indeed, PEPFAR does not recognise marriage as a risk factor or include married couples as a focus of its programming interventions. By designating certain groups as 'high risk', the programme not only promotes stigma and discrimination, but implies that other groups are somehow immune from HIV. Furthermore, its focus on couples where only one partner is infected is futile in countries where the majority of people are unaware of their HIV status.

3.2. Technologies and medical interventions: putting prevention directly in women's hands

Condoms

Condoms are the most effective method of HIV prevention currently available. However, many women and girls do not have sufficient resources, information, knowledge or negotiating power in their sexual relations to demand the use of a male condom. One sex worker in India explained that at the time of her infection, *"I did not know anything about safe sex. Some clients brought condoms that they used but [I] had no idea why it was used."* Even when women have the information, cultural expectation among both men and women can block condom use. As one Zimbabwean woman living with HIV and AIDS reported:

> *"…my husband tested positive before me, but my aunties together with my late husband disapproved [of] condom use, arguing that he had paid up all the bride wealth and therefore [I] was supposed not to deny him sex, unprotected or not… they accused condom use with lack of love for my late husband… everyone was against me and [I] had no option… [ended in tears]."*[97]

Similarly, one woman in South Africa explained:

> *"because of Venda culture, men initiate things. So if a man does not initiate condom use, we don't use it. We think female condoms will help. It won't be easy because he can think I want to use a condom because I am having an affair."*[98]

Although many women and girls may still need to negotiate using the female condom, it may mitigate some of the problems facing women and girls. In South Africa, for example, women surveyed were eager to see more female condoms, arguing *"that way we do not have to ask the man because the condom is in my body."*[99] Despite this interest, the female condom has never been promoted or distributed on the same scale as the male condom. In Nigeria, for example, most women and young girls did not know what a female condom looked like.[100]

Health officials and donors argue that this is the result of cost. The current cost of a female condom is approximately ten times the cost of most male condoms,[101] although this could be reduced with high-volume distribution and global purchasing.[102] The South African government, which has one of the largest female condom programmes in the world, is still distributing less than 3 million female condoms per year, compared to 386 million male condoms annually.[103] According to a recent study, increasing female condom distribution to 10% of current male condom use could avert a further 10,000 infections annually.[104] Furthermore, UNAIDS' recent guidelines to scale up HIV prevention efforts in-country[105] barely mention female condoms, and most governments and donors have not increased financial support to develop cheaper alternatives for production of the female condom.

While promoting male condom use can help to foster greater responsibility amongst men for their actions, and protect them against risk, there is a risk that an over-emphasis on male condoms reinforces men's control over sexual relations, at the expense of women. Governments and donors must take urgent action to invest more in female condoms, raising awareness of their availability and empowering women and girls to use them. As expressed by one South African interviewee: *"It can be difficult introducing new things, but male condoms became known because they were made available, we were not born with them here. We think it will be easier for young women. They will be interested to test new things."*[106]

Simon Rawles/VSO

Halima is an HIV and AIDS peer educator for Aparaje, a local NGO for street children in Dhaka, Bangladesh. She works with young people explaining the realities of HIV, trafficking and abuse.

Microbicides

Microbicides are products, in the form of a gel, cream, film, suppository, sponge or vaginal ring, which would gradually release an active ingredient to block or disable the HIV virus. While they do not yet exist, both contraceptive and non-contraceptive microbicides are under development, to allow women the option of becoming pregnant while remaining protected against HIV transmission. Such products would protect women's right to health, but also allow them to realise their reproductive rights.

Microbicides represent a crucial advance in female-initiated HIV prevention methods, increasing women and girls' control over their body and sexual autonomy by giving them the power to protect themselves. Indeed, research by the London School for Hygiene and Tropical Medicine and the Rockefeller Foundation indicates that access to and regular use of a microbicide by just 20% of women, even when only 60% effective, "could result in 2.5 million HIV infections averted among females, males, and children in lower income countries".[107]

There is increasing scientific confidence that with sufficient funding, a safe and effective microbicide could be developed within five to seven years. However, almost all microbicide research is conducted by publicly funded, non-profit and academic institutions, or small biotech companies. Large pharmaceutical companies *"have not yet invested, primarily because microbicides are a classic 'public health good' which would yield tremendous benefits to society but for which the profit incentive to private investment is low."*[108] External funding is therefore crucial. According to the Global Campaign for Microbicides, approximately US$280 million is needed per year over the next five years.[109] Donors and governments must invest more in the development of microbicides and subsequent distribution in parallel to investment in female condoms, and in programmes to increase women's power to negotiate safer sex within relationships.

Male circumcision

Recent research suggests that male circumcision offers men and boys added protection from HIV and AIDS. However, many unanswered questions must be resolved before it is considered a safe and effective HIV-prevention method for both women and men. Furthermore, given women and girls' limited negotiating power, emphasis on male circumcision should not come at the expense of female-controlled HIV prevention methods.

Research on male circumcision so far has mostly focused on reducing sexual transmission of HIV and AIDS from women to men,[110] largely neglecting the impact it may have on transmission to women, as acknowledged by UNAIDS and the WHO. Indeed, research has shown that there is no clear sign of increased protection for women when men are circumcised.[112] In fact, there is concern that circumcised men may feel they no longer need to use condoms.

As a result, donors, governments and multilateral organisations must be careful not to promote male circumcision in isolation from other, female-controlled HIV-prevention methods, including female condoms. Furthermore, information on male circumcision must be accurate and presented in a way that promotes the rights of women and girls and emphasises male responsibility.

Post-exposure prophylaxis

Post-exposure prophylaxis (PEP) is a short course of antiretroviral therapy that, if delivered promptly after exposure to HIV, may reduce the risk of infection. Many European countries,[113] Botswana,[114] South Africa,[115] the WHO and others recommend it as a crucial protection for health professionals from HIV. Yet PEP remains unavailable in many countries to community care providers (see Chapter 5), sex workers and victims of gender-based violence, the majority of whom are women.

PEP is most effective when delivered within 24 hours of exposure, so it is crucial that it is easily accessible. For women and girls who are the victims of sexual violence, this can cause particular problems. They may be too traumatised to report the crime. When they do, police specialised in sexual violence cases must act swiftly. A lack of training or awareness may leave women or girls who are already victims of violent crime deprived of their right to health and their right to enjoy the benefits of scientific progress.

For example, women interviewed in South Africa[116] complained of the lack of protection by state actors, the inefficient processes to claim their rights, and the indifference and lack of response by the police. As one woman said, *"Our biggest problem here is that the dockets get lost and cases get dismissed."*[117] Staff from the Thohoyandou Victim Empowerment Project also quoted incidences where women who complained of domestic violence were told to come back with real evidence, such as bruises.[118] In Zimbabwe, a recent study found that PEP was available only in provincial hospitals, thus preventing women living in rural areas from accessing it; 99% of the women involved in the study had no information about PEP.[119]

Box 3. The Gender Violence Recovery Centre (GVRC), Kenya

Based in Nairobi's women's hospital, GVRC was launched in 2001 and focuses on the provision of medical and psychosocial support to survivors of gender-based violence in east and central Africa. It is the only such facility in Kenya and the east Africa region.

To date, the GVRC has treated more than 4,500 survivors of violence, an average of 150 per month; 45% of those treated are children below the age of 16, and 4% are men and boys.[121] The centre provides integrated services for sexual violence, including immediate emergency medical examination, organ reconstruction and surgery, high vaginal swab to test for infection, hepatitis B and syphilis testing, pregnancy testing, HIV testing and PEP; it also provides counselling, with special attention to pregnancy prevention, medication and antiretrovirals.

Counselling is given on a one-to-one basis and is linked with group counselling for the families of survivors, providing information and referrals for long-term shelters and legal aid for survivors and their families. Separate monthly support groups for survivors of rape are available as well. GVCR also provides information, including simple written materials, statistics, awareness-raising through the media and community awareness-raising programmes.

The centre provides accommodation for family members.[122] This is particularly important in cases where *"a survivor requires constructive surgery to repair damaged sexual and internal organs, especially in the case of children, since the average operation can cost between KShs 95,000 and KShs 130,000 [between $1,400 and $1,900]. Often the children require up to three operations and the GVRC normally has to provide accommodation for the parent or guardian for the duration of the treatment."*[123]

GVRC invests in training and capacity-building for health workers, police, community leaders and counsellors, to eradicate stigma and discrimination in service delivery and to raise awareness about taboo issues such as violence and sexuality. Police and judicial officers are invited to meet survivors at the hospital rather than in police stations or court to provide a safe and comfortable space for survivors to take legal action. Despite GVRC's mission to make its experience replicable and available for the public sector around the country, there is still no other facility like this in Kenya. Women in rural areas need to travel long distances to benefit from this service, and bear all the costs and complications that this represents physically and emotionally for them.

As part of universal access to treatment, UNAIDS has set the target of increasing the global coverage of PEP for women who have been raped from approximately 19% in 2005 to 100% in 2010.[120] PEP must be widely available to sex workers and victims of gender-based violence. To achieve this target, it is crucial to raise awareness of PEP among women, health professionals and the police. It is also crucial that donors support governments to replicate and expand initiatives such as the Gender Violence and Recovery Centre in Kenya (see Box 3), particularly in rural and more remote areas.

It is also important to make PEP part of a comprehensive sexual and reproductive health service. Providing PEP primarily to sex workers and women who have been raped risks stigmatising women and causing further discrimination. It also neglects the right to health of one half of a married couple where, for example, the other partner is living with HIV and AIDS. If their condom splits during sex, the morning-after pill may currently be available, but not PEP. Interventions such as the GVRC must be expanded and multilateral and bilateral donors must encourage the use of PEP for women and girls.

3.3. Services: prevention of mother-to-child transmission-Plus

Prevention of mother-to-child transmission (PMTCT) has proven to be an effective response to reducing infant mortality rates at a very fast pace. Traditional PMTCT strategies take a child-centred approach by preventing vertical transmission of HIV through the use of anti-retroviral drugs during pregnancy and labour, and by promoting safer feeding practices. However, the narrow focus on 'mother-to-child' transmission may undermine women's rights by focusing responsibility for children solely on women and reinforcing the idea that a woman's worth is only in her reproductive capabilities. For example, in some cases, women involved in PMTCT programmes are unable to continue their drug therapy after their pregnancy.[124] Even the term 'mother-to-child' risks labelling women as the main bearers of the disease to their offspring. Some organisations and service providers have thus chosen to use the term 'parent-to-child' transmission interventions (PPTCT) which acknowledges responsibilities of both parents.

In response to these issues, new kinds of interventions are also being scaled up. Prevention of mother-to-child transmission-Plus (PMTCT-Plus), with the 'plus' representing treatment for women and other family members living with HIV and AIDS, represents important progress in this field. Not only do PPTCT or PMTCT-Plus programmes offer a more holistic set of services for pregnant women living with HIV and AIDS, providing preventative therapy, treatment and care for women in their own right (including treatment options beyond pregnancy), they encourage the participation of men at all stages of pregnancy, delivery and care. This is of particular importance because, as we have noted throughout this report, threats of violence or fear of partner desertion are significant obstacles to women's testing, treatment, care and support. For example, as part of a PMTCT-Plus programme in Côte d'Ivoire, trained counsellors not only help prepare for disclosure, but mitigate possible adverse consequences following partner notification of the woman's HIV status. Services include counselling to sero-discordant couples to avoid blame and help them to make risk reduction plans together, as well as referrals to support services for women experiencing abuse, violence or abandonment.[125]

Such comprehensive programmes must be scaled up significantly. Globally, fewer than 20% of pregnant women and girls living with HIV and AIDS receive PMTCT,[126] leaving many women and girls unable to prevent their children's infection. Moreover most women receiving PMTCT are still not receiving confidential pre-test counselling services that could protect their right to informed consent.[127] A considerable number of women in high-prevalence countries still do not know that HIV and AIDS can be passed from mother to child, exposing the way in which knowledge is still not widely available to everyone – in particular women – making counselling efforts more difficult and violating women's rights to information and health.[128]

3.4. Services: voluntary counselling and testing

Voluntary counselling and testing (VCT) is the gateway to treatment, care and support services. If women and girls are prevented from accessing counselling and testing, they are, by implication, denied their right to treatment, care and support and indeed to sexual and reproductive health information (including on HIV prevention) (see Chapter 2 for more information). VCT services must respect women's rights, in particular their right to privacy. However, this doesn't always happen. For example, poor staff training means that VCT is not always voluntary or confidential. The growing trend towards provider-initiated testing and counselling (PITC) is of particular concern. It is crucial that this is delivered in a rights-based manner, for example, by ensuring that informed consent is given before a test is taken and that follow-up care, support and treatment services are available and accessible to all who are tested.

Women and girls must also be given the information to make an informed decision whether or not to take an HIV test.[129] They need to understand what the test is for and what the post-test implications and outcomes might be. Antenatal care, for example, has often led to the violation of women and girls' rights to privacy and informed consent.[130] In some cases, it seems to be standard medical practice to test for HIV without properly informing or consulting the woman.

If testing takes place without counselling and support, women are denied the psychosocial support they are entitled to as part of their right to health (see Chapter 5). Testing must also be free of charge to enable many women and girls to access these services and subsequent treatment. Moreover, counselling has the potential to reduce stigma if it involves couples as well as individuals, and is supported with more resources for training and group education.[131]

In order for VCT to have a strong rights-based approach, women must be consulted in their communities by health policy makers and officials about what would make the services most accessible and acceptable to them. Programmes should emphasise the importance of counselling and evidence-based information to avoid stigma, and allow women to make the decision to have an HIV test. Moreover, policy makers and health officials need to find ways to encourage VCT without resorting to coercion. This requires respect for women's right to information and right to privacy.

As this chapter has shown, HIV prevention for women and girls must address their *"inadequate knowledge about AIDS, insufficient access to HIV-prevention services, inability to negotiate safer sex, and a lack of female-controlled HIV prevention methods, such as microbicides."*[132] If HIV prevention activities are to succeed they must occur alongside other efforts, such as legal reform, promotion of women's rights, programmes to challenge gender inequalities and norms, and socio-economic empowerment.

3.5. Recommendations

Donor governments

1) Donor governments should help country governments to expand and support existing initiatives that provide integrated sexual and reproductive health rights (SRHR), gender-based violence (GBV) and HIV and AIDS services for women and girl survivors of violence, especially in rural areas and where violence against women is a driver of the pandemic.
2) Donor governments should contribute their fair share to the $280 million needed per year over the next five years for research for microbicides.
3) Donor governments should work with the UNFPA, UNIFEM and other multilateral organisations to significantly increase access to female condoms.

Multilateral organisations

1) UNAIDS and WHO should provide best practice guidelines for the integration of SRHR, GBV and HIV and AIDS services, to enable service providers to provide a one-stop service for women and girls, in particular for survivors of violence.
2) UNAIDS, UNFPA and the WHO should support a global-level campaign to make the female condom available and target men's education to increase their acceptance of female-controlled HIV prevention methods.
3) UNAIDS and the WHO, with the support of the Global Coalition on Women and AIDS, should develop guidelines for governments to make their HIV-prevention services women's rights-based, in particular within the context of initiatives for provider-initiated counselling and testing.

Developing country governments

1) National governments should require education curricula to include effective and comprehensive sexuality education for adolescents that incorporates structural issues such as violence against women and girls.
2) National governments should scale up HIV-prevention campaigns using innovative methods. Campaigns must be designed to provide long-term, evidence-based information and create empowering messages to women and girls and emphasising male responsibilities.
3) National governments should increase investment in information materials that explain to women and girls their rights and the HIV-prevention methods available to them. This information should be provided in a way that is locally relevant and sustainable in the long-term.


Gideon Mendel/Corbis/ActionAid

Night nurse Joan Kadzangwe examines patients in the TB ward of Bottom hospital in Lilongwe, Malawi.

4. Women's rights and universal access to effective treatment

> *"Treatment costs are often impossible for them (women) to bear. The ironic part is that, when a woman discovers that her husband is infected, she never ever leaves his side. She tends to him even with the knowledge that he is the one who infected her. Yet after his death, and sometimes even while he is alive, he refuses to aid her survival even though it was him who had jeopardised it in the first place."*[133]
>
> *Walking the talk* research, Bangladesh, 2007

Chapters 1 and 2 have already highlighted many of the broader inequalities that hinder women and girls' access to essential HIV and AIDS services. However, as this chapter will highlight, additional gender bias and violations of women's rights specifically undermine women and girls' access to ART. There is an urgent need for expanded access for men and women to ART. Evidence suggests that more women than men have access to ART. However, at least as important is ensuring people adhere to treatment. Breaches of the right to privacy and the right to adequate food, for example, may leave some women and girls who are living with HIV and AIDS disempowered, discriminated against and/or unable to access or adhere to treatment.

International and national efforts must therefore ensure women and girls living with HIV and AIDS have universal access to effective treatment for HIV and AIDS. Such access is grounded in fundamental human rights, including women's right to health, privacy, equality and non-discrimination. Failure to do so may make universal access to effective treatment a distant dream for many women and girls.

4.1. Access to treatment: is there a gender bias?

Are more men than women taking ART?

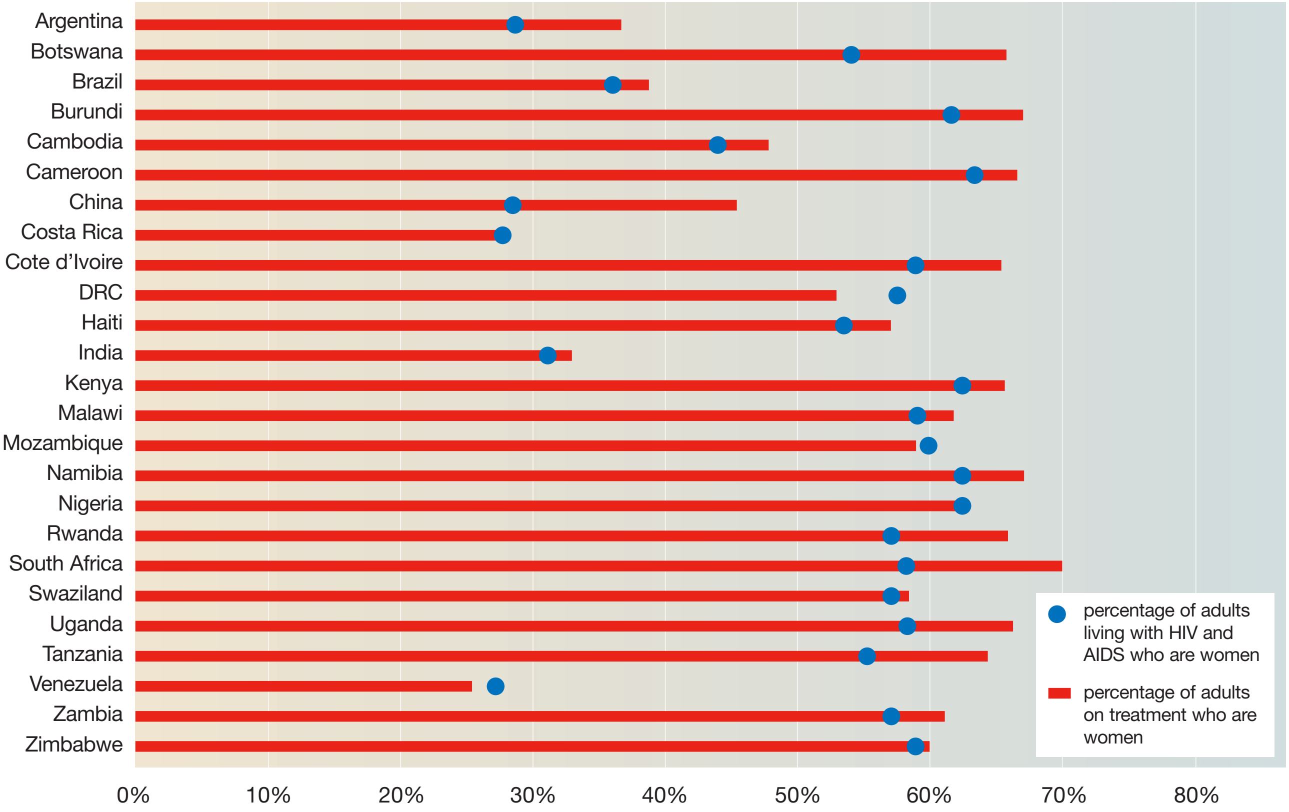
UNAIDS estimates indicate that just over two million people living with HIV and AIDS in low- and middle-income countries were receiving ART by December 2006.[134] Yet this number represents only a fraction of total need: a further five to seven million people – almost four times the number currently receiving treatment – are in urgent need of ART.[135]

Current data indicates a gender bias *in favour of women*, and that more women than men receive ART, at least in the public health system. Of 25 low- and middle-income countries with disaggregated treatment data available for at least 5,000 adults, 57% of those receiving treatment were women.[136] In those same countries, women accounted for 51% of adults living with HIV and AIDS. Data collection must improve in order to build up a more comprehensive picture of treatment needs for women and men. Further research is necessary to determine whether including statistics of people insured through the private sector would significantly change the ratio of women to men receiving treatment. Furthermore, countries, donors and international organisations must collect disaggregated data across age cohorts and other social groups, as one Malawian study has done already,[137] data on adherence of women and girls to treatment once they begin ART (see below), as well as numbers of those undergoing HIV testing and counselling. Furthermore, criteria regarding who can access ART need to be made more transparent and subject to public debate. Only then can we obtain a comprehensive picture of equity in treatment and ensure that every country's National AIDS Plan is rooted in an accurate picture of women's and men's current access.

Barriers to accessing treatment for women and girls

As countries scale up services to achieve universal access to treatment, initiatives must incorporate a rights-based analysis of the barriers faced by women and girls. In particular, treatment initiatives should mitigate the overarching economic and social inequalities (see Chapter 2) that hinder women and girls' access to HIV and AIDS services. Freedom of mobility, distance from travel clinics, safety issues around transport and the overall cost of travel are some of the main obstacles

Figure 2: Women as a percentage of all adults receiving antiretroviral therapy versus women as a percentage of all adults living with HIV and AIDS



(Source: UNAIDS/WHO estimates 2007)[138] women expressed to accessing treatment. For example, in Rwanda, women living with HIV and AIDS reported their fears of night-time travel to reach the health clinic early in the morning when ART is distributed. As one woman remarked, *"How can I get up at 3am then travel alone during the night to make sure I get ARVs? But a man can easily walk during the night."*[139]

As a result, one woman living with HIV and AIDS reported that she slept in the corridors of Nyagatare hospital without covers to ensure she could collect her prescribed ART the following morning. Mobile and decentralised treatment centres in rural areas may be one way to help overcome some of the obstacles of distance and travel. In India, for example, mobile clinics offering counselling and testing services were set up, offering various models of service delivery tailored to the epidemiology, needs and lifestyles of particular populations. In a little under a year and a half, the number of clients using these clinics increased by 84% from the first four months the clinic was in existence.[140]

Costs associated with healthcare itself, as well as opportunistic costs such as the lost time and money associated with travel, are other significant obstacles described by women. For many women running female-headed households, the need to work, cook and care for others makes these barriers insurmountable. In Zimbabwe, the introduction of user fees in hospitals, as well as the high costs of doctor consultation fees makes accessing healthcare services a challenge.[141] Costs are also an issue for the prevention and treatment of opportunistic infections (see Chapter 2). Paradoxically in many country and donor programmes, ART may be free but medicines for treatment of opportunistic infections are not.

Finally, given that women living with HIV and AIDS may face particularly severe discrimination if their status becomes public (see Chapter 2), treatment centres also need to protect women and girls' rights to privacy. One example of a good practice in this area is the health service provided by a mining company in Free State, South Africa. In order to protect the confidentiality of patients living with HIV and AIDS, the clinic name is not explicitly linked to HIV and AIDS. Instead, the HIV and AIDS clinic is in the same outpatient department as other specialised clinics. Furthermore, hospital files are stored in a separate, password-protected database.[142] In contrast, certain rooms in many healthcare centres in South Africa are reserved for women living with HIV and AIDS.[143] ICW have reported the case of one woman living with HIV and AIDS who, while waiting to see a doctor with other patients, was told by a nurse, *"you, who has come for your ARVs, go home and come back after two days because we do not have them".*[144]


Jenny Matthews/ActionAid

Field worker in Mozambique.

4.2. Adherence to treatment: it's not just about access

Data must be collected to monitor the adherence of women and girls to treatment. At present, there is no consistent global collection of gender disaggregated data on adherence to treatment. However, available data shows that nearly 40% of patients within sub-Saharan Africa abandon treatment within two years of beginning it.[145] Research from a South African study illustrates gender differences in adherence to ART, with women actually experiencing *more* success in adherence and superior clinical outcomes.[146] However, anecdotal evidence from our study and other research suggests that women and girls in many other communities face particular barriers to adherence. More rigorous research is needed to establish whether there are common gender differentials in adherence across countries.

Many women and girls receiving treatment are forced to share medication with a non-tested husband.[147] A Tanzanian woman, for example, told ICW, *"Most of us*

Box 4. The power of ART in Nigeria: from HIV and AIDS to health and wealth[154]

"My name is Mary Bulus, the third wife of late Mr Bulus. I live in Amper village, which is just 200 km from Jos. Unfortunately, after three months of marriage, our husband died of a 'terrible health condition'. The other wives also died of the same condition.

I went back to my parents. After some months, I started having frequent diarrhoea and drastic weight loss. I was advised to visit the hospital where I tested positive. It was then I realised that my husband and the other two wives had all died of AIDS. The doctor lamented that my CD4 count was very low and that I stood little chance for survival. I was very afraid. When the community people heard about my condition, they stigmatised me and would not buy the *kunu zaki* and *zobo* (local non-alcoholic drink) [that I sell] saying it must have been contaminated with the virus. I started the ART drugs with the help of the church and Gospel Health and Development (GHaDS), an NGO. Then I became stronger and could do other jobs.

Two months later, I added weight and felt stronger. I decided to embark on farming. On one occasion in the farm, one of the villagers, surprised at my improvement said:

"Am I seeing a ghost or a human being? Or have they started removing the virus from those living with it?"

I now live a normal life and my parents are happy to see me agile again. I have improved my farm and sell several bags of grains to retailers in the market. This was made possible through the Positive Living Support Scheme of N50,000 [about $400] provided by GHaDS. Right now I am the only benefactor who has paid back the loan successfully and have enough capital to sustain my business."

women living with HIV and who are using ARVs face a common problem that our husbands or partners tend to force us to give them our ARV dose while he has not tested for HIV and doesn't know his CD4 counts… Even if you refuse he will find where you keep your medicine and steal them."[148] Fear of disclosure and subsequent violence, discrimination or abandonment also leads many women and girls to try to hide their medication in order to conceal their HIV status. A recent study of 560 women in Zambia, for example, found that 76% of women on ART did not adhere to their treatment as prescribed because they were trying to hide their pills.[149] More research is necessary however to determine the global impact of gender relations on women's adherence to ART.

While the adherence of some women to ART is undermined by economic dependency on their husbands, or inadequate information regarding the course of treatment they must follow (see Chapter 2), efficacy of treatment may be undermined by lack of access to food. Effectiveness of ART directly correlates with a well-balanced diet. Lack of nutrients undermines an already weakened immune system, thereby increasing the susceptibility of women living with HIV and AIDS to opportunistic infections. According to the World Health Organization, *"optimal antiretroviral treatment requires safe, clean drinking water and a balanced diet rich in energy, protein and micronutrients …good nutrition and clean water may make anti-retroviral therapy easier to take and help ensure that treatment works effectively".*[150]

However, in situations such as extreme poverty, natural disasters or conflict, food security may be compromised. Furthermore, such situations mean that women may be forced to choose between treatment and food. In one reported case, a 44-year-old woman in Tanzania sold a six month supply of ART to get money to take care of her grandchildren.[151] New research conducted in two districts in Rwanda found that women living with HIV and AIDS who stayed behind in the villages had little money to afford nutritious food while their men worked and lived in cities. Furthermore, despite the fact that women gather, prepare and serve the food in almost every society, research from multiple sources indicates that women eat last, after ensuring their partners and children are fed. In situations of famine, this often means that women may not eat adequately or don't eat at all.[152]

For ART or treatment for opportunistic infections to be effective, the full course of treatment must be strictly followed and the correct dosage taken as prescribed. Failure to do so can increase an individual's risk of severe illness or can lead, in some circumstances, to the development of a drug-resistant strain of HIV. As already mentioned, it is therefore important that governments and multilateral organisations monitor and evaluate women's adherence to ART and design treatment initiatives in response to the collected data.

4.3. ART in resource limited settings

Scaling up to universal access to treatment presents an enormous challenge for developing countries. In resource limited settings, there may not be enough supplies for all patients living with HIV and AIDS who require treatment. Limited availability raises thorny ethical questions as to how to 'ration' supplies and who gets priority in treatment distribution. Such issues are of particular concern to women and girls who may not have the social and political power to advocate on behalf of themselves. Recently, such issues have taken international prominence. UNAIDS has called for the establishment of national ethics panels in recipient countries, while WHO has commissioned a series of background papers and a guidance document on ethics, equity and access to ART.[153] Whereas decisions on resource distribution must ultimately be made at country level, guidance by the multilateral agencies must take into account the particular needs of women and girls.

As the story of Mary Bulus (see Box 4) indicates, effective treatment can make a dramatic difference to the lives of women and girls living with HIV and AIDS. While the limited data currently available suggests that more women than men access public sector ART, women must overcome a distinctive set of barriers to access treatment and to follow the treatment regimen. Economic dependence, a lack of autonomy and confidentiality turn accessing treatment into an ordeal for many women and girls. Donors, multilateral organisations and country governments all have a critical role to play in addressing these barriers in their HIV and AIDS interventions.

4.4. Recommendations

Donor governments

1) Donor governments should ensure that their funding and funding processes address the barriers faced by women and girls in accessing and adhering to treatment.

2) Donor governments should provide more help to country governments to fund treatment literacy programmes and increase their funding for female-friendly health systems, including provision for mobile drug distribution and treatment points.

3) Donor governments should strengthen their capacity to collect and disaggregate data on their own treatment initiatives by gender, by developing sound indicators on gender equality and women's rights, and sharing their technical knowledge to support national governments to do the same.

Multilateral organisations

1) WHO should develop rights-based treatment guidelines that focus upon, for example, increasing the accessibility of treatment information, facilities and medications for women and girls living with HIV and AIDS.

2) UNAIDS should develop and encourage the widespread use of indicators to monitor women's adherence to ART, including indicators on nutrition.

3) The Global Fund to Fight AIDS, Tuberculosis and Malaria, WHO and other multilateral organisations should strengthen their capacity to collect and disaggregate data on their own treatment initiatives by gender, use the data to support national AIDS treatment plans and budgets for developing countries, and tailor their treatment programmes accordingly.

Developing country governments

1) National governments should ensure that treatment is accessible at the local level by making sure that ART and other HIV-related treatments are available to women and girls living with HIV and AIDS through mobile and decentralised treatment centres, and by ensuring a wide range of distribution points. These centres and distribution points must provide nutritional support for women and girls living with HIV and AIDS, and provide accessible treatment information.

2) National governments should develop and strengthen their capacity to disaggregate national data on access to ART. In particular, they must disaggregate access to ART by age as well as gender and monitor women and girls' adherence to treatment.

3) National governments should develop, fund and implement national treatment plans and budgets with a strong emphasis on women and girls in order to achieve universal treatment.


Jenny Matthews/ActionAid

Members of Tilla Association of People Living With HIV and AIDS, Awassa, Ethiopia.

5. Women's rights and universal access to HIV and AIDS care and support

> *"The care economy that was forced upon them as women's natural lot …not only cornered them in the most dire circumstances, it… made them vulnerable to the disease against which they labor so hard. Their cultures of origin and near universal systems of patriarchy… put them at the beginning and at the end of HIV's engine of disease."*[155]

The right to health encompasses *"a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health"*.[156] Indeed, access and adherence to treatment, as explored in the previous chapter, is only one of many factors relevant for the health and wellbeing of women and girls living with HIV and AIDS. Care and support represent such critical "underlying health determinants", ensuring that those living with HIV and AIDS have the means to attain the highest standard of physical and psychological health and live their everyday lives with dignity.

Chapter 2 has already touched upon how women and girls fill the void in the absence of functioning national healthcare systems, providing most of the care and support for people living with HIV and AIDS, despite having limited access to HIV and AIDS services themselves. This chapter explores specific challenges faced by women and girls in relation to care and support. While their efforts support whole families and entire communities, women and girls are neither sufficiently supported nor recognised for their care-providing efforts. They face an unacceptable extra burden and an inability to claim their rights in environments that are often already highly challenging.

5.1. What do we mean by 'care and support'?

Care and support, the least examined components of the HIV and AIDS continuum, have been defined in varying ways. For the purpose of this report, we define care and support for people living with or affected by HIV and AIDS as a package of interventions aimed at supporting positive living and improving the quality of life for people living with and affected by HIV and AIDS (see Box 5). In effect, care and support services contribute to the realisation of the right *"to the enjoyment of the highest attainable standard of health conducive to living a life in dignity,"* as established by the International Covenant on Economic, Social and Cultural Rights.[157]

5.2. Women and girls' access to care and support services

Care and support services are essential to the physical and mental wellbeing of women and girls living with HIV and AIDS. While little disaggregated data exists to determine the gendered aspects of access to HIV and AIDS care and support services, research conducted for this report shows that women and girls who do access these services face formidable barriers. For example, women and girls may find it difficult to take time away from household and income-generating duties, and often need to seek permission or money from male relatives to attend support groups, counselling or health facilities.

Access to psychosocial care and support

Whereas many families provide loving care and support to their relatives living with HIV and AIDS, others reject and stigmatise them. In such cases, psychosocial and emotional care and support – in the form of counselling, support groups and spiritual sustenance – are even more critical. Access to such support helps women and girls living with HIV and AIDS to disclose their positive status, live positively and prevent HIV transmission. It also helps to reduce the sense of shame and subsequent isolation, providing information on life after a positive diagnosis. As Fatima, a widow living with HIV and AIDS in Jalilpur, West Bengal said:

> *"Peer educators from Child in Need Institute (CINI) came for sensitisation talks in my village promoting VCT [voluntary counselling and testing]. I developed interest and the next day I went to CINI for counselling. The counsellor was good to me and I thought, 'there is actually someone out here who cares to listen to my problems'. She referred me to the South 24 Parganas network for positive people. It was a dream come true to actually join with women of my type. For a long time, I thought I was the only one in a basket full of problems. Everything improved since then; we started up a support group and a small poultry farm. Life went on a bit smoothly."*[159]

Box 5. Care and support

Care and support for people living with HIV and AIDS and their families can be categorised as four interrelated domains:

1. Psychosocial – emotional support; spiritual support; counselling; bereavement support; reduction of stigma and discrimination, and positive living.

2. Medical – testing; treatment of AIDS-related illnesses and opportunistic infections, treatment information and treatment adherence; prevention and treatment of sexually transmitted diseases; nursing, home and palliative end-of-life care; prevention of parent-to-child transmission; post-exposure prophylaxis; pre-exposure prophylaxis and management of opportunistic infections, including TB.

3. Socio-economic – such as welfare provisions (stipends, cash transfers, grants, food parcels, income generation, help in the home) and employment opportunities; orphan support; adoption services; nutrition; education.

4. Human rights and legal – access to care and protection against violence and discrimination; land, property and inheritance rights; succession planning.

However, as highlighted in Chapter 3, VCT, PITC (provider-initiated testing and counselling) and other counselling services may not be accessible to women and girls. These services are crucial gateways to support groups (including faith-based groups), which provide the mainstay of care and support for women and girls. These groups provide them with an opportunity to share survival strategies, information and experiences, and to access counselling and advice. They also often provide life-changing emotional support networks for those who may have been abandoned or ostracised by friends and relatives, as well as offering a source of collective strength for advocacy on human rights and gender equality.[160] Some support groups provide other kinds of assistance such as income-generating activities, advice on nutrition, positive living, orphan care and succession planning. The extent of the impact of this psychosocial support is illustrated by the comments of one support group member interviewed by ICW:

> *"The people whom I met at Mashambanzon gave me the strength to go on. They were always cheerful and they were always laughing. During my first few days I could not believe that they were HIV-positive. How can one be so happy when she knows she is going to die?"*[161]

Research undertaken for this report in Namibia found hundreds of support groups, mostly attended by women. A similar situation can be seen in Ethiopia, where 50 out of 70 members of one association were women. Focus group participants in Namibia and Ethiopia felt this disparity existed because women are more likely to identify a need for support while men *"curtain themselves and hesitate to come forward, take medicine secretly without any information and consent of their family members"*.[162] In some circumstances, focus group participants in Namibia reported that male partners opposed women attending support groups for fear it will reveal their own HIV status:

> *"Men make jokes about the activities of support groups and therefore create a barrier for other people to become a member of our group."*[163]

In Namibia, women attending these groups are typically older widows who do not need permission from a spouse. Members agreed that girls and young women were often unable to attend because of dependence on their family, husband or boyfriend. Leonard Shikollolo, Director of an HIV and AIDS NGO in Namibia called TKMOAMS, highlights that many women in the community would like to start a support group, but do not have the information, skills or funds necessary to organise or sustain counselling, income generation and information-sharing activities.[164]

Donors and governments must deliver more funding to support groups of women and girls. Capacity-building support must also be channelled to organisations of women and girls living with HIV and AIDS to enable them to develop skills around management, leadership, group dynamics, team building, community mobilisation, advocacy and self-empowerment. Support must also be given to groups dominated by males to increase female membership and leadership within their organisations. Such support must be both sustainable and provided on a much larger scale by donors, both geographically and in terms of breadth of financial support.

Access to medical care and support

The majority of medical care and support for people living with HIV and AIDS takes place in the home. However, research for this report suggests that women and girls' access to home-based medical care and support often relies on men's approval. A community care provider highlighted to ICW the impact on women and girls' ability to seek care when sick:

> *"… it is difficult to access a sick female client until the husband approves... some men even lock their gates when they see us coming, in most instances men accept caregivers at their homes when they become sick or bedridden… as long as they are still mobile, they do not accept us…"*[165]

In Ethiopia, for example, our research found that, when both the wife and husband are living with HIV and AIDS, care preference will often be given to the male.[166] Furthermore, women and girls may be encouraged to put the health of the family before their own health because of their role as primary care providers. This often means they seek healthcare at a later stage than men, frequently when their illness is already well advanced. One research participant from Pakistan, for example, reported her in-laws telling her, *"You are responsible for everything for your children because their father remains ill. So forget about your disease for the sake of your children."*[167]

Another barrier to accessing medical care revolves around culture and belief. A significant number of women in the developing world go to traditional healers instead of formal health systems. Approximately 70-80% of the population in sub-Saharan Africa initially see a traditional doctor when they become sick.[168] In Vanuatu, for example, while some areas lack nurses, doctors, or other medical staff, almost every community has a *kleva*, or traditional healer. She or he is often the first point of contact for any illness, including opportunistic infections and STIs. While traditional healers may offer crucial emotional and spiritual support, they do not always provide correct information and advice on HIV and AIDS.

Access to socio-economic care and support

Socio-economic care and support includes access to income-generating activities, food security, credit schemes, skills and vocational training, access to loans and banks and social protection. Socio-economic care and support is essential to ensure women and girls cope with the impact of HIV and AIDS and are able to realise their *"right to a standard of living adequate for the[ir] health and wellbeing"* [and that of their family] *"including food, clothing, housing and medical care and necessary social services".*[169]

Social protection interventions, for example, have been shown to increase the quality of life and health of women and girls. A recent DFID pilot project in Zambia found that *"social transfers can have an immediate impact on hunger and poverty, and a wider impact on the poor accessing health and education services".*[170] Despite this, access to social protection and income-generating activities is at best patchy, at worst non-existent. As a result, there is an overwhelming demand for these services from civil society, support groups and women and girls living with – or vulnerable to – HIV and AIDS so that they can realise their right to a decent standard of living. To protect the economic rights of women and girls, governments, with donors' support, should increase social protection mechanisms to support women living with HIV and AIDS with the costs of (among others) their rent, children's education, food and clothing.

Even where social protection interventions do currently exist, poor local implementation or poor awareness amongst potential beneficiaries undermines their value. Governments must therefore provide accessible information on available assistance such as disability grants, child support and pensions, and remove customary or civil laws that prohibit women from accessing banks, loans, land or credit.

Research for this report shows that support group members wanted to become more independent and self-supporting by earning their own money to visit medical facilities, and living healthy and productive lives. Yet many NGOs lack the expertise to accomplish income-generating projects successfully. In Pakistan, support-group members called for income-generation activities so that people living with HIV and AIDS could live independent lives. They added that socio-economic care and support should include accommodation costs, utility bills, marriage expenses, education costs for their children and unemployment allowance. In South Africa, respondents cited vegetable gardens, bread-making and knitting as areas where they could undertake income-generation activities – respondents wanted to work and earn to support themselves and their families but lacked the funding and skills training to do so on anything but a very small scale.[171]

Despite the inadequacy of support for income generation and economic empowerment of women and girls, success stories abound. For example, an intervention by the Provincial Directorate of Women and Social Action in Maputo, Mozambique, provided women living with HIV and AIDS with mobile phones and training on money management. The women were unemployed, unable to buy sufficient food or some of the medications necessary for treatment of opportunistic infections. However, after charging community members to use the mobile phones, the women were able to earn enough money to eat three meals a day and to buy medicines. One of the women reported that her family treated her with more dignity. Because of the income she earned, she was seen as somebody with something to contribute to society.[172]

To enable women and girls to claim their rights to a decent standard of living, to work and earn a living, governments and donors should increase their support for, institutionalise and expand strategies designed to increase poor women's financial independence. This would include microcredit schemes, financial support for care providers and local employment and education/training opportunities. These strategies must also be designed to empower women and girls to make key financial decisions (see Chapter 2). Finally, governments and donors must fund the capacity-building of grassroots women's organisations, support groups and networks of women living with HIV and AIDS to develop income-generation initiatives.

Women's rights and legal support

Ensuring that legislation and policies respect women's rights is key, but is of little practical value if women and girls are unable to assert their rights. Despite lofty legislation and ratification of international human rights instruments, a lack of legal proceedings for rights violations contravenes the rights of women and girls to legal redress. These violations can also leave women and girls living with HIV and AIDS deprived of property, trapped in abusive relationships, or isolated from their children and families.

Gideon Mendel/Corbis/ActionAid

Brenda Namukimba provides home-based care as part of the Community Care Programme, Uganda.

In many circumstances, an absence of training for police and legal officers has meant a lack of awareness of women's rights. Lawyers often do not have the necessary legal expertise to assist women who have been disinherited, or they are simply not aware of laws relating to women's rights. In India, for example, legal processes can be accelerated for people living with HIV and AIDS, but this is not widely known within the legal profession.[173] Training must therefore be provided for legal officers and for national legislatures on women's legal rights around property, inheritance and family law. This must not only include training on the law itself, but also around the duty to respect and uphold laws in situations where women's rights have been violated.

Furthermore, legal redress is often impossible for the majority of women and girls because of the prohibitive cost of legal services, community disapproval, reprisals for betraying one's culture or simply limited awareness of their rights.[174] Women and girls may avoid civil courts, for example, because of a lack of resources, to keep families together, or because they are unable to travel.[175] The latter is particularly the case for rural women as courts are often located in urban areas. Where legal support is available, clear information on how to access this support is rare.

To improve women and girls' access to legal support, governments must provide materials on property and inheritance rights and succession planning through a variety of settings such as secondary school curricula, clinics and hospitals, support groups, marriage preparation and VCT.[176] Governments and donors must also develop and fund accessible legal support and advice services, including drop-in centres and legal advice clinics that are open at times when women can access them. These services must provide information in accessible ways, for example, in local languages and through community radio. Provision of legal aid for many women and girls is also essential if they are to access the legal system.

5.3. Women and girls providing care and support services

The 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. Community and home-based care are provided by 'community care providers' – a term that includes all people working in homes and communities who are responding to the health crisis and caring for the sick and the dying.[177] In this report we use the term ‘care provider’, rather than the often-used ‘care giver’, because the latter implies that the care is ‘given’ freely, almost as a gift, and therefore is assumed not to need recompense. Part of this assumption is due to worldwide gender stereotypes that expect women and girls to take responsibility for domestic and care work, and to do so for free. In South Africa, for example, one evaluation of home-based care found that 91% of community care providers were women.[178]

To ease the burden on failing health systems (see Chapter 2), community care providers in many countries have taken on responsibilities for primary healthcare. Health services that are not considered a priority, especially those services governments think can be provided by the community, are either under-funded or ignored altogether. Care and support services for HIV and AIDS fall into this category. In sub-Saharan Africa, for example, hospital-based care is almost non-existent[179] and very little provision is made for home-based care services. A 2003 UNAIDS study showed that, globally across 88 low and middle income countries, only 14% of people living with HIV and AIDS who required home-based care had access to these services.[180] Given the spread and growing impact of HIV and AIDS in Africa, for example, the resulting burden on communities is reaching a critical point. This is starting to be replicated across the developing world. In Thailand, for example, “*two thirds of all adults with AIDS-related illnesses are nursed at home by parents”.*[181]

Women and girls as primary (informal) care providers

Community care providers can be split into two broad groups: primary (or informal) care providers and secondary (or formal) care providers. Primary care providers are family members or close friends who provide care and support in the home, in what is often termed the ‘informal’ sector. These responsibilities fall almost exclusively on women, and increasingly older women and girls, who have little or no support and receive no recognition for their work. Older women, for example, are increasingly looking after their dying adult children and taking on parental responsibilities for their grandchildren and other orphans. In sub-Saharan Africa, up to two-thirds of people living with HIV and AIDS are cared for by people in their 60s and 70s. Up to 60% of orphaned children live in grandparent-headed households.[182]

The impact on girls is also particularly severe.[183] They are often expected to care for their siblings and dying parents, and take on caring and domestic duties when parents are sick. These duties are particularly harsh for a child, but are made even worse by the psychological trauma of losing one or both parents. This unsustainable care burden on women and girls is exacerbated when women, who are already providing care in their family or community, fall sick with an AIDS-related illness. They then turn to another female relative or to a secondary care provider, increasing the burden further on care providers.

Secondary (formal) care providers

Secondary care providers are visiting nurses, health workers or community care providers from NGOS or community groups using staff for care delivery. They are based in the ‘formal’ sector and provide a range of services for people living with HIV and AIDS (see Box 6). Unsurprisingly, the strong gender demarcation of care provision means that most secondary care providers are women. Some are also living with HIV and AIDS, and have been involved with providing care in their broader community since the beginning of the pandemic. As a home-based care coordinator from Mozambique states:

> *“I came from a state of being critically ill to being well as you can see today. It was this that motivated me to do this kind of work and help my neighbour. There are a lot of people who are in the state I was in then.”*[184]

Currently most care and support services are beset by a lack of coordination, unsustainable numbers of patients and unreliable funding from external donors, all of which have a negative impact on the lives of female care providers. For example, although an increasing number of secondary care providers work for home-based care projects established by networks of people living with HIV and AIDS, NGOs and community-organised groups, many secondary care providers work individually in their communities. Furthermore, many of these networks are not linked to or supported by state health systems, and have to work independently.

Civil society and NGOs must create and/or strengthen local, national and regional community and home-based care alliances to allow care providers to share knowledge, skills and resources. Recent examples of this are grassroots peer networks such as the Home-Based Care Alliances launched in Kenya in 2006 and Uganda in 2007, which provide national platforms for policy lobbying and coordinated livelihoods work.[185] However, the sustainable long-term solution to this must be greater investment in government care and support services as well as greater levels of support for – and co-ordination with – NGOs or community-based care organisations. National state-led coordination and

Box 6. Home-based care activities in Namibia

- Education
- Personal hygiene
- Environment hygiene
- Positive living
- Counselling in the home-based care setting
- Family counselling
- Spiritual counselling
- Bereavement counselling
- Different types of medical care, for example: diarrhoea, fever, skin rash, etc.
- Plan for follow-up care
- Monitoring of drugs adherence
- Record keeping
- Referrals

Resource: National Volunteers' Conference, 2006

standardisation of state and civil society responses, accompanied by the development of systems of referral through National AIDS Plans are critical to ensure the equitable delivery of a good standard of care, and also the rights of community care providers.

5.4. The impact of providing care and support on women and girls

The true impact on women and girls providing care for people living with HIV and AIDS is difficult to assess. It is only in recent years that international studies have specifically focused on the issue.[186] Drawing on national studies, they have shown that women and girl carers can experience many positive effects from providing care, including building their skills, the appreciation of the patient and their family, and the pleasure of seeing a patient recovering. However, without proper recognition and support, care providers are forced to confront a staggering range of negative impacts that deny their basic rights.

The financial and material cost for primary care providers

When a family member becomes infected with HIV or develops AIDS, the cost of treatment and care is extremely high. Even if ARVs are free or subsidised, the cost of CD4 tests and treating opportunistic infections can be excessive. A study in Zimbabwe, for example, found that the cost of care was about twice as high for HIV and AIDS patients than for patients with other illnesses.[187] [188] This considerable cost of care can be too much for many women and girls to bear, especially given that some women and girls are economically dependent upon male relatives (see Chapter 2).

A study in South Africa showed that members in 40% of 312 households had to take time off from work to care for ill relatives.[189] Another study in South Africa found that, with the intense time commitment of caring, two-thirds of HIV and AIDS-affected households reported a loss of income.[190] For women and girls working in the informal sector, or for households reliant upon subsistence farming, this can be particularly difficult. Older women and young girls are particularly hard hit because they are often either too frail or too young to generate sufficient income. They are also often 'invisible' to authorities and so are frequently missed by whatever support policies and programmes might be created by the state.[191]

If their income cannot meet the costs of care, poor families may be forced to redirect resources from their own needs, eventually using up any savings they have and selling assets such as land or property. When a family member dies, there is the additional cost of the funeral. If it is a male member of the household, women care providers may lose their land and resources.

In some circumstances, the cost of care plunges women and their dependents deeper and deeper into poverty, denying their rights to an adequate standard of living. With no remaining resources, some women and girls turn to informal or transactional sex work for funds, or for the support of a man who can provide the basic necessities. In Tanzania, 8 out of 18 older women in one focus group discussion said they had resorted to transactional sex to pay for food when they were unable to find casual work, or were *"tired of begging from neighbours or relatives"*.[192] It is bitterly ironic that, in the midst of caring for people living with HIV and AIDS, some care providers find little option but to engage in transactional sex that so dramatically increases their vulnerability to infection and re-infection with another strain of HIV or other STIs.

As covered earlier, there is a range of possible state or NGO-provided financial support options that should be extended to primary care providers – including social protection, cash transfers, loans and microcredit schemes. In South Africa and Botswana, for example, a care grant or allowance system is in place that is crucial for the families that receive it. The challenges to providing these are much bigger in low-income countries. In addition, specific support should be targeted at more vulnerable groups, such as girls and older women, who are increasingly providing care.[193] Some countries are now targeting support for older women carers, such as Botswana and Lesotho, which have introduced a non-contributory pension fund, and this has made a crucial difference in providing for essential items and reducing financial distress.

There are also other general initiatives such as income-generation projects, food security schemes and the abolition of health-system user fees that would all ensure that a sickness in the family did not automatically mean the gradual impoverishment and, in many cases, destitution of primary carers and their families.

The financial costs for secondary care providers

Many secondary care providers find they have to cover some of the financial costs of care out of their own resources. Even when secondary care providers receive a stipend or financial support of some sort, it very rarely covers these types of expenses. As one care provider in a study for this report states:

> *"We walk for miles and miles in order to reach clients in other homesteads. Once we are there clients expect a lot from us, like food and even money. This puts pressure on our personal resources."*[194]

Where secondary care providers may not have any financial support to give, many rely on their resourcefulness, networking with social workers for the patients to access social grants where they are available.[195] In addition to supporting patients, secondary care providers often have to cover their own work costs, including providing their own equipment and paying for their own transport to visit patients. In addition, providing care often leaves secondary care providers with little or no time for extra income-generation activities. A recent study for this report found that 85% of secondary care providers in Ethiopia spend all their working day providing care and support services to patients in their homes, and

Box 7. Case study in Mozambique: the importance of financial support

Carla Tivane is a member of Ahitipaluxene, an association of women living with HIV and AIDS in Mozambique. She provides care twice a week to other people living with HIV and AIDS in her community. At first, she only received £6 a month, which barely covered her transport costs and was insufficient for her to support her four young grandchildren. Furthermore, food insecurity undermined the effectiveness of her ARVs.

In July 2006, Carla was one of the women who received the equivalent of £25 from an INGO small grant scheme to start a small income-generating activity of her choice. She decided to sell bread, fruit and a home-made filling called *badjia*, which is traditionally eaten with bread. At the end of two months she began to repay the money, making payments slowly over the next 20 weeks. By August 2007 she reports that things are going better for her. *"I no longer experience hunger and I can support my grandchildren. The business is going very well."* Using her savings she has been able to expand her business and now sells biscuits to local children. When she is not providing care twice a week, Carla is working on her business. One of the unexpected changes of this small grant has been that the women now value their time. Any activity proposed to Carla, such as extending the number of days for home visits beyond the agreed two days, is considered in terms of how much money she will be losing that day. This economic empowerment has assisted Carla to say no to exploitation.

have no time for other sources of income to feed their children and themselves.[196]

Secondary care providers' right to be paid

A survey in southern Africa in 2005 identified seven different models of care services across the region, ranging *"from the very basic community-driven model which is reliant on home visits by volunteers, to the fully comprehensive care model which provides a whole spectrum of medical, psychological and spiritual care."*[197] The more comprehensive models, like Bwafwano home-based care in Zambia, provide good support for women care providers, such as training and some form of pay. However, currently, many home-based care organisations use large numbers of what are collectively termed 'volunteers' to provide secondary home-based care, who receive little or no remuneration at all.

Volunteers are an immensely valuable and important part of society, especially in communities seriously affected by HIV and AIDS. They will continue to provide an essential part of the response to HIV and AIDS. However, because most secondary care providers are women, and women's work is routinely undervalued within societies, the term 'volunteer' in this context has been expanded and applied incorrectly to include all women within the formal economy who provide care to members of their community, but who receive little or no training or recompense for the work they do.

The UN defines volunteering as having three essential characteristics:

> *"First, the activity should not be undertaken primarily for financial reward… Second, the activity should be undertaken voluntarily, according to an individual's own free-will… Third, the activity should be of benefit to someone other than the volunteer, or to society at large, although it is recognised that volunteering brings significant benefit to the volunteer as well."*[198]

Some secondary care providers have the resources to volunteer their time and thus meet the UN definition of a volunteer. However, most secondary care providers can only be called 'volunteers' because they currently work without pay. These are non-volunteer secondary care providers because it is not necessarily the case that they do not want (or have) the right to be paid, or that they are willing to be made poorer for the work they do. Many secondary care providers are not willing volunteers in this respect and, as the epidemic worsens in their communities, many secondary care providers have too many people to care for and little or no time to make an alternative living. With the many extra costs of providing care, this means that many secondary care providers plunge into deeper levels of poverty. Secondary care providers, therefore, should no longer be referred to as volunteers unless they explicitly and willingly meet the UN criteria above.

The situation is complicated by the fact that definitions of volunteering vary around the world. For example, in southern Africa, the concept of *ubuntu*, which reflects a strong community spirit and sense of responsibility to support other members of the community, means many poor and unpaid women secondary care providers feel a strong motivation and experience it as a source of pride in being referred to as 'volunteers'. Research to explore and understand the differing national and regional varying definitions of volunteering is needed instead of universally applying largely western definitions. This research can only really take place at a national level with the active participation of care providers whom it most affects. Only then can clear distinctions be made between volunteering and work that should be recognised as paid employment. Secondary care providers should have the right to choose to be a volunteer or a paid worker, a choice that is currently denied them.

Until now, many governments have regarded community care as a 'cost-effective response' to the crisis – women's free labour saving money for the health system. This short-sighted, needs-driven approach ignores secondary care providers' right to earn a living from their work. It is nothing more than the exploitation of unpaid labour. Given the cycle of deprivation it creates, it is both unsustainable and a false economy.

The realisation of the call for secondary care providers to be recognised and remunerated as workers will be progressive. The transition will need the involvement and support of secondary care-providers and all 'duty-bearers' responsible for the rights of secondary care providers, including community-based organisations, NGOs, governments, donors and multilateral institutions.

Some countries have begun to address the lack of remuneration given to secondary care providers by introducing legislation to ensure they are paid. In Mozambique, for example, the government legislated that care providers receive 60% of the minimum wage (the current minimum salary is £26).[199] However, these wages/stipends are still very low, and as such reinforce the low valuation of women's work in society. In most cases it is insufficient to sustain a woman or her family and so forces her to seek alternative income generation.

The stipends can also be hard to access. For example, in order to receive the stipend in South Africa, it is first necessary to take an expensive training course to be accredited, something way beyond the means of many community care providers.

It should be recognised, though, that some regular financial remuneration is an important step forward. A recent regional study of care providers in four countries in southern Africa found some evidence that because a stipend was available in South Africa, care providers there now viewed providing care as a legitimate source of employment.[200] However, in order to recognise secondary care providers as workers that deserve a fair wage, there must be a huge conceptual shift at all levels in the understanding, appreciation and recognition of the work they do. This involves a massive change in the understanding of gender roles and of the value of women's work *per se*.

One solution is the greater involvement of men in providing care. A model project that encourages young men to become involved in home-based care is 'Changemakers' in Cameroon. By training young men to understand gender and male and female sexuality, and demystifying traditional beliefs and myths about HIV and AIDS, the men are developing more positive attitudes towards people living with the disease. They have further demonstrated a willingness to care for them. However, governments, CBOs and NGOs need to be careful not to marginalise women or entrench gender inequality within the care system for the sake of involving men. One important way of preventing this from happening is to ensure women are involved in decision-making and take leadership roles within CBOs and NGOs providing care and support. Another is for governments, civil society and NGOs to work with men, and particularly community and traditional leaders, to challenge gender norms, and encourage them to role model 'caring male behaviour'.

Another crucial change is the recognition of non-volunteer secondary care providers as healthcare workers so that these low-income female care providers are no longer dismissed as invisible free labour. A rights-based approach demands that governments, donors and international institutions recognise this category of secondary care providers as workers within the heathcare profession. As such, this classification helps justify their right to a fair wage.[201] While the WHO has recognised that *"current methods of identifying health workers do not allow unpaid carers of sick people or volunteers who provide other critical services to be counted,"*[202] a major step forward would be the recognition of secondary care providers within the upcoming International Standard Classification of Occupations by the ILO in 2008.

Furthermore, all community and home-based care organisations, and the NGOs that support them, must develop comprehensive policies that recognise and protect community care providers' rights. International guidelines, such as the NGO Code of Good Practice[203] and the WHO Care Guidelines,[204] should also be updated to directly support the remuneration of care providers and provide clear guidelines for community-based organisations and NGOs on how to develop such policies. These policies might include pay scales, regulated hours, numbers of patients and guidance on including care providers' pay as part of funding proposals.

Finally, it is important to state that secondary care providers who willingly meet the criteria of 'volunteer' must receive sufficient training, counselling and financial support. Furthermore, workplace policies in home-based care organisations must ensure volunteers have – and are aware of – their rights within the workplace. A volunteer charter that enshrines these rights, such as that recommended by the Secretary General's Task Force report in 2004,[205] must be pushed forward by the UN, integrated into National AIDS Plans and implemented within community-based organisations using volunteers.

The denial of educational, social and cultural rights

Women and girls are often unable to claim their educational, social and cultural rights as a result of their role as care providers. As care provision and domestic duties increase, girls in the family are nearly always the first to be pulled out of school, thus losing their right to an education. This is demonstrated by the example of two provinces in Kenya in 2001. The province of Nyanza, for example, recorded a very high HIV-prevalence rate, and only 6% of those graduating at grade 5 were girls. In contrast, Eastern Province recorded the lowest HIV-prevalence rate and 42% of those graduating were girls. Education officials noted that 20 years before, the two provinces had roughly equal percentages of girls graduating to grade 5.[206]

The importance of girls attending and finishing school is recognised by policy-makers worldwide for the positive effect that it has on empowering women, reducing child mortality, and reducing the prevalence of HIV and AIDS (see Chapter 3). When girls leave school to act as care providers it perpetuates a cycle of female disadvantage, leaving girls more vulnerable to HIV and AIDS. Governments must therefore ensure that girls and their parents have every support necessary to realise girls' rights to education. This has been accomplished in some areas through the provision of cash transfers and pensions for families affected by HIV and AIDS.[207] If necessary, these social protection interventions can include positive conditions so that families can claim financial support to allow their daughters to stay in school.

Both primary and secondary care providers are increasingly denied their right to recreation and leisure time because of the overwhelming care responsibilities they face. The intense time, financial and mental commitment of providing care also mean that care providers often lose their right to participate in community activities or decision-making platforms. This is often exacerbated by the discrimination that care providers face from some members of society, either because they are living with HIV and AIDS or because they are caring for someone else living with the illness. As highlighted in Chapter 2, women and girls' political participation is crucial to improving health systems. As mentioned earlier, the regulation of work performed by care providers, including limits on the number of patients they support in a day and the numbers of hours they work, would go a long way to ensure care providers' right to leisure and recreation. This would also allow time for care providers to play a more visible role in community life, perhaps creating more opportunity to break down stigma and discrimination.

The physical and psychological impact of providing care

In addition to, and partly as a result of, the costs of providing care outlined above, women care providers experience a wide range of psychological impacts from their work that violate their right to favourable conditions of work. Caring for and then watching large numbers of people die from AIDS-related illnesses pushes most care providers to the extremes of emotion, stress and depression. A care provider in South Africa recently explained the psychological impact providing care can have:

> *"I feel like a balloon, I am full of air in the morning and as the day goes by, the air disappears little by little until what's left is a crumpled piece of rubber."*[208]

This is a stark image of what is happening to individual care providers in countries with high HIV and AIDS prevalence, where care providers have little or no access to counselling, support or training. In Lesotho, for example, 90% of community care providers are reported to be clinically depressed.[209] In the absence of any external psychological support, care providers in South Africa report that they are talking to each other in support groups and sharing experiences in order to cope.[210] Much more work needs to be done to provide specific counselling and psychosocial sessions for care providers. Governments, specifically, must introduce or revive mental health programmes at the primary care level to help community care providers deal with the psychological stress of providing care.

The scant training received by care providers exacerbates their stress. As noted before, lack of training can affect a care provider's ability to claim a stipend (as is the case in South Africa), but it also significantly affects the standard of care received by the sick. Furthermore, it may place the care provider herself at risk. Care providers cannot operate effectively and safely if they are not well trained, if they are not properly supervised and mentored, and if they are not embedded within referral systems that allow them to help people they are caring for get access social and medical services. Although it is beyond the scope of this paper to detail the specific components of training,[211] supervision and referral systems, it is absolutely essential to clarify that the absence of such support will decrease the quality of care provided, demoralise care providers, and lead to turnover and unsustainability.

Most government training for care providers is based near urban centres and frequently costs more money and time than a care provider or even a CBO can afford. There is sometimes peer-to-peer training among secondary care providers. However, this occurs less often with primary care providers, especially girls, who seldom have access to support groups or other care providers. Home-based care organisations have a duty to ensure regular training on home-based care for all staff by an accredited trainer. Care providers should have full access to information on vertical transmission, post-exposure prophylaxis, adherence and treatment literacy. This training should also be targeted at primary care providers by building secondary care providers' skills to provide outreach training to primary care providers. For example, in Ahitipaluxene in Mozambique, the carers receive on-the-job training from the nurse who works with them. Those who have received training mentioned that they feel more appreciated and have greater confidence while performing their work duties:

> *"It [the training] was very important. That is why I say that it is forbidden to forget what we learnt."*[212]

Even when care providers manage to acquire proper training, their work is often physically dangerous because they do not have access to the equipment they need, such as home-based care kits. In Mozambique, home-based care kits cost 2,000 meticais each (US$78) – more than care providers earn in a month.[213] In Ethiopia, around 70% of respondents in a recent study said that they do not receive a full kit from their associations and have to replace essential items such as soap and painkillers themselves.[214] Basic equipment such as gloves and home-based kits including soap, detergent, disinfectants and antiseptics etc are essential and should be provided by the government. Secondary care providers would also benefit from having a work uniform. Not only would this enhance perceptions of their work as a profession, but it would increase their recognition and standing among hospital staff.

The stigma of HIV and AIDS also adds considerable stress to care providers, whether or not they themselves are living with HIV and AIDS. Care providers sometimes have to provide care to a patient secretly, so as not to expose the patient to discrimination. Other care providers report being isolated by their communities and creating, in response, their own 'families' of care providers and people living with HIV and AIDS. Society-wide campaigns to tackle stigma may tackle the problem in the long-term but governments, donors and NGOs should also seek to develop or build the capacity of care providers' associations and support groups, which create important peer support for care providers.

It is amazing that despite these incredible levels of stress and psychological trauma associated with caring, women care providers seem to be able to carry on. South African care givers, some of the few who do receive a stipend for their work, report that there are three things that help to keep them going:

> *"One, despite being a very stressful job, care giving gives them the satisfaction of being able to help those in need. Second, it gives them some form of financial resource, however meagre the stipend is. Third, it gives them skills and the opportunity to hone them through continuous practice." However, it is "the popular saying, 'wathinta abafazi, wathinta imbokodo' (you strike a woman, you strike a rock) that comes to mind as probably the simplest explanation of how these women keep on providing care despite the odds."*[215]

As this chapter has shown, women and girls face repeated violations of their rights when trying to access care and support services, and as a result of their role as care providers. Donors, governments, multilateral organisations and civil society all have a role to play in redressing these violations.

5.5. Recommendations

Donor governments

1) Donors should increase support to country governments to introduce social protection measures, financial support for primary care providers and build the capacity of grassroots women's organisations, support groups and networks of women living with HIV and AIDS to develop income-generation initiatives, microcredit schemes, local employment and education/training opportunities for women and girls.

2) Donors should increase capacity-building support to organisations of women and girls living with HIV and AIDS to enable them to develop skills around management, leadership, group dynamics, team building, community mobilisation, advocacy and self-empowerment. Support should also be given to official bodies with a male bias to increase female membership and leadership within their organisations.

3) Donors should increase support and funding for care and support services. They must increase funding to remunerate, train and supervise secondary care providers and to support the delivery of community and home-based care that reduces the burden of care on women and girls. This should include funding programmes to involve men in delivering community and home-based care.

Multilateral organisations

1) The WHO should lead multilateral organisations, donors and governments in recognising non-volunteer secondary care providers as workers with a right to a fair wage. To do so, they have to start by revising the current classification of health workers to include all secondary care providers.

2) The WHO must revise its Care Guidelines[216] to directly support the remuneration of all non-volunteer care providers and provide clear guidelines for CBOs and NGOs on how to develop such policies.

3) The UN must ensure that care and support, and the role of women and girls in providing care and support, is recognised fully in international statements and that future declarations on universal access address this issue.

Developing country governments

1) Governments should increase the provision of social protection mechanisms to support women and girls living with HIV and AIDS and primary care providers with rent, children's education, nutritional support, clothes and other costs. Governments should also provide accessible information on available assistance such as disability grants, child support and pensions, and remove customary or civil laws that prohibit women from accessing banks, loans, companies, land or credit.

2) Governments should develop and fund accessible legal support and advice services, including drop-in centres and legal advice clinics, open at times when women can access them and providing information in accessible ways. This must include legal aid for women and girls, and training for legal officers and for national legislatures on women's legal rights around property, inheritance and family law, not only on the law itself, but also around the duty to respect and uphold laws in situations where women's rights have been violated.

3) Governments should increase investment in care and support services, and ensure there are proper systems of referral between community home-based care (CHBC) programmes and the public health system; they must ensure that CHBC programmes are incorporated into district health service plans and National AIDS Plans; and they must make sure that Standard of Care Guidelines are introduced or revised within National Health Plans to reduce the burden of care.

Civil society organisations

1) Civil society must create and/or strengthen local, national and regional community and home-based care alliances, to allow care providers to share knowledge, skills and resources.

2) All community and home-based care organisations, and the NGOs that support them, must develop comprehensive policies that recognise and protect care providers' rights and ensure appropriate pay for non volunteer care providers.

3) Home-based care organisations must ensure regular training for all secondary care providers by an accredited trainer on home-based care, with full access to information on vertical transmission, post-exposure prophylaxis, adherence and treatment literacy. This training should also be targeted at primary care providers directly, building on secondary care providers' skills to provide outreach training.

HIV rally, Nairobi, Kenya.
Jess Hurd/Report Digital/ActionAid

6. Conclusion

> *"[HIV and AIDS represents] the most ferocious assault ever made by a communicable disease on women's health, and there is just no concerted coalition of forces to go to the barricades on women's behalf."*[217]
>
> Stephen Lewis, former UN Special Envoy on AIDS in Africa

The HIV and AIDS pandemic is not just a health concern, it is an issue of human rights – and it is increasingly also an issue of women's rights. This report has highlighted how the denial of women's rights and gender inequalities time and again undermines universal access to prevention, treatment, care and support.

Growing awareness of the gender dimensions of HIV and AIDS has created an important opportunity to address the disproportionate impact that the pandemic is having on women and girls. Formal commitments to universal access – and the universal access process itself – is a powerful framework from which to advocate for women's rights. However, the lack of global targets addressing women's rights and empowerment, and the absence of consistent country-level targets, makes the move from merely recognising that HIV and AIDS has a female face, to actually acting on it, a major challenge. To date, this challenge has been met by a devastating state of inaction.

This report recommends the following immediate actions:

Donor governments

1) Donor governments must consult with women's movements, local networks and movements of women living with HIV and AIDS to ensure donor funding reflects local priorities of the people infected and affected by HIV and AIDS. They must also ensure that their policies and programmes do not reinforce inequalities.

2) Donors must only fund evidence-informed, gender-sensitive programmes that take a rights-based approach, including contributing their fair share to microbicides and increasing access to the female condom and other female-initiated HIV-prevention methods.

3) Donor governments must ensure long-term, predictable funding for the strengthening of health systems, in particular to ensure women-friendly and pro-poor health systems that integrate HIV and sexual and reproductive health rights services with HIV and AIDS prevention, treatment, care and support services.

Multilateral organisations

1) UNAIDS and the World Health Organization must develop clear targets, guidelines and a strategy to support country governments to develop a rights-based and gender sensitive analysis for scaling up HIV and AIDS action.

2) The Global Fund to Fight AIDS, Tuberculosis and Malaria must improve expertise on women's rights at all levels of the decision-making process and develop adequate indicators to monitor that country coordinating mechanisms are reflecting the priorities and rights of women and girls.

3) The World Health Organization should lead multilateral organisations, donors and governments in recognising secondary care providers as workers with a right to a fair wage. To do so, they have to start by revising the current classification of health workers to include all non volunteer secondary care providers.

Developing country governments

1) National governments must base national AIDS plans on a rights-based analysis of the barriers faced by women and girls in regard to HIV prevention, treatment, care and support services. This must have the participation of women and girls, living with and affected by HIV and AIDS, at its heart.

2) National governments must provide training and funding and put systems in place to ensure that adequate staffing, diagnostics, medicines and other provisions are made to treat opportunistic infections that particularly affect women and girls, such as cervical cancer.

3) National governments must develop, fund and implement their national treatment plans and budgets with a strong emphasis on women and girls, particularly women and girls in poor and rural communities, in order to achieve universal access to treatment.

Civil society organisations

1) Civil society must ensure that a women's rights approach is at the heart of their HIV and AIDS programmatic interventions and political advocacy.

2) Civil society must create and/or strengthen local, national and regional community- and home-based care alliances, to allow care providers to share knowledge, skills and resources.

A look to the future

Scaling up towards universal access demands a new approach that goes beyond mere rhetoric to make a real difference on the ground. Indeed, only a few years ago, the very concept of universal access was not even on the radar of governments, donors or multilaterals. Now, it represents an international public commitment to which the majority of governments have agreed. While the current reality of implementation may be different, the process itself has the potential to effect significant change.

The next step is for governments to commit to gender sensitive, measurable and time-bound indicators and targets for scaling up access in all areas of prevention, treatment, care and support.

With political will, proper resources, and the cooperation of multiple stakeholders, we can stem the course of the pandemic. The lives of millions of women and girls depend on it.

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