
8. Dignity Overdue: National HIV Strategies and Unpaid Carers' Rights

'Containing' women: situating policy responses

It has become a truism that national strategic plans have, for the most part, been gender blind. This has meant that women have only appeared in them as pregnant women in prevention of vertical transmission programmes (in the attempt to identify HIV-positive mothers and ensure babies are not born HIV-positive), as sex workers and as youth. Otherwise women and girls are mostly invisible and their contribution goes unrecognised, including their work as unpaid carers. Yet there is a pattern to the way in which even these responses treat women that is telling as national HIV prevention and treatment strategies continue to rely on stereotyped perceptions of women's sexualities even as they attempt to strike a balance between 'containing' women in the interests of public health and recognising women's needs and interests given the realities of gender inequality, poverty, powerlessness and violence in their daily lives.

For example, the response strategies have been primarily medical for women living with HIV, although now there is an expanded response for HIV-positive mothers that includes a range of support including ART where indicated (and where available) as well as support for safe breastfeeding and/or access to formula after the child is born. However, evidence shows that women who access prevention of vertical transmission programmes are seen as immoral and are often coerced into having abortions or being sterilised. The ideal scenario expressed in policy documents is thus belied by the abusive realities reported by communities of women living with HIV.¹

For female sex workers the response is deeply conflicted, with technically sound prevention strategies that include condom distribution, access to justice programmes, legal reform and support for the development of social capital mixed in with raid and rescue 'missions'. The fact that such 'missions' disrupt or destroy female sex

workers' lives and include incarceration in 'rehabilitation' camps - with consistent reports of women being raped by State authorities both en route to the camps and inside them - does not stop such strategies from being used or funded.² For young women in school the response is also heavily moralistic and based on promoting delay of sexual debut or 'secondary virginity' alongside withholding contraception and family planning options. For out-of-school young women the response has been similar but also includes moralising pressure to not have sexual relationships with older men. In a recent World Bank study in Malawi, the researchers tested cash incentives as a prevention technology to see if it led to less sex with older men, increased retention in schools and from there fewer HIV infections (World Bank 2010a; 2010b).³

These deeply contradictory approaches, so rife with human rights breaches and abuses, are themselves a reflection of the inability of national plans to engage women's vulnerabilities in a systematic way that respects, protects and affirms their human rights. This fundamental failure undermines the ability of HIV responses to be effective at the general population level and even more so when it comes to women. In the contexts of HIV and AIDS, women's vulnerability is complex and driven by pre-existing gender inequality. The deeply conflicted responses to women sketched above demonstrate this. Because many people still see HIV as the result of immoral behaviour and so a source of shame, it is also seen to provide license to discriminate, often harshly, against women and girls in the design and practice of programming. As could be predicted, in instances where men are equally responsible for the stigmatised behaviours it is women who are blamed and bear the brunt of punishments while the men remain outside the reach of these strategies.

In fact, if we examine the basic structure of most national strategic plans, they include a component on creating an enabling environment (addressing laws, social norms, policy, and so on); a prevention component; a component on treatment, care and support; and perhaps something on research or monitoring and evaluation. In each of these areas, however, women's needs remain marginal. So in addressing the enabling environment, the social and cultural factors that make women vulnerable are often left intact or superficially addressed. Similarly, there are inbuilt assumptions in prevention programming about who has control over when, where and how sex takes place that often do not reflect women's actual lives. Strategies for treatment, care and support assume that access to ART is predicated on self-interested individualism on the part of the person living with HIV (and so there is no sharing of medication or giving medication

to others), and where care and support are 'soft' issues compared to ART. This is where women's/gendered unpaid care work becomes central in reality and ignored in policy. And because of this gender blindness, gender analysis is not used in monitoring and evaluation except to enumerate the gender of those with HIV and AIDS.

These policy silences obscure women's realities. The complex range of ways in which HIV and AIDS actually affect women is lost in the narrow conceptualisation of women as 'pregnant seropositive women,' 'sex workers,' and 'young women'. Moreover, societal ambivalence towards such women means that societal conflict over women's rights to their reproductive health and rights (for women living with HIV) and to their sexuality (for all three groups) then plays out in HIV programming. Traditional HIV responses are thus structurally blind to women's needs.

A case in point – and the example with which this book is most concerned – is that when AIDS enters the household, women are very hard hit. Already disproportionately impoverished, women who live in a household where someone falls ill from AIDS-related illnesses, or fall ill themselves, feel the brunt of the loss of access to resources inside the household. The social exclusion that, some 30 years into the epidemic, still comes when someone has been touched by HIV means women are also far more likely to feel the impact at the personal, family, household and broader social levels. Women's inequality and breaches of their human rights therefore remain a central factor in both the impact of and responses to HIV and AIDS at the household and community levels.

The problem of defining targets: national HIV strategies, women's rights and the MDGs

Given the foregoing, the issue raised at the macro level is whether the Millennium Development Goals (MDGs) can be achieved without addressing both what is happening to women in the context of HIV as a symptom and gender inequality as a major underlying cause of women's vulnerability to HIV. This means MDG 6 on stopping the spread of HIV, TB and malaria is inextricably linked to MDG 3 on achieving gender equality. The World Health Organization (WHO) has shown that, in fact, AIDS is the leading global killer of women of reproductive age. Indeed, over 60 per cent of people living with HIV in sub-Saharan Africa are women. All of these women will

need ART, but the majority will never have access to it (WHO et al. 2009). Despite this, women become primary caregivers for those with AIDS-related illnesses even when they themselves are ill or dying of AIDS (WHO 2009).

Similarly, the MDGs on maternal and child health cannot be achieved without greater progress on addressing women's needs in response to HIV, TB and malaria. One South African study found that 38 per cent of maternal deaths were primarily due to HIV, TB and pneumonia (Countdown Coverage Writing Group 2008). More than 700,000 women are estimated to die every year of TB (Maraia et al. 2010). Children under 15 years of age comprise 10–15 per cent of the global TB burden (ibid.) and almost 80 per cent of malaria deaths occur in children (WHO 2008).

Thus there can also be no progress on MDG 6 without progress on MDGs 4 and 5. To improve maternal health, we need to ensure that women living with HIV have access to ART, to rights-based prevention of vertical transmission programmes and to integrated care and support programmes (we will come back to this last point at the end of this chapter). AIDS is the leading cause of under-five mortality in the six highest HIV prevalence countries (WHO 2008). As a result, in order to improve child health, prevention of vertical transmission programmes must be scaled up and include support to mothers so that their children do not seroconvert during breastfeeding, and children born HIV-positive must have access to infant and child formulations of ART.

Similarly, as AIDS affects most those who are in the prime of their working years, individual households are seriously affected when primary or major income earners fall ill. The economic shock of AIDS, in both health and stigma, wrecks household economies.⁴ This means that care providers and children are also hard hit as the ability of the family to meet its needs collapses. When the adults' bodies fail, and they are no longer able to contribute to the household's requirements, those who are not ill have to step in to maintain some modicum of income in kind or cash so that everyone does not starve. This means child labour easily and quickly becomes essential and one or more of the children is pulled out of school to provide for the family and themselves. The gendered division of labour so taken for granted in most societies means that often the girl child is the first. The achievement of universal education (MDG 2) thus becomes impossible for households hit by AIDS. The voices of the carers throughout this volume demonstrate this.

Thirty years into the AIDS epidemic, and 10 years since the landmark UN General Assembly Special Session on HIV/AIDS,

global leaders came together to review progress and chart the future course of the global AIDS response at the 2011 UN General Assembly High-Level Meeting on AIDS, held from 8–10 June in New York. At the heart of the deliberations was the future of international co-operation, MDG 8. Even as the Political Declaration adopted by the meeting reaffirmed commitments to guide and sustain the global AIDS response, the need for immediate action on the ground has never been more compelling, with real but fragile gains made in a context of reduced resources because of global public debt.

The Joint United Nations Programme on AIDS (UNAIDS) and the GFATM are the two global institutions charged with achieving MDG 6. Their work, as we have seen, is essential to achieving all of the MDGs as the world contemplates how to respond to the 34 million people and counting now living with HIV. Of these, 12 million people urgently need treatment but only 3 million have access to it as governments failed to achieve universal access by 2010. AIDS ushered in a new era of international co-operation that saw the right to health and dignity enshrined in agreements that were based on international solidarity with regard to funding and making commitments to principles and practices for their realisation.⁵

Yet despite this governments in both the developing and developed countries have reneged on these agreements, especially when it comes to challenging social norms that deny the dignity of women and socially excluded groups. While the revolution in the structure of international co-operation has been a model of what is possible, there is unfinished business that itself stands as a lesson of how human rights and dignity for all is fundamental to development. The question is whether States and societies will continue to allow this crucial link between human dignity and political and financial commitment to be the place at which development initiatives flounder. The rights of women, and the dignity of those who care for those within their household and communities without being paid and whom society has cast out, are key to this. Nowhere is this more strongly evidenced than in the voices of the carers documented in this volume.

Listening to unpaid carers' voices

Our research suggests the ways in which women's roles in the household and society are invisible and embedded but nevertheless essential. This is especially critical when it comes to understanding what happens to the 'care and support' components of 'treatment, care and support' strategies in national plans. In many ways this is

because actually grappling with care and support for people dying of AIDS at the macro level is in direct conflict with many indicators of efficiency, such as hospital bed days per patient. This key indicator drives hospital management behaviour, meaning that at the individual level hospital staff have a strong disincentive for allowing people dying of AIDS to remain in their hospital. That this means someone whose body has broken down has nowhere to go but home, where there is no one to care for them but the women or girls in the household, becomes irrelevant. Within the household, the physical presence of a body dying of AIDS triggers stigma and discrimination from the community and from some within the household. This leads to social exclusion for the carer. Our research shows that carers, most often women and girls, believe they have no choice but to provide for their dying loved one; it is in this feeling of no choice that rights and dignity are breached, invisibly, and replaced by 'capability servitude' (Waring 2011).

This volume is based on data demonstrating this, and the extent to which the experience is the same across the Commonwealth and around the world cannot be emphasised enough. To look at concrete examples, we can recall the voice of the sex worker from Guyana who was caring for her sister in the hospital, where national strategies mandate tertiary care be provided. She had to go to the hospital herself in order to care for her sister because the nurses shunned her. Similarly, the gay man from Jamaica had to care for his dying lover by himself under the growing threat of homophobic violence. In Papua New Guinea the carer laments that she received no support with counselling or assistance as she and her family grappled physically and emotionally with her daughter's deteriorating condition and eventual death. However, she was asked to be part of a health workshop after her daughter had died. These examples demonstrate the extent to which national strategies are failing to come to terms with people's realities.

Breaches of rights and dignity are rendered invisible simply because unpaid carers' voices are ignored. As the young girl from Uganda put it: 'I loved going to school and I wanted to complete it so I could look for a simple job and sustain my siblings. No one comes to give me rest.' These breaches of rights worsen as carers slip into servitude. Recall again the voice of the young Ugandan carer who makes her servitude so explicit:

I had no choice because there was no other person close to my mother to assist her when she fell sick or to look after my young brother and sister. ... I think of our future as being hopeless when our mother has passed away.

Here the challenge is State accountability – or the lack of it. Where the State has failed in setting human rights as a dominant social norm at the community level, it also fails consistently within institutions under its purview. We have seen the examples above from the hospital – traditionally the focus of extensive anti-stigma and discrimination programming but where stigma and discrimination remain institutionalised – but we could also include the prison as a site of concern because of the higher percentage of people living with HIV encountered in prison settings for a variety of reasons. In truth, prison culture as it is traditionally interpreted is at odds with a compassionate care response, even for those who are dying, once it is a stigmatised illness. Even in those areas where the State has provided for care, the fact that such policies are at odds with the institutional culture means that they are often undermined or are not implemented at all.

This persistent failure is also responsible for carers falling into servitude as the State relies on the household (or officially ‘the community’, which means women, children and gay men’s lovers and friends) to provide care for the millions dying of AIDS now and for the foreseeable future. Many carers – including in this research – are already or are forecast to be members of the new transmission demographic. Who then will care for them?

Valuing care and unpaid carers in the AIDS response

But it is not always the case that the responsibility of care and support is not taken seriously. Two country examples show what is possible if governments take up the needs of those who need care and their carers. In closing we will look at the work being done in Botswana and Australia in this respect.

Social protection programme in Botswana

Botswana is one of the countries hardest hit by the epidemic, with 24.6 per cent of the general population of approximately 1.8 million people living with HIV. For the most part HIV is affecting people in the prime of their working lives and so it is having a dramatic effect on households. Botswana’s own analysis has shown that household expenditure for medical expenses increases dramatically with the onset of AIDS and that other members of the household, most often women and girls, have to divert their labour to care for the sick person. This is particularly important as about half of Botswana’s households are

headed by women. When death occurs, the household is even harder hit with permanent loss of income, lower remittances or income from farm work, funeral and mourning expenses, and children being taken from school in order to reduce expenses on education. A 1992 study showed that when mothers die and children are orphaned, about 95 per cent are absorbed by extended families, a percentage that includes children orphaned by AIDS (Tsiane 2010).

Botswana defines social protection as

‘... a set of policies, programmes and strategies designed to reduce poverty and vulnerability by promoting employment opportunities, diminishing people’s exposure to risks and enhancing their capacity to protect themselves against psycho-social and economic hazards and the loss of income.’ (Ibid.)

Their response programme is accordingly designed to address a wide range of vulnerable groups – including the elderly, people living with disabilities, destitute/needful and vulnerable families, dwellers in remote areas, the able-bodied poor and war veterans, as well as orphans and vulnerable children, mothers, infants and children – via feeding and health/growth monitoring and community home-based care. The last four categories being supported are particularly important for our purposes, as they provide a framework for community care that can mitigate the impact of AIDS on the household. Importantly, it also means that social protection is a government priority and an accepted part of government policy.

The programmes include cash transfers; transfers in cash and kind, with development support; transfers in kind; and transfers in kind with other psychosocial/development support. In some cases, the programmes are conditional while in others they are unconditional, as shown in the table below:

	<i>Unconditional</i>	<i>Conditional</i>
Cash transfer	State old age pension War veterans’ pension	Ipelegeng [able-bodied poor]
Transfer in cash and kind, with development support	Destitutes’ programme	
Transfer in kind		Primary school feeding Secondary school feeding Vulnerable Group Feeding Programme
Transfer in kind, with other psychosocial/development support	Community home-based care Orphans and vulnerable children Remote Area Development Programme	

Source: Tsiane 2010

The number of people on these programmes varies widely, however, with approximately 302,000 children in the primary school feeding programme and only about 3,700 people receiving community-based care. Some 48,000 orphans and vulnerable children are receiving benefits, suggesting multiple points of entry into social protection for households that lose income because of AIDS in the absence of treatment. Botswana's social protection response also includes programmes to promote equity and inclusion across society as well as programmes to support civil society and promote culture, sport, recreation and social values. Clearly the coverage of these programmes is not sufficient to meet the need, but the policy framework is there to provide a platform and there are ways in which the Government is trying to address vulnerability and marginalisation that can help to reduce the burden on families with someone dying of AIDS.

Carers' action plan in New South Wales, Australia

Australia, and in particular New South Wales (NSW), similarly has a strong social protection platform. This is particularly important for NSW as national surveillance shows that the State has by far the highest rate of HIV diagnoses relative to population size:

'The rate of HIV diagnoses in NSW has been almost double that of the next most prevalent State (Victoria), with 220.8 people per one hundred thousand people having been diagnosed with HIV by 31 March 2009. 55.9% of all AIDS diagnoses in Australia up until 31 March 2009 took place in NSW. Correspondingly, 55.4% of all deaths from AIDS have occurred in NSW.' (D'Amore 2010)

In the instance of carers, the social protection approach has two substantive prongs. The first prong is a strong response to HIV that includes health promotion for prevention, care, treatment, support and research. NSW has also identified six priority populations to which programming is targeted, which means resources are deployed where they are needed rather than in a scattershot way.

In a briefing paper on HIV in the State, Member of Parliament for New South Wales Angela d'Amore (ibid.) demonstrates the point about women's vulnerabilities for her constituency:

'Women continue to have particular treatment, care and support needs. Overall, women living with HIV/AIDS are believed to have poorer health outcomes than men, with more rapid disease progression and more reservations about the effectiveness and safety of treatments. Women may experience greater difficulty adhering to treatment regimens as their responsibilities for caring

for children and other family members may leave limited time, money and capacity to focus on self-care. In addition, women living with HIV/AIDS are particularly vulnerable to poverty and report experiencing difficulty paying for food or medication. The need for vigilance is supported by the recent small but significant increase in HIV notifications among women in NSW.'

This strong focus on the specific realities of groups affected by HIV and AIDS is complemented by the second prong of the approach: the *Carers Action Plan 2007–2012* for NSW. Like the programme in Botswana, it is based on a commitment to social protection for those who need care – and the responsibility of the government to provide this.

The carers' plan begins with the recognition that 'more than one in ten members of the NSW community are carers' and identifies them as 'dedicated citizens making an unsung yet indispensable contribution to our social fabric'. It pulls together services from a matrix of existing ones that can be used to support carers and speaks directly to the pressures of care-giving as well as the need to ensure caring and carers are no longer invisible. Its 'five priorities for action' are:

1. Carers are recognised, respected and valued

Strategies to increase the respect and recognition of carers to demonstrate their role is valued and to ensure they are not invisible or taken for granted.

2. Hidden carers are identified and supported

Strategies to identify and reach hidden carers so their needs can be assessed and they can be provided with timely information and linked to support.

3. Services for carers and the people they care for are improved

Strategies to improve services for carers and the people they care for that focus on affordability, accessibility, flexibility, cultural competency and quality.

4. Carers are partners in care

Strategies that improve the interaction between carers and public agencies and that focus on carers as partners in care.

5. Carers are supported to combine caring and work

Strategies that support carers to combine caring and work including mechanisms that promote family-friendly practices in the workplace and the provision of flexible services to support working carers. (New South Wales Department of Health 2007, p. 7)

The vision of the action plan speaks directly as well to the importance of well-being for carers:

'The NSW Government will contribute to carers achieving quality of life for themselves and the people they support. In the context of their caring role, carers will be:

- supported to achieve physical and emotional wellbeing and to participate in work and community life
- valued as key contributors to community wellbeing and as key partners and providers of care
- considered in the development of public policy in NSW.' (Ibid.)

Importantly, the carers' strategy is for all carers and not specific to HIV, although it explicitly includes HIV in its remit.

Giving dignity its due

In the end, this is perhaps the best strategy for governments: a broad approach that understands the role of carers as well as the specific needs of households struggling with loved ones who are dying. It ensures that care and support policy as part of a national response to HIV is predicated on rights. This means respect for the economics of dignity and what it takes to fulfil State and community obligations to ensure the dignity and rights of people living with HIV and their unpaid carers.

Notes

1. See, for example, Vivo Positivo and Centre for Reproductive Rights 2010 and ICW 2009.
2. See for example Rights Watch 2010.
3. For a critique, see Kohler and Thornton 2010.
4. The breakthrough study on this issue was Collins and Rau 2000.
5. See for example the *Political Declaration on HIV/AIDS* (2006); the *Declaration of Commitment on HIV/AIDS* (2001); *The Framework Document of The Global Fund To Fight AIDS, Tuberculosis And Malaria* (2002); United Nations 1995; and UNAIDS 2010b.

