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A Case-Study of HIV and AIDS Care-giving

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Commonwealth Secretariat

Commonwealth Secretariat
Marlborough House
Pall Mall
London SW1Y 5HX
United Kingdom

Published by the Commonwealth Secretariat
Edited by Tina Johnson
Designed by S.J.I. Services, New Delhi
Cover design by Tattersall Hammarling & Silk
Printed by Hobbs the Printers, Totton, Hampshire

Cover photo: Smiling mother and son after starting antiretroviral treatment, Botswana
Credit: WHO/UNAIDS/S. Toffin, 2004

Copies of this publication may be obtained from:

Publications Section
Commonwealth Secretariat
Marlborough House
Pall Mall
London SW1Y 5HX
United Kingdom
Tel: +44 (0)20 7747 6534
Fax: +44 (0)20 7839 9081
Email: publications@commonwealth.int
Web: www.thecommonwealth.org/publications

A catalogue record for this publication is available from the British Library.

ISBN (paperback): 978-1-84929-019-7
ISBN (e-book): 978-1-84859-068-7

For
Robert Carr (1963–2011)
Researcher, activist and a dear friend – gone too soon

About the authors

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From left to right: Anit Mukherjee, Marilyn Waring, Meena Shivdas and Robert Carr

Acknowledgments

This research would not have been possible without the participation of the unpaid carers who gave up so much of their valuable time for us. We are indebted to them as they shared the everyday realities of caring for loved ones who are HIV positive. Their generosity and dedication have touched us in many ways.

We are also grateful to our research partners who anchored the interviews and filming by reaching out to households in various locations to tell the previously untold stories of unpaid carers. Particular thanks are due to Giselle Dias, Anne Speir, Dobi Kidu, Anjali Gopalan, Meena Seshu, Anandi Yuvaraj, Jennifer Gatsi, Lillian Mworeko, Ian McKnight, Marguerite Newland and Karanina Sumeo.

Institutional partners include the Naz Foundation India Trust, SANGRAM India, Mukto Akash Bangladesh, International Community of Women Living with HIV (Asia-Pacific, East Africa and Southern Africa), and Caribbean Vulnerable Communities.

Contents

Acronyms and abbreviations

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CRC	Convention on the Rights of the Child
CSW	(United Nations) Commission on the Status of Women
DALY	disability-adjusted life years
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
GDP	gross domestic product
GFATM	Global Fund for AIDS, TB and Malaria
HIV	human immunodeficiency virus
HRC	(United Nations) Human Rights Committee
MDG	Millennium Development Goal
NGO	non-governmental organisation
NSW	New South Wales (Australia)
OVC	orphans and vulnerable children
PASAN	Prisoners' HIV/AIDS Support Action Network (Canada)
PEPFAR	US President's Emergency Plan for AIDS Relief
QALY	quality-adjusted life years
SNA	System of National Accounts
TB	tuberculosis
UDHR	Universal Declaration of Human Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UPR	Universal Periodic Review
VAMP	Veshya AIDS Muqabla Parishad (India)
WAMM	(Commonwealth) Women's Affairs Ministers Meeting
WHO	World Health Organization

Foreword

In 2000 the international community committed itself to eight ambitious but achievable Millennium Development Goals (MDGs), among them halving the number of people living in poverty and stemming the spread of HIV. It also promised to provide leadership and uphold the human rights of people living with HIV. Commonwealth governments, being part of the international community and its commitments towards the MDGs, are working towards the achievement of the MDG targets.

The Commonwealth carries much of the global HIV burden – two-thirds of those who are HIV-positive today are in the Commonwealth and 56 per cent of them are women. The Commonwealth is home to all major epidemic profiles – ranging from the generalised epidemics of sub-Saharan Africa to epidemics in high-risk groups such as sex workers and drug-users in South and Southeast Asia and Canada and men who have sex with men in the Caribbean. The response of Commonwealth countries to HIV and AIDS is guided both by national laws and policies and by international law relating to human rights.

This publication is about research on gender and the policy dimensions of unpaid HIV care in the household commissioned by the Commonwealth Secretariat. The study highlights the voices of unpaid carers in Bangladesh, Botswana, Canada, Guyana, India, Jamaica, Namibia, New Zealand, Nigeria, Papua New Guinea and Uganda. The voices of these unpaid carers recount personal struggles, challenges and survival strategies. The research findings demonstrate that upholding the human rights of unpaid household carers in accordance with international human rights standards is crucial to protecting the dignity of all people living with HIV and/or experiencing symptoms of AIDS and their unpaid carers. Protecting the rights of unpaid carers in the household is not only part of the Commonwealth's commitments to international human rights standards but also crucial to member governments' commitment towards the achievement of the MDGs.

The voices therefore provide the foundation for national treatment and care strategies to respond to HIV and AIDS in a resource-reduced context brought on by the global public debt crisis. More importantly, amplifying those voices serves to bring home the duty of care.

The 1978 Alma Ata Declaration on primary health care has particular resonance for unpaid HIV carers as they struggle to help their loved ones realise the rights to health. The Declaration affirmed that the attainment of the highest possible level of health is a fundamental human right and emphasised key principles such as the importance of equity and international co-operation to ensure the realisation of that right.[1] The Declaration also went further and highlighted a number of health interventions including the promotion of food supply and proper nutrition and provision of essential drugs that are necessary for the realisation of the right to health and therefore the right to dignity.

The right to dignity is inalienable and enshrined in all human rights conventions. As duty-bearers, States have a duty to protect the human rights of their citizens and protect their dignity. The State's commitment to a duty of care in hospitals and prisons is also part of the commitment to international human rights standards. The duty of care in relation to HIV extends to responsibility towards education about dignity and stigma.

As rights-holders, unpaid carers expect to exercise their rights to have freedoms and choices.

Most Commonwealth governments have ratified key international human rights conventions, particularly the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the Convention on the Rights of the Child (CRC).

Reports to treaty bodies place a moral responsibility on governments to uphold the human rights of their citizens. CEDAW and the CRC, in particular, outline the commitment of governments and the international community to the rights of women and children, who are most likely to bear the brunt of unpaid care as households are hit hard by HIV and AIDS and the recent trends in relation to reduced funding for health and other developmental interventions. States are also part of the Universal Periodic Review[2] process.

Further, the 'special procedures' mandates of UN mechanisms on human rights call on mandate holders to examine, monitor, advise and publicly report on human rights situations in specific countries or territories, known as country mandates, or on major phenomena of human rights violations worldwide, known as thematic mandates.

The report[3] of Paul Hunt, the UN Special Rapporteur on health (2002–2008), is particularly important for HIV issues and for the carers of those with HIV and AIDS as it provides the framework for the right to heath. The report states that this right is an inclusive one, extending not only to timely and appropriate health care but also to the underlying determinants of health including access to safe and potable water and adequate sanitation, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health. All of these were issues for the carers in this research.

This research draws on the rights framework to health and builds on the concept of capability to understand the situations of unpaid HIV carers by focusing on aspects of HIV care that concern the carer's daily lives and struggles and have implications for their dignity and rights. The research makes the case for a gender-responsive human rights-based approach to policy and programmes on HIV treatment and care. It calls for the recognition, consideration and inclusion of unpaid carers' perceptions and experiences when formulating national and international HIV policies.

Greater involvement of people living with HIV is now an accepted part of policy formulation, but the dignity, needs and rights of unpaid household carers must also be recognised. As we develop policy and programming to address the needs of those struggling with AIDS-related illnesses, we need to move to **greater involvement of people living with HIV and those struggling with AIDS and their carers**. The Hon Michael Kirby (former Judge, High Court of Australia, and expert, UN Global Commission on HIV and the Law) has asserted that the only way in which we will deal effectively with the problem of the rapid spread of the epidemic is by respecting and protecting the human rights of those already exposed to the virus and those most at risk.

As this timely publication demonstrates, as long as we fall short in promoting universal human rights, we will continue to fall short on achieving universal access for the prevention, treatment and care of those with HIV and AIDS. International human rights commitments are crucial in focusing and reinforcing a comprehensive response. Universal human rights work best from both the top down, when countries commit to the principles, and from the bottom up, when people can live them. Another crucial aspect is maintaining the international and national commitments made to expenditures on health.

For this and many other reasons, HIV will continue to be on the Commonwealth agenda for Heads of Government and we will strive to learn lessons from across the Commonwealth and beyond, where much headway has been made to respond to the HIV epidemic and protect the human rights of those affected.

Dr Sylvia Anie CSci, CChem, MRSC
Director
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(Education, Gender and Health Sections)
July 2011

1. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/HRC/7/11, 31 January 2008, United Nations.
2. The Universal Periodic Review (UPR) is a unique process that involves a review of the human rights records of all 192 UN Member States once every four years. A State-driven process under the auspices of the Human Rights Council, the UPR provides the opportunity for each State to declare what actions they have taken to improve the human rights situations in their countries and to fulfil their human rights obligations. As one of the main features of the Council, the UPR is designed to ensure equal treatment for every country when their human rights situations are assessed.
3. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, E/CN.4/2003/58, 13 February 2003, United Nations.

1. Introduction

> *'He was in the same clothes in a corner bed [of the hospital], no sheets nothing. The food that they had taken for him was lying there. He was blind, crippled and not talking.'* – L, unpaid carer, Jamaica
>
> *'When we started getting the basket people use to laugh at us saying we are eating AIDS food....'* – Lillian, unpaid carer, Botswana
>
> *'Right before she was brought to the hospital she was found lying in her own vomit with rotting food in her cell, cigarette butts everywhere and fruit flies all over.'* – Cynthia, unpaid carer, Canada
>
> *'There is nobody on earth who can really stand beside me. Today I cannot do any work properly due to my HIV infection because people rebuke me or neglect me.'* – Hamida, unpaid carer, Bangladesh
>
> *'The most difficult is that you have to stay indoors, you don't go out. Since she don't walk you have to stay indoors. She needs drinking water, she wants to go to the toilet, you have to carry her.'* – Amira, unpaid carer, Nigeria
>
> *'My anger was with my own family because they would not come and visit us or bring food for her like what is normally done when someone is sick. It was like I had no family.'* – Ruth, unpaid carer, Papua New Guinea

These voices are those of unpaid carers living without human rights, living without dignity, living without protection, living without freedom and equality. They live with fear, live with want, live in servitude.

At the centre of the HIV and AIDS response are the estimated 34 million people living with HIV. Of the 12 million people who urgently require access to treatment, care and support, 9 million do not have access to treatment and will die of AIDS (UNAIDS 2011). In these cases, where the bodies of people living with HIV have begun to break down as the virus takes control over their ability to function, carers are essential providers of physical, social and psychological support. They walk hand in hand with those they love and those for whom they care, especially in resource-poor settings. Yet, as the voices of these carers of people struggling with AIDS-related illnesses reveal, they are often as invisible as they are taken for granted by the system that depends on them.

This study is about the millions of carers of people living with AIDS – carers who form no part of the global strategic policy frameworks that are supposed to deliver effective and efficient outcomes in the global response to HIV and AIDS.

The impact of the international public debt crisis on HIV programming has resulted in an increased focus on efficiency of resource use. Reaching or even maintaining treatment targets has therefore become a priority. The missing factor in the treatment equation is those who care for the 9 million who require treatment but cannot access it. Evaluation criteria to assess HIV programmes focus on reduction of the national burden of HIV and AIDS without acknowledging where that burden falls. AIDS is a crisis that hits hardest at the household level.

Public debt, HIV funding and households in crisis

The current public debt crisis that developed countries are facing will have serious consequences for funding global HIV programmes. The impact of the economic downturn on national budgets and the resultant reduction in public spending will lower household capacity to access HIV and AIDS-related services that are already under severe pressure due to cuts in external aid. Consequently, unpaid carers in the household will be required to shoulder even more burden as they effectively subsidise public health provision. Of particular concern therefore is the non-acknowledgement of budgetary targets for education, health, agriculture and water at a regional 2010 meeting of African ministers of finance, planning and economic development (AFRO-NETS 2010). This would have serious implications for the realisation of the Millennium Development Goals (MDGs) and confronting the AIDS crisis – especially for young women in sub-Saharan Africa, given that 4 out of 5 million HIV-positive young women live in that region (UNAIDS 2011).

Measures that reduce the burden on the household receive the least financial and implementation support. But it is the household – and, by and large, the women of the household – who subsidise HIV care. However, in many cases, gay, bisexual and transgender people also care for their partners. The impact on families is also rarely recognised, such as a lack of access to basic necessities due to stigma and discrimination. These and other direct and indirect effects cannot be easily measured in monetary terms.

To date, the main focus of AIDS care has been on treatment, yet this focus fails to acknowledge the vital contribution made by unpaid carers in the household. Undoubtedly cutbacks, including the lack of maintaining international and national commitments on health expenditures, will have a severe impact on institutional and cross-sectoral aspects of health care. As a result, HIV-related advocacy, human rights protection and civil society activism towards the achievement of gender equality and the empowerment of women and men will be disadvantaged, under-resourced and compromised.

Rights, resources and the invisible care burden

The invisibility of 'who cares' underscores core inadequacies of the global AIDS response, exacerbated by the failure to apply a human rights framework to the implementation and delivery of care and support programmes. Retention of a definition of work that excludes unpaid care work is a fundamental breach of a basic human right. In those rare instances where home-based care is compensated as part of care and support programmes, it is based on outmoded notions of the family[1] and household. Part of the reason for this is the predominant focus on hyper-endemic contexts in Africa. This ignores not only the diversity of households, families and support systems in Africa itself but also the families and support systems providing critical care work in countries around the world experiencing concentrated epidemics among sex workers, drug users, gay and bisexual men and migrant populations, among others. The diversity of care and support systems is invisible or ignored in the AIDS response where the experience of social exclusion and indignities may be even more extreme. If we are to reach universal access goals and the MDGs, this fractured understanding is untenable.

Access to treatment, care and support are the pillars of the global response to HIV and AIDS. Governments and the international community are focused on preserving treatment enrolment targets and ensuring prevention dollars are invested according to epidemiological profiles. Most national plans are driven by considerations of available donor resources and convenient implementation arrangements. In most countries with concentrated epidemics, efficiency is equated with achieving targets for prevention coverage of high-risk groups and for antiretroviral treatment (ART). The effectiveness of the programmes is judged by whether these interventions have been able to reduce the burden of HIV and AIDS in the long run. Yet the evaluation criteria do not consider where that burden falls. There is a disjuncture between the burden of HIV at a national level and the burden of HIV that falls on the household. Home is the primary site of care for those living with AIDS.

Measures that reduce the burden on the household such as care and support programmes are the ones that get the least amount of finances and implementation support. Concerns about creating entitlements through the continued scaling up of treatment have already begun to impact donor funds made available for access to ART. This is resulting in proposed and actual caps on enrolment in treatment programmes. We therefore face a crisis in the rights to life and to the highest attainable standard of health for people living with HIV. We also face the hidden crises experienced by those who care for them, especially in resource-poor settings most vulnerable to decreases in donor support for treatment. Securing the rights of the carer in these scenarios is essential if the household is not to collapse under the burden of lost life years that could have been saved.

Focusing on the carer is therefore an efficient and effective response to reduce the burden of AIDS on the economy. It is at the household level that the most important decisions about the allocation of resources are made. Over time, different policy provisions – for example nutrition programmes aimed at children or the payment of child benefit support as in the OVC[2] programme in Botswana supported by the Global Fund – have targeted carers for delivery. AIDS Free World, a non-governmental organisation (NGO), also has a small project where they pay home-based carers. However, focusing on carers is not generally the case in AIDS care provision programmes around the world.

The household experiences greater costs related to caring. Financial costs include increased costs of food, medications and commodities needed for caring. Opportunity costs include loss of income, loss of subsistence production and loss of children's education. Invisible costs include the deteriorating physical and mental health of the carer, plummeting nutrition levels of the household, deteriorating worsening living conditions and sometimes complete loss of shelter, loss of educational opportunities and loss of community participation and personal safety. Barnett and Whiteside (2003) have observed that HIV has been the fastest way for a family to move from relative wealth to relative poverty. This disconnect between the realisation of human rights and the 'efficiency' approach in AIDS programming is evidenced by the state of carers.

Listening to carers' voices

Employing a gender-responsive human rights lens to reconcile a cost benefit analysis of HIV and AIDS with a political economy approach, this research listened to the voices of unpaid HIV carers in the household. This approach enabled an assessment of 'dignity' and 'rights' in unpaid care and helped to make the case for placing unpaid HIV care-work in the household at the centre of policy formulation for care and treatment as it makes financial sense and leads to social justice.

Eleven Commonwealth countries were identified based on their particular epidemic profiles and the fact that their unpaid care experience and burden would resonate with other countries in the Commonwealth. The study acknowledges that the unpaid care experience would be exacerbated by factors such as disability and disadvantage stemming from situations including unemployment, lack of education, social class, caste and age. In addition discrimination based on factors such as sex, colour and sexual orientation would make the unpaid care experience more onerous.

Within the conceptual framework that is elaborated in the next chapter, key aspects of the unpaid carer's work, life choices and perceptions of rights and responsibilities were examined against particular articles of international human rights instruments to identify how, when and why the unpaid carer's rights were compromised and their dignity eroded. The research process advanced the analytical framework as it led to the examination of the concepts of dignity and servitude in a new way.

The unpaid carers' voices were situated within the analytical contexts of (1) capability servitude in the household – access to and experience of basic freedoms and rights; (2) experiences and perceptions of stigma and discrimination; (3) access to and experience of health services in a public hospital setting; (4) experiences of prisoners living with HIV; and (5) experiences of gender-based violence.

The literature review made it obvious that the research focus in the field would be most usefully situated within a rights-based framework and in particular focused on the dignity of the caregiver in a capability approach analysis. It highlighted different impacts on carers by age, cultural expectations, religion, sexual orientation and gender, and most of this was overlaid with stigma. The second phase of the research involved primary qualitative research with women, men and girls from households affected by HIV as well as with those involved in caring for family members or partners living with HIV or with a clinical diagnosis of AIDS. This phase consisted of key informant interviews. The methodology outlined in the Annex details the theoretical underpinnings and research approach that shaped the study.

The research findings not only lay the groundwork for more conceptual work towards bringing together economic, social, political and human rights strands in examining HIV and AIDS but also embed the layered analysis in the different contexts in which unpaid carers live and experience the epidemic. The findings call into question States' and donors' obligations to the standards agreed in key human rights conventions. By demonstrating that putting carers at the centre increases the efficiency and effectiveness of investments in responses to AIDS, the research asserts that respecting the rights of caregivers contributes to the achievement of universal access targets and the MDGs.

Notes

1. See the section on 'Diversity of family structure and composition' in the ICPD Programme of Action (United Nations 1994), which recognises the process of rapid demographic and socioeconomic change throughout the world that has influenced patterns of family formation and family life and altered family composition and structure.
2. Orphans and vulnerable children.

2. Dignity in Daily Life: A Conceptual Framework

> *'All human beings are born free and equal in dignity and rights.'*
> – Article 1, Universal Declaration of Human Rights (UDHR), 1948

> *'(We)...commit ourselves to intensifying efforts to enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and developing strategies to combat stigma and social exclusion connected with the epidemic.'*
> – Para 29, 'Political Declaration on HIV/AIDS', UN General Assembly, 2006

Introduction

The central tenet of this study is that dignity is an inalienable human right. Dignity is understood here as a key concept for understanding equality. A seminal 1999 decision by the Canadian Supreme Court[1] provides us with a definition of dignity in which the purpose of equality is 'to prevent the violation of essential human dignity and freedom from the imposition of disadvantage, stereotyping, or political or social prejudice, and to promote a society in which all persons enjoy equal recognition at law as human beings ... equally capable and equally deserving of concern, respect and consideration'.

In the recent past, the rights-based and capability approach to development policy has become part of the mainstream discourse. The pressing development challenges of our times such as poverty, hunger, illiteracy, malnutrition, infant and maternal mortality, discrimination and violence are increasingly being studied through a gender-responsive, human rights-based lens. Although States and international agencies have instituted policies and programmes that draw on a gender-responsive, human rights-based approach, human dignity has not yet received the attention it deserves. Even in the expanded framework of human rights, inclusion of dignity as an instrument for achieving other fundamental rights has not been systematically explored. This study asserts the centrality of human dignity as a tool of analysis and applies it in the context of unpaid work in the HIV and AIDS care economy.

There have been very few studies that have dealt with the issue of unpaid work in HIV care at both a conceptual and programmatic level. While almost every report on HIV and AIDS highlights the role of gender, stigma and discrimination, the analysis is mostly from the standpoint of comparing the conditions of women and men living with HIV and AIDS. Although the discourse of human rights has been used extensively in prevention and treatment aspects of HIV policy, there has been very little use of the same tools in the case of care and support of HIV-positive individuals.

One common theme that emerges is that 'women bear a disproportionate burden of HIV since they are caregivers and in many cases have to deal with their HIV-positive condition themselves' (Commission on AIDS in Asia 2008). However, the role of the carer is not only limited to women; gay and transgender men and women also care for their partners, often under very difficult societal pressures and discrimination by the wider community.[2] It is also recognised that there are other outcomes on families as a result of HIV-positive status – such as lack of access to basic necessities, girls being pulled out of school to help in care work, and denial of health services as a consequence of entrenched discrimination against persons living with HIV. These and other direct and indirect impacts, 'externalities' in economics, cannot be easily valued in monetary terms and have been missing from the whole analysis until now.

The purpose of this conceptual framework is to place the unpaid care work performed by women and other carers at the centre of the discourse in order to privilege the dignity and rights of carers in HIV prevention and treatment strategies. It is also intended to provide an alternative to traditional economic methods of value judgement (economically understood) that are prevalent at the programmatic level. In situating unpaid HIV care within the context of human rights and social justice, and by emphasising State obligation and responsibility via international human rights instruments, the study intends to hold governments accountable for the conditions of servitude under which carers often live their lives.

Discourses and interventions in prevention and treatment

Policy approaches in both developing and developed countries have emphasised the role of prevention in containing the spread of HIV.

In the early years of the epidemic, certain groups that were thought to be 'responsible' – such as homosexual men in the United States and female sex workers in parts of Asia – were identified. The containment strategy ranged from aiding and abetting discrimination against such groups to outright incarceration on the pretext of safeguarding public health. From a public policy perspective, the solution in both cases was deemed to be cost efficient – it appeared to prevent the spread of the virus at least cost to the exchequer. However, as the epidemic has demonstrated, this was neither efficient nor effective.

A similar strategy was followed in the case of treatment; with the inordinately high ART prices until 2000 (WHO 2010), donor governments rationalised that the high costs of publicly funding this did not justify the social benefits. Such a line of argument can still be heard in certain quarters, although the use of generic ARTs has substantially reduced the cost of providing treatment to a large number of persons living with HIV.

Given the above, what actually changed the landscape of HIV interventions? The spread of and response to HIV in the context of violations of the fundamental rights of individuals led to a sustained campaign by activists, lawyers, academics, people living with HIV, international organisations and many others. Epidemiological evidence also resulted in the organisation of groups that are often marginalised – sex workers, sexual minorities, drug users – so that governments today cannot use the veil of HIV prevention to violate their basic rights and freedoms. At the same time, public action has led in some contexts to legal redress for these groups and brought long-standing issues of identity, sexuality and discrimination to the forefront of the public debate.[3]

This comes at a time when the combination of the public debt crisis and improved epidemiological data/profiling is showing that groups often deemed marginal – gay and bisexual men, sex workers and drug users in particular – are experiencing concentrated epidemics everywhere in the world. Evidence is also showing that political and social inequality undermines prevention efforts with women, given that power in sexual decision-making is deeply compromised in these situations. Epidemiological evidence has further demonstrated that for many of the communities hardest hit by HIV, human rights violations – or the absence of human rights protections – compromise prevention work as well as access to treatment, care and support for those living with HIV. Therefore the pivotal role of the placement of rights at the centre of prevention and treatment and care strategies becomes obvious; this has now led to access to justice and the removal of punitive laws as core components of the ‘prevention revolution’ being called for in many quarters.

Economic analysis of the HIV care economy

At a conceptual level there is a tension between the economic analyses of HIV care and the rights-based approach to development. It is undeniable that there has been a massive mobilisation of resources worldwide for the fight against HIV. The total resource envelope for HIV stood at nearly US$13.7 billion per year in 2008, but estimates put the annual requirement at nearly US$25 billion in 2010 (UNAIDS 2010a). The bulk of funding for ‘treatment, care and support’ is spent to support treatment, with minimal expenditure on care and support – especially in the home. To give one example pertinent for women, programmes to tackle violence against women constitute only 1 per cent of the estimated total needed, although a detailed breakdown of the care component is not available (it is collapsed with treatment in the UNAIDS report). In a world where gender inequality and expectations of gender roles lead to women being expected to and assuming the burden of care when someone in the household is sick – whether their husband/partner or children or both – it should stand as no surprise that the global HIV response fails to take into account the burden of care borne by women, children and partners of people with AIDS-related illnesses. Gender analyses consistently document this oversight in policy and programmes where ‘women’ and, more generally, ‘carers’ go missing (Ogden, Esim and Grown 2004).

It is to be noted here that a plethora of government agencies, international development organisations and private foundations make up most of the HIV funding going into the developing world. Most governments in Africa, Asia and the Caribbean spend a small proportion of their own resources for HIV prevention, treatment and care in the face of small health budgets compared to the scale of the epidemic. This has two significant implications: first, the strategy for combating HIV and AIDS is decided by a global compact including various United Nations agencies, the Global Fund for AIDS, TB and Malaria (GFATM), the World Bank and bilateral development agencies of large donor countries such as the United States Agency for International Development (USAID), UK Department for International Development (DFID) and others, and large private donor agencies and international NGOs such as the Bill & Melinda

Gates Foundation, World Vision, the Clinton Foundation and others. Second, the prevailing consensus is that the effectiveness and efficiency of the resources spent on the programmes are evaluated on the basis of a target-oriented results framework. An evaluation criterion that incorporates human rights and social justice has largely remained outside the scope of donor frameworks, although change seems to be on the horizon with such initiatives as PEPFAR and the Ford Foundation's HIV programmes among others.

To illustrate, in the MDG framework a set of policies is effective if conditions improve in line with the indicators as defined in the goals and targets – in the case of HIV and AIDS, halting and reversing the epidemic along with providing universal access to treatment (Goal 6, targets 1 and 3). Three of the 8 MDG goals and 7 of the 18 targets set by the international community relate to health, and the Millennium Declaration admits that one major cause of low health status in developing countries in general, and among women in particular, is the discrimination that females face even before they are born (Jones et al. 2010).[4] The MDG targets are quantifiable measures to track the progress of countries over time. They do not, however, address the underlying process of removal of discrimination against women through protection and enjoyment of basic human rights as an instrument of achieving the goals.

In terms of the efficiency argument, the standard framework applied in the health economics literature involves the evaluation of alternative policies vis-à-vis their impact on disability-adjusted life years (DALY) or quality-adjusted life years (QALY) gained per dollar of expenditure. For example, if there are two treatment regimens, one is more efficient than the other if the same amount of DALYs or QALYs is enhanced for a lower unit cost. In this scenario, universal access to first-line ART is more efficient than limited access to second-line ART due to the higher unit costs in the latter. As resistance to first line drugs deepens, the policy priority should be to ensure that cost-effective and efficient second and third line treatment is available in developing countries, perhaps through generics. However, the public debt crisis is leading to cutbacks in enrolment in ART programmes because the cost per patient has come to be seen as a burden on the donor country and so an inefficient use of development aid monies, referred to in a famous US paper on the subject as 'treatment mortgage' (Jack 2010). In contrast, and in anticipation of the increasing influence of the efficiency argument in development policy and spending, the UK All Parliamentarian Group on AIDS argued in *The Treatment Time Bomb* (2009) that it is a global responsibility to not deliberately sacrifice human lives in the name of economic efficiencies. As the debates on universal access have shown, the efficiency argument completely negates the right to life of people living with HIV and AIDS and is therefore untenable from the human rights standpoint.

As a logical extension to this approach, most macroeconomic studies on the economic cost of HIV in both developed and developing countries have estimated the impact of the epidemic on gross domestic product (GDP) or labour productivity. In countries of Southern Africa where the prevalence rate has touched 20 per cent or more of the adult population, the mathematical models predicted a sharp decline in the rates of GDP growth and an absolute decline in per capita GDP if the epidemic spread further. Similar conjectures were also made for countries such as Brazil, China and India, the underlying assumption being that an unchecked HIV epidemic would reduce the productivity of labour, increase the cost of health care and hence reduce productive investments elsewhere in the economy, with adverse consequences for long-term economic growth (Haacker 2004; Bloom and Godwin 1997).

The reality, however, is completely different from what the models predicted. Economic growth has been robust in most of the high-prevalence countries in Africa and Asia and no country has experienced an absolute decline in GDP. With a strong upsurge in international funding for HIV programmes, most affected countries have upgraded their health systems and appointed medical staff. On the flip side, this has increased aid dependence and a consequent diminution in the role of the governments in formulating health policy tailored to their own needs.

The incapability of the macroeconomic analysis to explain the impact of HIV and AIDS on economies has spawned a large body of work looking at the micro and household level evidence. Here, the impact of the epidemic comes out clearly in qualitative studies. These highlight the role of social and economic exclusion stemming from the presence of an HIV-positive individual(s) in the household and the adverse impact such exclusion has on children (especially young girls) who are often the silent victims (Pradhan et al. 2006). More recently, there have been attempts to quantify the psychological cost of HIV and its impact on individual welfare. This shows that in terms of mental well-being, the costs far exceed the expenditure on HIV and AIDS programmes – and that these can be substantially reduced by ensuring basic dignity to people sick with AIDS-related illnesses and their carers (Das et al. 2008). In other words, we have the foundation for merging the economic costs associated with HIV and AIDS with the concept of dignity and non-discrimination without recourse to the efficiency argument used until now.

Dignity, social justice and human rights: a framework for evaluating unpaid HIV care work

Given all of the above, there is an obvious need to develop an appropriate framework using the concept of human rights to ensure the enjoyment of freedoms and expansion of the capabilities of individuals involved in HIV care (Sen 1999). The 'capability approach' departs from other frameworks by providing direct support for a broad characterisation of fundamental freedoms and human rights that takes account of poverty, hunger and starvation, dignity and conditions of servitude. Individual substantive freedoms in the form of the capabilities and functionings that people can and do achieve can be included among the constituent elements of human freedom and incorporated into a framework of rights.

Capability freedoms focus on the set of valuable things that a person is able to do and be. For example, if a person has reasons to value a life without hunger and would choose such a life, then the capability of this person to achieve adequate nutrition is directly relevant to her/his real opportunity to promote her/his objectives and expand her/his freedom. Conversely, deprivation in the capability to achieve adequate nutrition restricts the person's real opportunity to promote her/his objectives and is admissible as a 'freedom-restricting' condition. The classical case is that of servitude, which directly restricts the person's choice to do and be. Similarly, discrimination on the basis of creed, religion or state of health (as in the case of people living with HIV) also prevents a person from achieving a life that s/he values and prevents her/him from 'taking part in the life of the community', which Sen regards as a basic functioning of human beings.

The central idea of 'capability freedom' is then associated in Sen's conceptual framework with a set of 'capability rights' and obligations that protect and promote valuable states of being and doing. The 'capability approach' provides direct support for the characterisation of poverty, hunger and starvation, discrimination and servitude as 'freedom-restricting' conditions. In this way: 'Minimal demands of well-being (in the form of basic functionings, e.g. not to be hungry), and of well-being freedom (in the form of minimal capabilities, e.g. having the means of avoiding hunger)' can be conceptualised as rights that 'command attention and call for support' (Sen 1999). The 'attention' is the catalyst for public action, including action on the part of the international community, and the 'support' is from human rights instruments such as the Universal Declaration of

Human Rights (UDHR), the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Rights of the Child (CRC) and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) – which have been ratified by most countries – along with international jurisprudence and case laws.

In the context of HIV and AIDS, it is important to associate the indignity of living with the disease with the idea of 'freedom restricting' conditions in the capability approach explained above. There is enough empirical evidence in this volume to suggest that the feeling of living without dignity is part of the reality for both people struggling with AIDS-related illnesses and their carers. The sense of living a life where they feel stigmatised and discriminated against flows directly from societal norms that disregard the ethical values of dignity and rights. Social justice demands that both people living with HIV and their carers be treated with equal respect and dignity to that afforded to each member of society (Jaising 2010). Unfortunately, most policies and programmes that seek to 'halt and reverse' the HIV epidemic in line with the MDG goal exacerbate rather than ameliorate the condition of HIV-positive persons and their carers. In our framework, therefore, States have to take responsibility for violations of the norms of social justice when a community or an institution discriminates against those living with HIV and/or experiencing symptoms of AIDS and their carers.

Until now, the critique of the efficiency argument has not been used to analyse women's unpaid work in HIV care. The extension is straightforward. First, by definition, the effort of women caregivers is not valued in economic terms since it falls outside the 'boundary of production' defined by the UN System of National Accounts (SNA) (Waring 1988). In this case, evaluation of DALY or QALY is not possible since there is no monetary value attached to the 'work'. The fallacy, however, is that having 'no unpaid work' would reduce the efficiency of the system from an economic perspective.

In the area of HIV care the 'work' is nearly always performed by women, especially if the situation relates to unpaid care-giving for family and friends in household settings. The definition of 'household' in this case might be different than the usual conjugal marital definition prevalent in mainstream discourse. It might refer to a community of sex workers or transgendered women. It might also refer to single mothers and same-sex couples who are involved in the care economy. In the case of same-sex couples, social sanction and stigma often force them to separate, pushing them into the ambit of the more familiar definition of the family where he or she is looked after by a female member of the household. Therefore, we can focus on the analysis of women's unpaid work in HIV care without loss of generality and applicability of our framework from a policy perspective.[5]

Second, there have been efforts to value the 'time cost' of unpaid work in household production, especially in the context of recent developments in gender budgeting. However, in the specific case of unpaid care the concept of 'choice' usually does not exist – the caregivers do not optimise between less time spent on market as opposed to non-market transactions. Any time that is left after the basic subsistence needs have been met is spent on providing care; the choice between 'work' and 'leisure' becomes non-existent. The efficiency argument therefore breaks down completely (becomes untenable) and cannot be used as a tool to evaluate unpaid work in HIV and AIDS care.

The economics of capability and human rights

Governments and the international donor community often argue that fulfilment of rights requires resources that far exceed what is available at present. Sen has argued that where there are resource constraints, the positive obligations associated with 'capability-freedoms' and 'capability-rights' may not relate directly to valuable states of being and doing that may be currently unachievable but to policies and programmes that promote the achievement of rights and freedoms as an immediate or cumulative outcome. The violation of obligations of this type involves the absence and inadequacy of policies and programmes rather than the non-fulfilment of obligations per se (Sen 1982; 2000).[6] This approach is reflective of a critical element in the establishment and development of international legal obligations in the field of poverty alleviation and human rights. For example, articles 26–29 of the Bill of Rights attached to the South African Constitution (1996) entrench a cluster of socioeconomic rights essential for an adequate standard of living including the human rights to housing, health care, sufficient food and water, social security and education.

In this conceptual construct, a set of policies would enhance 'capability-rights' if it protected and fulfilled the basic human rights of women in care-giving situations. The gender dimension can be addressed by taking into account the implications of care-giving for girls – whether their enjoyment of basic freedoms are circumscribed by the exigencies of taking care of persons sick from AIDS-related illnesses in the household. The framework can be extended to include children since international covenants and conventions specifically deal with the rights of the child. Apart from the notions of poverty and starvation that are linked to HIV-positive status, violation of specific provisions of the ICESCR (articles 11–14 related to food, shelter, physical and mental health and free primary education) constitute the basis for the violation of 'capability rights'.

This study demonstrates that capability rights are violated for not only the person dying from AIDS but also the caregiver. The case studies based on the voices of unpaid carers that form the conceptual basis of our argument bear this out. In addition, the carer does not have the freedom to choose those functionings that are valuable to her/him – for example, rest from work and participating in the life of the society. This condition can be termed as 'capability servitude', where the carer's dignity and freedom is circumscribed by her/his inability to break away from the situation of constant work and no leisure. The violation of capability rights comes from the fact that, in most countries, policies and programmes do not exist that unshackle caregivers from the situation of 'capability servitude'.

Capability servitude

Given the conceptual framework in the context of unpaid HIV care, we need to determine whether the condition of the unpaid carers in AIDS affected households can be termed 'capability servitude', where their dignity and freedom are circumscribed by an inability to break away from the situation of constant work and no leisure. Do we recognise to what extent the burden of unpaid care work undermines women's capacity to take an equal part in civil and political life? Do we think that the children who work long hours in unpaid care work might be losing out on access and opportunities – to the right to education, leisure and enjoyment of life as enshrined in the UDHR?

In terms of a rights-based approach applied to those in the unpaid workforce, we need to ask the following questions: To what extent does the discrimination and different treatment of girls and women in unpaid, long-term care in AIDS-affected households compromise or inhibit their capacity to participate effectively in political or community life, to attain the highest possible standard of physical and mental health, to exercise their right to opportunities of lifelong education or to enjoy safe and healthy working conditions?

Did the carers freely choose to deny themselves these opportunities or are there systematic violations of their fundamental rights and freedoms? Does this condition prevail in unpaid AIDS-care situations in different geographic, political and economic contexts? If so, can we outline a methodology for understanding the universal notion of capability servitude?

The capability model is not about what people are or what they do but what they can or cannot be, and what they can or cannot do, given the opportunities or the freedoms. Unpaid care of the sick is a critical part of the health-care system that compromises the well-being of the carer – who is then further penalised by the system in terms of loss of earnings, or time to do subsistence and other care work, or with no recognition at all.

The narratives in this volume help us understand the myriad ways in which the rights of women and other caregivers are systematically violated in the framework of capability and rights explained above. Our examples are taken from different geographical and cultural contexts, demonstrating the universal nature of the violations, and the analysis of dignity in the care-giving context in situated in terms of the obligations set out in international human rights instruments. Applying the conceptual framework proposed above to real-life situations also helps us identify a set of policies consistent with international human rights standards that would ensure dignity and justice to women involved in HIV and AIDS care.

A number of international human rights instruments, resolutions and statements in recognition of and for securing of women's human rights have been issued by the UN system since 1995.[7] Ironically the increased endorsement of human rights has taken place at a time when neo-liberal policies adopted worldwide advocate a far lesser responsibility for the State in resource distribution and service delivery, with such mechanisms left to the market and the private sector.

While States may have signed and ratified human rights conventions as a commitment to achieving gender equality, by placing reservations on key elements and clauses they effectively negate the intent and purpose of that ratification. A case in point is CEDAW, the most 'reserved' of all treaties. Adherence to a treaty involves more than just recognising the framework it provides and making provisions through certain juridical and legislative devices. At a fundamental level, it involves a clear understanding of the responsibility in knowing what is the standard expected for achieving women's rights and how to get from that standard or norm to realising basic rights within national domains. It has been asserted that it is imperative for States and other stakeholders to recognise that commitment through treaty ratification means more than ownership of the 'unreserved' articles and clauses; it is binding on all aspects of governance (see Bleie et al. 2001).

In the chapters that follow, as the narratives traverse such diverse settings as public hospitals, prisons and homes across various Commonwealth regions, we listen to the voices of carers and grapple with the erosion of their rights. In situating the policy and programme solutions, our primary aim is to privilege the dignity and rights of all those who are most affected by HIV as their households are the hardest hit by the epidemic.

Human rights instruments, work and the United Nations System of National Accounts (SNA)

As an illustration of how the conceptual framework and, more specifically, particular articles of human rights instruments are applied to the narratives/voices, we provide a snapshot here.

Article 8 of the ICCPR states:

> '2. No one shall be held in servitude.
> 3. (a) No one shall be required to perform forced or compulsory labour;
> (c) For the purpose of this paragraph the term "forced or compulsory labour" shall not include:
> (iii) Any service exacted in cases of emergency or calamity threatening the life or well-being of the community;
> (iv) Any work or service which forms part of normal civil obligations.'

What is the status of the unpaid carer in terms of the human rights available to workers? Four institutional units provide care:

- The private sector (private health providers),
- Government units (hospitals, prisons, health clinics, schools),
- Non-profit institutions (churches, NGOs, community groups), and
- Households

In the context of care-giving of HIV and AIDS patients, regardless of the unit providing care, these services are consumed as they are produced. However, only those working – paid or unpaid – in the first three listed, are deemed to be 'workers'. The definition of what does and does not count as 'work' excludes household work.[8]

Women and men working unpaid for charitable organisations engaged in assisting households with people living with HIV and AIDS are at 'work' and have all the human rights of workers available to them.[9] Staff in educational facilities or prisons, as well as hospitals and health centres, are 'working' when taking care of those with HIV and AIDS, but only for a period of time per day deemed to fulfil 'safe and healthy working conditions'. None of them is on duty 24 hours a day, 7 days a week. Neighbours assisting a local household with care are 'at work'. These are all 'economically active persons', engaged in productive activities as defined in the SNA (United Nations 1993, para. 1.22). The result is that unpaid community and voluntary care-giving counts as 'work', caring for your neighbour counts as work, but caring for a member of your household does not. 'Domestic and personal services produced and consumed by members of the same household are omitted' from the boundary of production and from the definition of work. It is the single major exception to the measurement of 'value added by all residential institutional units' (ibid., para. 1.75).

The work that does not count is specified in the SNA:

- The cleaning, decoration and maintenance of the dwelling occupied by the household, including small repairs of a kind usually carried out by tenants as well as owners;
- The cleaning, servicing and repair of household durables or other goods, including vehicles used for household purposes;
- The preparation and serving of meals;
- The care, training and instruction of children;
- The care of sick, infirm or old people; and
- The transportation of members of the household or their goods. (Ibid, para. 1.75)

Overwhelmingly it is women who perform this work and thus are excluded from the definition of 'work'. This is itself a breach of the intention of the key equality articles of ICCPR, namely articles 2(1), 3 and 26.

Just what is the context in which women (and men and girls and boys) who are carers of people living with HIV and AIDS in their households can be seen as having no human rights because their situation in the current policies constitutes a justified limitation on the right to be free from discrimination? How can this be if article 4 explicitly denies a right to derogation from the right to be free from servitude?

Examining ‘servitude’ and human rights

There has been no test of the meaning of servitude in UN human rights jurisprudence. However, it is possible to distinguish servitude from slavery. In the Oxford English Dictionary (Vol. 15, 2nd edition) ‘servitude’ is defined as ‘the condition of being a slave or serf or of being the property of another person, absence of personal freedom’. In the first definition it notes that the word usually carries the additional notion of subjection to the necessity of excessive labour. The second major definition is ‘the condition of being a servant, service, specially domestic service’. We are informed that its use in this context is now rare or obsolete.

Whenever the International Court of Justice seeks the origin of a specific challenge in international human rights law – for example, where/how the issue first arose, what a word might mean, what the intention of the Drafting Committee was – they trace back through documents and deliberations that led to the final text of recommendations, resolutions or covenant articles, including the sources of the original debate and the notes of the rapporteur.

Andrew Clapham (1993) has reported that in the debates on the drafting of the ICCPR ‘it was pointed out that “slavery”, which implied the destruction of the judicial personality, was a relatively limited and technical notion, whereas “servitude” was a more general idea ... While slavery was the best known and the worst form of bondage, other forms existed in modern society which tended to reduce the dignity of man. A suggestion to substitute the words “peonage” and “serfdom” for servitude was rejected as those words were too limited in scope and have no precise meaning.... A proposal was also made to insert the word “involuntary” before servitude in order to make it clear that the clause dealt with compulsory servitude and did not apply to contractual obligations between persons competent to enter into such obligations. The proposal was opposed on the ground that servitude in any form, whether involuntary or not, should be prohibited. It should not be made possible for any person to contract himself into bondage’ (p. 97).

Richard Lillich (1984) believes that there is no doubt that customary international law now prohibits slavery and servitude, and that prohibition against those practices now constitutes *jus cogens* (‘compelling law’ that may not be violated). In respect of ‘normal civil obligations’ in article 8 (3)(c) of the ICCPR, he comments: ‘what is meant here is primarily the obligation of citizens to undertake joint efforts in the common interest on a local level, such as taking part in fire brigades or similar measures against other calamities. It cannot be translated into a general subjection to direction of labour for economic purposes’ (ibid., 125–126).

The linkage of women and article 8 are rare in UN reports. In 1982 a report on slavery to the Commission on Human Rights indicated that women were ‘among the victims’ of institutions such as slavery (United Nations 1982, para. 31). A special rapporteur noted ’new forms of servitude and gross exploitation’ (para. 72) and recommended that ‘at a proper time the UN might find it convenient to consider a consolidated convention aimed at eradicating all forms of servile status’ (para. 33). The revision of this report contained a whole section on ‘Slavery-like practices involving women’.

Some may attempt to argue that the responses to HIV and AIDS constitute a state of emergency. But the ICCPR (article 4, para. 2) explicitly prescribes that no derogation from articles 6 (right to life), 7 (prohibition of torture or cruel, inhuman or degrading punishment), or 8 (prohibition of slavery, slave-trade and servitude) is available (HRC 2001, para. 7).

Notes

1. Law v. Canada (Minister of Employment and Immigration), [1999] 1 S.C.R. 497, quoted in Brown 2005.
2. Please refer to the case studies of Jamaica and New Zealand in this volume.
3. See, for example, Misra 2009 on India.
4. For an exhaustive list of titles on this issue, see: www.chronicpoverty.org/uploads/publication_files/RefAnnIndex.pdf
5. For an exception, please see the Jamaica narrative below.
6. See Vizard (2005) for an extensive discussion of Sen’s capability approach and the human rights framework.
7. International human rights instruments specific to women’s rights that have been issued in the 1990s and beyond include General Assembly Resolution 52/86 on Crime Prevention and Criminal Justice Measures to Eliminate Violence Against Women, 1997; Statute of the International Criminal Court (Rome Statute), 1998; Optional Protocol to CEDAW, 1999; General Comment 28 on Equality of Rights Between Men and Women (Article 3, International Covenant on Civil and Political Rights), 2000; UN Security Council Resolution 1325 on Women, Peace and Security, 2000; The Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children that supplements the UN Convention on Transnational Organized Crime, 2000, in addition to the Protocol against the Smuggling of Migrants by Land, Air and Sea, supplementary to the UN Convention against Transnational Organized Crime which entered into force on 28 January 2004. Other Conventions with specific reference to women include the International Convention on Home Workers, passed at the International Labour Conference in 1996, and the Convention on the Protection of Migrant Workers and their Families.

8. 'The SNA is … designed to meet wide a range of analytical and policy needs. A balance has to be struck between the desire for the accounts to be as comprehensive as possible and the need to prevent flows used for the analysis of market behaviour and disequilibria from being swamped by non-monetary values. The System therefore … excludes all production of services for own final consumption within households … [that] are consumed as they are produced' (United Nations 1993, para 1.22).
9. 'Many goods or services are not actually sold but are nevertheless supplied to other units: for example, they may be bartered for other goods or services or provided free as transfers in kind. Such goods and services must be included in the accounts even though their values have to be estimated. The goods or services involved are produced by activities that are no different from those used to produce goods or services for sale. Moreover, the transactions in which the goods and services are supplied to other units are also proper transactions even though the producers do not receive money in exchange' (ibid., para. 1.72).

3. The Conditions of Choice: Capability Servitude in Unpaid HIV Care

After the elaboration of the conceptual framework in the previous chapter, we turn to an examination of capability servitude in the stories of unpaid caregivers as told in their own voices to demonstrate how women, men and children perceive and experience the caring.

In the absence of jurisprudence on 'servitude', what might be the conditions that could determine capability servitude? What might be the elements of the carer's life that would speak to the denial of human rights?

From the literature review, we determined that the following questions would be of use in our analysis:

1. Do you choose to be the carer?
2. Does anyone come to help you?
3. Did you get any training for this work?
4. What is the work like?
5. Do you get any rest or a holiday?
6. Were you at school or in paid work?
7. How do you see the future?

Under each question we highlight aspects of caregivers' lives as they voice their perceptions, perspectives and experiences. There may be multiple caregivers in a household for one ailing relative with each carer experiencing the care-giving differently.

1. Do you choose to be the carer?

Article 6 of ICESCR 'includes the right of everyone to the opportunity to gain his living by work, which he freely chooses and accepts'. In the capability analysis, the presence or absence of choice is fundamental. None of those participating in our research felt that they had any choice. Carers were daughters, grandmothers, sisters, best friends and gay partners. Of course some said they would do anything for the loved one in their care, but that does not negate their experience of lack of freedoms and choices. While the universally accepted definition of work does not encompass them, they cannot be seen to be at leisure. Servitude must be examined as an alternative description.

Here are the voices on choice:

> ‘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.’ – Jessy, Uganda
>
> ‘After the death of our own mother my aunt took care of us. Nobody else can do this. My grandmother is old now so I am the primary caregiver.’ – Geeta, India
>
> ‘I didn’t have any choice about becoming a caregiver. It wasn’t a choice, I would do anything for my brother. D lived with us for about 7 years, and he was diagnosed about 15 years ago. There was certainly no choice about becoming a caregiver. We thought it was better for him to spend his time in Auckland with all his friends around him because that’s where his support was….’ – Sharon, New Zealand
>
> ‘I have no choice about being the primary caregiver. There are four in the house who are HIV positive, myself, my husband, my brother, who also has cancer, and my 14-year-old daughter. My mother passed away, then my son passed away. A few months after giving birth, the mother of my grandson just dropped her son off with his dad, my son, and ran away. I am taking care of my husband, my daughter and myself, we are all HIV positive. I am taking care of my brother who is HIV positive and also suffering from cancer in his legs and feet. My 14-year-old daughter was not born with HIV, she was raped when she was 9 years old.’ – Sylvia, Namibia
>
> ‘The 16-year-old, I had no choice but to take him in at 4 months old when his mother, my daughter, died. In the case of the twins, she was my neighbour and we would share everything. The other girl is staying here to study. She is my granddaughter. Who would look after the children if I was not here?’ – Emily, Namibia
>
> ‘I didn’t have any choice about becoming a primary caregiver, there is no one else to take care of my aunt. My aunt’s first born is a boy so he cannot bathe his mother, and remember that my aunt took care of my mother too.’ – Lillian, Botswana
>
> ‘My daughter, B, was living with me at home when she got sick. Whatever she wanted me to do, I would do for her if I could. At times people get sick of looking after sick people, but I wouldn’t. This was my child.’ – Ruth, Papua New Guinea.

2. Does anyone come to help you?

If the carers had no choice about what they did, we needed to know if they got any assistance or relief from their work. Was the work 24 hours a day and 7 days a week, well beyond what might be 'a normal civil duty or obligation' (article 8 of the ICCPR), if that caveat was relevant to our analysis? How did the carers manage their endless responsibilities? Is Article 7 of ICCPR, which recognises the right of everyone to the 'enjoyment of just and favourable conditions of work', relevant here?

Once again, carers' voices:

> 'My mother's brother is the only person who comes to visit us, especially when she becomes very ill. He gave me his telephone number for use for calling him. But mum collapsed in the night and I was alone with her in the house, with no one to help me carry her to the bed. I was forced to scream to draw the attention of a neighbour.' – Jessy, Uganda
>
> 'Staff of VAMP[1], a collective of women in prostitution, helps us a lot. They visit our home regularly. They give in time proper information, they also support me. Women around my home routinely help me. No one of my relatives come and helps me in this way…'– Geeta, India.
>
> 'I had lots of friends and family that wanted to help provide care for D, but basically D was quite private and embarrassed really … There was a mobile health service that came to our home, near the end. They were good to him, but in most cases it was too late. It seemed like a lot of work and there were times when it was a strain on me and my partner so his sister used to take D then. That was a real help for me because it gave me time to recoup again. When D was with me he took all of my attention.' – Victor, New Zealand
>
> 'Nobody comes to provide me with help. Last year some people from the church came and they took some information from me but still no one has come.' – Sylvia, Namibia
>
> 'It is only me and I am always busy taking care of the children or the house. No one in the current household is HIV-positive but I look after all these people because of HIV.' – Emily, Namibia
>
> 'Sometimes once in a while the home-based care people come. I don't want to involve anybody else in the household to give me rest. I do not want to involve my sister, I do not want her to get frustrated and disturbed in her studies.' – Lillian, Botswana
>
> 'We didn't get any help from anyone, no one here helped us. During the time of caring no one came to give me or the family a helping hand. We had no support. No one helped me in this difficult time. I did it alone. Our traditional ways are that we help

> each other out during times of sickness but for some reason this time no one came, maybe they were scared. Normally family would be there for support. People bring food, help care for her. Why was this different? Why was I left to care for B on my own?' – Ruth, Papua New Guinea

3. Did you get any training for this work?

Article 6(2) of the ICESCR and CEDAW 11 (1c) commit State parties to provide 'technical and vocational guidance and training programmes' to everyone who 'freely chooses' the right to work. This caring activity is not, whatever the demarcations drawn by international rules on the definition of 'work', a state of leisure.

Examining carers' voices on the notion of care as work reveals the following:

> 'I have had no advice or training to help me with this work.' – Jessy, Uganda
>
> 'Women from VAMP gave me training. After their guidance I came to know how to take care of my aunt.' – Geeta, India
>
> 'I didn't have any training to help with care-giving but I'm a mother and D is my brother so it's not about care-giving it's just about being there.' – Sharon, New Zealand
>
> 'I'd not had any formal training. I had a little bit of advice from the doctors and the nurses. I think my angle was that I'd known D for so long. I knew what my partner was like, so I just wanted him to be as peaceful and calm … you know, it was a hard strain on him. He was panicking; he was dying.' – Victor, New Zealand.
>
> 'I have had training on home based care through the AIDS Care Trust.' – Sylvia, Namibia.
>
> 'I had no training on anything to help me with this work. When I attended a counsellor's conference, they educated us on hygiene, but that is all.' – Emily, Namibia.
>
> 'I got advice from a nurse at the clinic about how I should take care of my aunt and also to take care of myself so I do not get the virus from her.' – Lillian, Botswana
>
> 'We didn't see any counsellors or anyone. I asked around but nothing came. The night before she died I went across to the church and asked if they could put a line into our house and provide us with some light. I could see that my daughter B was in a bad way and it would not be long now. Her time had come. I didn't want to be in the dark when it happened. It was the only time I got any help from the church. After she died people from the AIDS clinic came and did a workshop here and asked me all sorts of questions

> about how I looked after her. Now she was dead they wanted to know everything. Where were they when she was alive?' – Ruth, Papua New Guinea.

4. What is the work like?

Article 7 of ICESCR recognises 'the right of everyone to the 'enjoyment of just and favourable conditions of work that ensure 'safe and healthy working conditions'. This is mirrored in CEDAW Article 11 (1f). In this context, we asked carers to describe their work.

> 'I did household chores like washing dishes, washing clothes, cooking, weeding the garden, keeping the house tidy, fetching water. For water we would go to the centre of the village but if that water was not running we would walk to Doru, which is a fair distance. We would be fetching water all the time to wash them, to wash their clothes, which would be soiled. If we had food I would prepare a meal. If we did not have food we would spend all the time looking for means of getting food. K and her husband M's sores made life very hard for them. Their skin was always itchy. We would try to soothe it with warm water. Sometimes I was up all night. You know when people are sick you don't sleep in case they want something like water so we would light the fires to boil water for tea and to wash them. If they slept soundly then so did we, but if they had a restless night due to the itchiness then we would not sleep either. My sister K's daughters are young girls and sometimes they would help and sometimes go and visit friends. But they would work very hard again, going out to collect shells or sea slugs to sell in order to get food for their mother. While they were sick the main thing was having the kettle on the fire. They would ask for hot water. They constantly wanted their bodies to be cool. We would massage them with warm water, and washed their sores with dettol mixed in warm water. Sometimes we used sea water.
>
> 'When their bodies were strong we helped them down to the toilet. When their bodies were really weak we opened up a slat in the floor in the corner and they would do their business. We would wash it with soapy water or seawater. Our hardest thing was the carrying, the urination, the diarrhoea – constantly, lots of it. Another hard area was food, trying to find food. We really struggled. Sometimes we would stay hungry because I didn't know who could help us. If we had any food the main thing was the sick would not go hungry. Sometimes I would put my pride aside and send the kids to beg for rice from our relatives. If not then we had nothing.' – Alice, Papua New Guinea.
>
> 'I could not buy B foods because I did not have any money. Our ways of getting food was difficult. My sons were little boys when I took them out of school to help me. "You have to fish, go to the

market and sell the fish, buy whatever you can." If no fish, no food and we stayed hungry. They were only young but they were trying to do the job of a man. During this time I was hungry all the time. If we had food I would spoon-feed her.

'I would give B hot water to drink. If she wanted cold I would ask around and try to find some cold water for her. I would wash her and rub her back and brush her hair. I would dress her, lie her down, help her up. If she wanted to go to the toilet I would dig a hole beside the house and take her and help her do her business and then I would bury it. I would take her outside and place a mat on the ground and I would wash her. I didn't only wash her in fresh water. Sometimes I would take her down to the sea and wash her and bring her back then dress her in clean clothes. I bought so many clothes from the second hand because she was soiling them and I didn't have enough time to wash them and no one wanted to touch her clothes. We also had to collect water in containers and that is a long way to walk – about a mile. Several times a day.' – Ruth, Papua New Guinea.

'I wake up early in the morning, wash clothes, prepare food and boil water for everybody. I do everything, breakfast, lunch, dinner and other work. Wherever my aunt goes I make sure that she should have everything with her, water, medicine. The hardest physical task I have is fetching water from outside and storing it in the house.' – Geeta, India

'The hardest physical task for me was lifting. Near the end D was just a dead weight and it was very heavy to lift him. I had to build up momentum just to get him off the bed, change his bed sheets, things like that; getting him up and down the stairs, into the car. I am a pretty strong man but you know, sometimes I just thought wow – heavy ...

'My toughest emotional task as a caregiver was watching him get sicker basically, that was quite tough watching him deteriorate. The meals I was preparing were nonstop and whatever he wanted, which got a bit extreme because he got really fussy. But then in the end he couldn't eat what we were cooking and I think that was the toughest thing....'– Victor, New Zealand

'There is a borehole for water and we buy the water by the bucket. I have to go back and forth and carry it. It is between Nigerian \$5-\$10. We buy it about three or four times a day. It is about \$5 when there is electricity and \$10 when there is no electricity.' – Amira, Nigeria

'The hardest physical task is fetching wood, the distance is very far away, you have to search. I am not healthy, it's not very safe near the riverbed and very far away from people. I can do gardening but there is no place to do it. The land is so stony, you cannot have a productive garden and rainwater is also scarce and

> tap water is expensive. The nearest tap is 10 minutes away but sometimes there is a long queue, up to an hour, especially in the weekends. For meals I normally cook pap, sometimes rice and macaroni.' – Sylvia, Namibia

> 'I have to go out every week and try to look for food at places where they sometimes are providing food for orphans so I can feed the kids. Sometimes I hear they are giving food away at these places for the elderly, but often when I go, by the time I get there the food will be finished. I go to the life centre on Wednesdays to do needlework and Thursdays to get food in return for my needlework. I make pap for breakfast, I clean the house. My washing machine broke so I wash all my clothes by hand. I make all the clothes and traditional bed and chair covers. We usually have just the two meals, pap for breakfast and dinner in a day. I use the chickens I have (10 of them) for eggs.' – Emily, Namibia

> 'The most difficult part for me is when I am bathing her and also changing her nappies. She has grown so thin but is still heavy and also what makes it even more difficult is the pain that she seems to be going through. Sometimes she begs me not to bathe her and sometimes I just listen to her. It is so painful and heartbreaking. I also do her washing and sometimes we do not have enough nappies. The most emotional moment that I never forget is when my aunt emotionally begged me to stop giving her the medication ARV [antiretroviral], saying that if I can stop she will be dead within two days and our suffering would come to an end.' – Lillian, Botswana

5. Do you get any rest or a holiday?

Article 7(d) of the ICESCR recognises the right of everyone 'working' to 'rest, leisure and reasonable limitation of working hours and periodic holidays ...'.

> 'No one comes to give me rest. I don't rest. I am always thinking of what is going to happen to my young siblings when my mother passes away.' – Jessy, Uganda

> 'I do not get any rest. Since my aunt became sick I take care of her all the time. I don't get any free time in the day. My grandmother can't do anything at home, she has an eye problem. I only can work at home and not outside. I have never had a holiday.' – Geeta, India

> 'I wasn't able to get free exercise time, I think running around and cleaning up after him was exercise enough. Whenever I needed rest or D had had enough of me we would call his good friend J. I used to have holidays but since D got sick no one wanted a holiday. My last holiday was his funeral.' – Sharon, New Zealand

> 'No one gives me time to rest. I have holidays from the centre when there are public holidays but I still have to care for my family in these holidays. I do not have any rest at all.' – Sylvia, Namibia

> 'I do not have any rest at all. My last vacation was in 1988. I just heard the municipality order to meet but it was too far for me to get to. I really want to go to meetings, to know what is going on so I can speak to them and hear from the horse's mouth.' – Emily, Namibia

> 'A poor person like me knows nothing about holidays.' – Lillian, Botswana

6. Were you at school or in paid work?

To demonstrate servitude, it must be possible to show that those who live in that position were doing something else, that they chose or wished to do, before the state of servitude, and that they had been in charge of their own labour or educational choices. All participant carers had been in formal or informal work or education before they 'had no choice' but to become carers.

> 'I loved going to school and I wanted to complete it so that I could look for a simple job and sustain my siblings.' – Jessy, Uganda

> 'Before D was sick I used to work all day and run my children to and from school and my partner worked through the evening. I had no savings when I went into full time care-giving, you just manage.' – Sharon, New Zealand

> 'Before my sister became so sick I used to go to the bush and fetch firewood for selling. I had to stop this. I used to buy melon seed and break it and sell it.' – Amira, Nigeria

> 'Before they (her sister K and sister's husband, M) got sick I would do my little marketing of juice, buatau or shell necklaces to help bring money into the household.' – Alice, Papua New Guinea

> 'Before she (B) got sick I would go out and tend the gardens, fetch water or go shell fishing.' – Ruth, Papua New Guinea

> 'I have lived here for more than 10 years, but I have been providing care for her now for over five. Before my aunt started to get too sick I worked in one of the teacher's quarters as a maid.' – Lillian, Botswana

> 'I went to volunteer at the centre because they help me a lot. The centre has 500 children and OVCs. They pay for school fees and sometimes they give me food to bring home. The only income I have is from the centre, about 200 Namibian dollars every month. Before joining the centre as a volunteer I was not getting anything but I told the centre I needed to go to the hospital and I needed

money for transport. I pay for ART every month. The hospital is 4-5 kilometres. If I have taxi money then I take a taxi, if I don't then I walk. I usually take a taxi there and come back walking. The centre helps pay school fees, toiletries, blankets and uniforms. Those services are only provided once a year for my 14-year-old daughter.' – Sylvia, Namibia

'I was a cleaner at the central hospital, I took the boy at 4 months and the twins when they were 2 years old, so I have been caring for them all for over 10 years. I receive an old age pension of $450 a month. From this pension $400 goes to water and electricity and to doctor's visits at the clinic. The remaining money is usually used up in one day and goes mainly on food. All the children go to school. For the twins I do not have to pay school fees because I got permission to excuse them from this for this year. I do have to buy their uniforms, like a shirt and so on. From the Government I get $300 in OVC grants and this helps to pay for their uniforms. This also goes to help pay for the school fees and uniform of the 16-year-old.' – Emily, Namibia

7. How do you see the future?

'I think of our future as being hopeless when our mother has passed away.' – Jessy, Uganda

'When I also became HIV positive, it was very difficult; I have always been faithful to my husband. He would go away for two days sometimes and whenever I would ask him where he was, he would get very angry and beat me. I don't feel sick. But I am not healthy. I started ARV treatment in 2006. Sometimes I am stressed because I have nobody to talk to. I have to keep it all inside. I don't get help for my 4-year-old grandson. I have a lot of difficulty because the Ministry of Home Affairs won't give him a birth certificate. They say go and look for the mother. Over Easter I went north to see his mother and try and get a birth certificate. I can't get one for my grandson and I do not know what his future is going to be like because without a birth certificate he is not going to be able to go to school and I cannot get any social grants for him.' – Sylvia, Namibia

'I am worried about my younger sister, who is doing her final junior certificate examination. If she does not do well in her final examinations it means that she will also be cut out of the food basket programme like me and we will only be getting one for my younger sister and my aunt's daughter who is also in standard 7. Since the death of my mother we have been struggling but we have been lucky because of the orphans' programme that the Government has. I also used to get my own share but now I have been taken out of the programme because I am old enough to take care of myself.' – Lillian, Botswana

Servitude: a perspective from Canada

This is the story of a Canadian caregiver, who was employed full time as a palliative care worker before having to give up her paid work to care for her daughter, grandson and, more recently, her mother. If she were not an immediate relative of this family, she would expect to be paid by the State for this provision of care. However, as an immediate relative she is not 'working' even though she employs the same skills, and more time, than her former paid work. She has not been eligible for any unemployment assistance, and Ontario Works has threatened to discontinue their basic payment to her if she does not find a regular position 'volunteering'.

'We picked E up at the station and took her down to the rehab at St. Joe's Hospital and we booked her in there. She was very pregnant and very messed up. We were there every day. All her needs were met. She had everything she needed, clothing, make-up, whatever. Anything that she needed she had, on the understanding that she was to stay in rehab and that at the time of the baby's birth in the hospital, that she go into a programme for mothers and children.

'I received a phone call that she was going into labour and she was in premature labour. With her background of using and with the HIV, I called the doctor into the hallway and had a long talk with him about what may happen, what could happen. He requested that I come into the operating room with her for the C-Section. They were talking a lot about the precautions of E and the baby. I knew this time there could be something not quite right maybe with the baby. I just kept talking to E and it was a little longer than I thought it would be.

'I was the first to see the baby, and he cried and everything was fine. He was taken up to the special unit I stayed with E for a minute or two while she got cleaned up and recovered. I went straight to the nursery and told them who I was and immediately, as before with all the children, the CAS (State welfare agency) was there. The doctors were there. They always come at me about E's situation: 'the baby would be safer in the long term' and whatever. I just kept repeating that this is my grandchild and he's coming home and this is not an issue and I won't have it.

'My boyfriend at the time and I said we would sign the papers. E and the baby would be given to us on condition that she's not to use, and if there was a situation like that I would report it. So we were given guardianship. We were there every day in the hospital. We made sure that her and the baby were very comfortable and then we brought them home.

'E became very sick with MRSA [Methicillin-resistant Staphylococcus aureus] and the baby became very sick: He was also on AZT [azidothymidine] to counteract the HIV. All the new doctors were being set up for her at St. Mike's and we were bringing the baby in, in the beginning, a lot to Sick Kids. He went through a lot of testing, which we had to do, and then blood work, a lot of that. So I was always with her. I went to every appointment with her to help her through this, because, you know, he was sick and she was sick. Then they both got MSRA. I took them to the hospital one night and they kept them overnight in quarantine. As a mom and living with her at that time, I found her to be very weak and not able to parent. I was very concerned so I intervened and just started care-giving her, caretaking both of them for a long time. My boyfriend started acting out at the amount of money and the attention that was being put out, so I decided that it would be best to separate. He was abusive. I removed my daughter and the baby to my mother's house, confronted the situation and walked out.

'My mom was sick at the time too. Her nerves were shot and she was just getting over pneumonia, so I went out and got an apartment, I set E up and we got everything going with her assistance and my assistance, we put it together and we created a home.

'The CAS were involved and E made a commitment to me that we were to stay together for two years so that I could be with her and the baby. I stuck to my guns and totally committed myself to the living arrangements I had with E and told the CAS that I was looking for work, but would still be in the home and monitoring E. I know E so well that I know her pattern of using. I know when she's agitated and know the certain moods she gets in, where I know she's going to use. So usually I can counteract that. I make her get on the phone and talk to her counsellors or I intervene and I have people call her. Or I talk her down. Sometimes I'll take the baby for three or four days just to get her rested so she doesn't go out and use.

'When we were together in the apartment, when she brought the baby home, he was premature and we had to go to the doctor's all the time, because he had to go on AZT. He needed a lot of needles and he was very tiny. The care-giving I did was meals, changing the baby, making her go to bed in the afternoon to rest. She wasn't resting at the time. She was put on meds for her HIV, you have to know that she hadn't been on her meds like that before, so she was being regulated.

'I was picking up the baby, taking the baby out, wiping him down and taking his temperature, checking his diaper, going in to see if she's okay, making her sleep, getting them up in the morning, getting up for feeding, stuff like that. Obviously she had the HIV before she was diagnosed in 2000, because there were many signs, looking back. In a lot of areas of being with her and taking care of her, it was her inability to care for herself and her destructiveness was a fear for me that she would die. And if that meant that I had to keep fighting for her not to die, then I guess I just, you know, I think, I'm pretty sure that moms just do that.

'After two years I thought that maybe it was better I kind of back off a little bit. I've got like a bachelor kind of place now. It's small and I now have to look for work, because apparently I'm not working! I'm in E's life and on my calendar today, I've counted 10 appointments this month that I have to be there for her. She has many appointments for doctors and I give her every second weekend off to be with her boyfriend overnight. And I take the baby from her in the afternoon until the next day, so she can rest. Sometimes she gets very agitated and impatient and I know it's from stress, and I'd rather she go away and take a breather than get to that point. So up to this date, that's basically what I do. I phone her every Monday to see what appointments are coming up that week for her. Actually, I phoned this morning to the Caregivers Association to see if there's any help that I could get to give me [laughs] some respite. But unfortunately, there isn't anything out there. I said a bill should be passed in Canada for women like myself. They told me to phone public health and they can offer babysitting and I already know that that's not a possibility because E has a very strong trust issue, which is understandable.

'Lately, I've noticed that's she's using the word that she's sick more than the usual. So I'm more there than I was say in the last month. I'm concerned about her with my grandson because he's into everything and he's not even two yet. I just need her to calm down. So I kind of calm her down and keep her at a kind of level where I know she's not going to just say, you know, screw it and hit the street.

'So I just hung in and hung in there and I'm still doing it. And I'll probably will do it until she gets to the point of her clean time now, where she can let go and do it on her own, you know. Or not. Or maybe she's going to become ill with the HIV and it's going to go to the next level. And it's going to full-blown AIDS at some point. In which case she has asked me to be there and be there at the end, which of all my palliative training and all the care-giving I've done with the elderly dying in my arms, I'm sure that this, to me, is another door that I have to pass through with her. And that's just … it seems like it's just something that has to be. So I've already pretty well resigned myself to the fact that I'm in it, you know, for the long haul.

'I may go make her bed. I do her dishes. I do little things around the house, because some days she's very, very sick. When she lays on the couch, I just sit with her and I rub her head and you know, she cries and I talk with her. And then sometimes she's so tired that she can't even stay awake at the table, you know. And I tell her, go to bed. You know, get some sleep. And I take over. Finally I've got her on her meds at the proper time. Because I went with her to the doctor not too long ago and he warned her, the nurse warned her that if she didn't take her meds on time that she could be in a lot of trouble. She wasn't taking her meds. She was taking them and forgetting them and taking them and forgetting them. Now she's having problems with her eating. She's not eating. She's weak. She's feeding the baby, but I see that she's not eating properly because every time I go there, the same food is in the fridge. And it upsets me a great deal. But I just … I see that she's losing a lot of weight. I try and talk to her about her eating and her habits and go grocery shopping, get fruits and vegetables. And we have our battles. You know, we have our ups and downs, but I think all and all, she knows that I'm only doing it because I just want her to stay healthy, you know.

'To get any assistance so I can survive, I am expected to volunteer for up to 20 hours a week, depending on where you are and depending on what's going on with the place where you're volunteering at. The extra $100 a month is for transportation to get there and back. So it's a kind of a no-win situation. But it does leave you, obviously, with a few more bucks than you had if you didn't volunteer. I go to the food bank downstairs to get my food. Sometimes E will give me a couple of dollars. Or mom will help me out a little bit here and there. But I have difficulty with that. I went from $1,000 a month to this.'

Notes

1. VAMP – Veshya AIDS Muqabla Parishad or Women in Prostitution Confront AIDS, a sex workers' collective, established in 1996 in Sangli, India, focuses not only on HIV and AIDS work but also works on the socio-economic impact of women sex workers' health and wellbeing. For more information see http://www.sangram.org

4. Stigma and Discrimination: The Situation of People Living with HIV and their Carers

> *'Recognizing that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying civil and political freedom and freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his civil and political rights, as well as his economic, social and cultural rights…'*
> – Preamble: International Covenant on Civil and Political Rights

> *'Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world…'*
> – Preamble: Universal Declaration of Human Rights

Stigma and discrimination have haunted the response to both HIV and to AIDS since the emergence of the epidemic.[1] This is as true of the Commonwealth as of the rest of the world, especially in societies with weak or non-existent legal frameworks offering human rights protections and programmes that support access to justice. Jonathan Mann (1987) famously predicted three phases of the epidemic that was unfolding in the early 1990s: first the wave of HIV, then the second wave of AIDS, and third, the epidemic of stigma, discrimination and denial. Recent data from the Stigma Index confirm its persistence.[2]

So too do the testimonials collected for this study. Just three country examples can illustrate the trends:

1. Jamaica

   'Initially he got along very well with individuals that live in the yard but as he got sick they started treating him badly not talking to him, scorning him, not hanging out with him as they usually did. There were times when he would try to make it to the bathroom to go use the toilet and was unable to make it because he was weak and as such he would sometimes filth on himself on his way, so there were times when I had to come home and get him from outside and take him in. He was scorn[ed] because people knew. People started talking how is it that he is losing weight, is the batty man [homosexual] etc. It was also the fact that it would be the gay disease and is because of our nastiness so.' – L

2. Papua New Guinea

   'We were in [the hospital] emergency [room] and she was very weak, she said she couldn't hold on anymore. She said "Look after my children". K died in the hospital. We brought her body back to the village. Only the immediate family went close to the body to mourn her but many didn't want to touch her. Only we touched her and cried over the body. Like with her husband, people were too scared to come close. They stood around but very few came close. Some came to pay respect while most came out of curiosity. (…) During the time of caring no one came to give me or the family a helping hand. We had no support' – Alice

   'My daughter B was living at home with me when she got sick. I took her to the Barracks clinic which is about a mile from our house. They said she had malaria and pneumonia. It was only later I heard from others that she had HIV/AIDS. I took her to the AIDS clinic. I was not scared, my heart did not fear, nor did I turn away from her. I would take her where she needed to go. Whatever she wanted me to do I would do for her if I could. Many times she would get angry and cry and feel sad and depressed that people were talking about her, the gossip really affected her. She would cry and tell me that she didn't have this "sickness" and wonder why people were saying she had. She was scared and angry. She felt that people were just labelling her for nothing. …No-one helped me through this difficult time. I did it alone. Our traditional ways are that we help each other out during times of sickness but for some reason this time no one came, maybe they were scared.' – Ruth

3. Bangladesh

   'Today I could not do any work properly due to my HIV infection because people rebuke me or neglect me. I worked in seven to eight houses as a maidservant when I was free from HIV. I cannot do heavy work after having infection of HIV.' – Hamida

Despite the extensive analysis of stigma – and the arguably less extensive programming that has tried to address it, as seen in the chapters on the hospital and the prison in this volume stigma appears consistently across the interviews as a starkly defining feature of living with HIV and caring for people living with HIV. The contours of stigma remain the same as they have been for a decade or more: the association of HIV with contagion and contamination that is both physical and moral in its association and identification with groups already outcast or considered second class by dominant social norms.

The preambles of the UDHR and ICCPR each remind States that recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family form the foundation of freedom, justice and peace in the world. But just as the texts of the international human rights instruments make clear State obligations, so the caregivers' testimonies attest to the omnipresent and debilitating facet of coping with a diagnosis of HIV in the absence of State protections.

Across developing countries of the Commonwealth, stigma, discrimination and the hard work of care-giving situations is exacerbated by the absence of treatment, the presence of misdiagnosis or the absence of any diagnosis at all.

Alice describes looking after her sister and brother-in-law in Papua New Guinea in terms familiar to the AIDS response since the 1980s and still the reality in many parts of the developing world where access to medicines standard in the developed world remains denied with devastating consequences:

> 'When we were caring for them it was so very hard. Their eyes were hollow and the eyeballs were bulging out. It was a very bad sickness. They were naturally big people and they lost so much weight, they looked like living bones. They were big people. They were not sick that long but if you looked at them they looked like they had been sick a long time. The sores made life very hard for them. Their skin was always itchy. We would try to soothe it with warm water but it didn't help very much.'

As a caregiver, the hardest things are the two most basic:

> 'Our hardest thing about caring is the carrying, the urination, the diarrhoea. The hardest thing was that. Another hard area in any sickness is food, trying to find food. People would see us and ask "Aren't you scared sharing food?" We would say no. The big thing was food and cleaning them. Food was a big issue and we tried hard. People who are working probably find it easier but we in the village really struggle.'

So too says Ruth, the mother looking after her dying daughter:

> 'At that time I bought so many clothes from the second hand because she was soiling them and I wouldn't have enough time to wash them and no one wanted to touch her clothes. They thought they would get sick if they touched her clothes.'

Alice takes her emaciated and dying sister to the hospital in Papua New Guinea, only to be told that it must be tuberculosis. After her sister has died, Alice takes the body home, only to be shunned by her community even in her grief:

> 'We brought her body back to the village. Only the immediate family went close to the body to mourn her but many didn't want to touch her. Only we touched her and cried over the body. Like with her husband, people were too scared to come close. They stood around but very few came close. Some came to pay respect while most came out of curiosity.'

For Ruth, caring for her daughter, the story of the misdiagnosis is almost the same:

> 'My daughter was living at home with me when she got sick. I took her to the Barracks clinic which is about a mile from our house. They said she had malaria and pneumonia. It was only later I heard from others that she had HIV/AIDS. I took her to the AIDS clinic. I was not scared, my heart did not fear, nor did I turn away from her. I would take her where she needed to go.'

As her body breaks down in the absence of anti-retroviral treatment, and with the weight of stigma and gossip. Her mother tries to shield her, but it is a powerful combination:

> 'Whatever she wanted me to do I would do for her if I could. Many times she would get angry and cry and feel sad and depressed that people were talking about her, the gossip really affected her. She would cry and tell me that she didn't have this "sickness" and wonder why people were saying she had. She was scared and angry. She felt that people were just labelling her for nothing.'

AIDS gives families and communities permission to break down traditional social support systems that are generally attributed to promotion of social cohesion within communities. Ruth's isolation from her family, community and government support is also palpable:

> 'When she died I sent messages to my family to ask them to come and help me. I wanted to know whether we would prepare her for burial in one of their houses or here in our house. Nobody came. I washed her and dressed her on my own and waited, a solitary figure beside her body. I found this really hard as normally there would be the support of family during times of grief and mourning. I was asking "God you have taken her and I have nothing. Will there be someone to help me bury my child?" My other children joined me and we mourned together.'

Finally, someone from the community steps in:

> 'At about 12 midnight someone came and said it was time to bring the body outside. I asked for help, for someone to help me put her body into the coffin. No one wanted to touch her. Only one lady came forward and with her help I lifted her body into the coffin. She was light, like a baby. They closed and nailed shut the lid on the coffin and carried her down to the ground. She was buried under cover of darkness. A burial shrouded by shame.'

This harsh reality is not an isolated incident they alone face, however, despite what these fragments of two Papua New Guinea women's stories would suggest. In ending her interview for this research, Alice makes an important point. 'There are others in the village you should talk to', she says.

> 'They have also looked after their loved one on their own. People are scared. There is no reason for this. Sicknesses, no matter what they are, are still sicknesses. When people get malaria, we look after them, when people get TB, we look after them. It is all the same. Someone is sick and we do what we can to make them better again.'

Alice knows that many others in her village have lost loved ones to AIDS in the absence of any acknowledgment of State responsibility or even accountability. The stigma gives community members permission to break social norms not once but repeatedly, undermining the social cohesion that has become the tradition for communities supporting their members in times of difficulty and grief caused by illness in the absence of any signs of social programmes. The State appears only after the fact, as noted earlier, to deliver a workshop and to debrief Ruth.

> 'Where were they when she was alive? Now that she was dead, they wanted to know everything! I never found any kind of support in the way of counselling, nothing. I didn't know where to go. Maybe the people living in the town area, the working ones know. I didn't.'

In the end, for both women, isolation from family support is combined with their commitment to ensuring their dying sister and daughter have someone to be with them as the virus destroys their immune systems and their bodies spiral out of control. Ruth speaks for both of them when she reminds us that:

> 'Normally family would be there for support. People to bring food, help care for her. This is what we do when people are sick and or dying. Why was this different? Why was I left to care for her on my own? I am not complaining, but I was angry at how my family were not there for us in our time of need.'

The personal narratives collected for this study lay bare the daily realities of the poor when AIDS enters the household as an additional shock that catapults the family house into deeper poverty. Hamida in Bangladesh says of the time before she and her husband got sick:

> 'That time I was in good position. Family was happy. I need to wake up early in the morning and prepare food for family members. Then prepare myself to go office and also taking food for lunch. After returning to residence I again prepare food for dinner and do care my child as well as other members.'

But Hamida is caring for a husband who is struggling with a drug addiction:

> 'In that time he [her husband] was picking up waste paper from street and managed his drug habit by selling the papers. He could not contribute to maintain the family. I maintained the family by the income of mine and my son. Some time he gives me 40 to 50 taka from his daily income to maintain the family expense. But when he has no money to take drug for his addiction than he claims money from me and I am bound to pay him.'

HIV enters the household first through him and then her own infection, which undermines her ability to work: 'after having infection by HIV I feel very weak' she says. Her own physical deterioration combines with the unchecked and unredressed social stigma and discrimination. Nevertheless, the burden of care falls to her: 'Still now I am working to maintain family' she says. Under the combination of her own ill health, discrimination from employers, her husband's efforts to eke out a subsistence life that mostly supports his drug addiction, the household processes begin to break down:

> 'I was not able to continue my son's education but my daughter is going to school by staying with my sister's house. My son is working for helping the family. If I don't work then where do we get the food. I am the only daughter of my family and always being upset by thinking what will happen to my children in absence of me. Who will take care of them and who will provide them food?'

Wives and husbands and children

All the caregivers speak of their fear of who will look after their loved ones if their own bodies give in, and they labour long and hard, denying their own failing health. Alice's sister's story in Papua New Guinea echoes the experience of Hamida in Bangladesh – breakdown of the family and household.

> 'We were living life day to day and then K's husband got what looked like scabies on him. It spread everywhere. We took him to the doctor but by then it was like it had gone under his skin

> and into his body too. We went to the skin doctor at the hospital and get medicine and cream. It didn't get better, his skin was looking worse and then his joints started to lock and he could walk properly, finally he couldn't walk at all. He was losing a lot of weight. We went to Three Mile and they admitted him at Port Moresby General Hospital. My sister looked after him and I watched the kids at home. The doctors discharged him and they came home. We returned to the village and he died here.'

After K's husband dies, K collapses:

> 'Once her husband died, K seemed to get weak very quickly. When looking after him she had stayed as strong as possible. I would do the heavy tasks like carrying the water for him to wash but she did the rest. She washed him, cleaned his sores and dressed him. My sister looked after her husband in the hospital while I looked after the children and when he was discharged they came here and we both cared for him. She was starting to get sick so needed help, so I helped her. I was trying to look after both of them. Only our elderly parents would come and see us, but they are old. While caring for him she got the scabies, he passed it on to her and she started getting sick. The sores were spreading … She would tell us and we would do what we could but the sores were getting bigger.'

It is K's funeral Alice describes above. K's children are left for Alice to raise, but it was K who was the breadwinner, whose illness threw the household into a poverty from which it has not recovered, where hunger is the daily reality. K's illness lasted just three months before she died.

For Hamida, who has been looking after her husband for three years, the hardest part is her husband's on-again off-again abuse:

> 'After doing whole day's work I feel very pain to serve my husband at midnight. When my husband burns cigarette randomly in the whole night and drowsing that is very much painful for me. During serving my husband some time he becomes angry due to addict. I do massage my husband legs, hands, body and also wash his clothes but if anything is wrong then he becomes cruel to me. It is really painful for me.'

What makes Hamida's situation far more bearable than Alice's or Ruth's is the presence of social support. Hamida is on ART, which is never even mentioned in the testimonies from Papua New Guinea. She has also been able to get assistance from CARE Bangladesh and Mukto Akash Bangladesh (MAB). The minimal support she gets for her health from MAB, combined with a toehold in the market economy through her office cleaning job, sustains her, she says, although she is still left to care for her husband when he comes home at midnight, and her son remains out of school.

Multiple forms of stigma in Jamaica

When double and triple stigmas make the caregiver's role even more difficult, it becomes an additional affront to human dignity as understood and guaranteed by international human rights instruments and the way they have been interpreted in national law. In one of their judgments, the Canadian Court of Appeals for Ontario defines human dignity thus:

> 'Human dignity means that an individual or group feels self-respect and self-worth. It is concerned with physical and psychological integrity and empowerment. Human dignity is harmed by unfair treatment premised upon personal traits or circumstances which do not relate to individual needs, capacities, or merits.'[3]

If poverty is exacerbated by the arrival of AIDS in the family home in the cases of Bangladesh and Papua New Guinea, the household structure at the centre of the testimony from an urban Jamaican ghetto is even more tenuous because of sexual orientation, for here indignity endorsed by the State is a central factor.[4]

The man at the centre of the caregiver's story is never named, but he worked in the market selling among the other small traders. It is there, in the street and in other public places that his illness begins to manifest:

> '...he had dizzy spells and sometimes I would wonder and asked him why was he passing out so often, he passed out a lot. He would pass out at the market, sometimes at home or maybe in the streets...'

The dizzy spells were accompanied by a frightening deterioration of his body: 'he had diarrhoea, loss weight, his eyes had sunken deep in his cheek bones, he was throwing up.' This was a marked difference from when he first moved into the tenement yard in which he was living:

> '.. people were used to seeing him as a healthy person going about his business and going about his daily life and as time progressed he started looking unhealthy so to speak. He was very good with the neighbours especially the people in the yard because it was like a tenement yard setting. ... Initially he got along very well with individuals that live in the yard but as he got sick they started treating him badly, not talking to him, scorning him, not hanging out with him as they usually did so. ... [E]ven the immediate neighbours weren't paying much attention to him, they weren't talking to him much anymore. The challenge that I have looking back is that I could remember when he was up and about he used to assist them, like give somebody a banana or take a bread to somebody, but eventually they [abandoned] him; they went about their business.'

Once a source of economic support for his family, he began to stay alone in a one-room home until his condition deteriorated to the point where he could no longer manage alone. The diarrhoea and his weakness became so extreme he could no longer hold his faeces on the walk from the house to the latrine:

> 'There were times when, as a result of his weakening stage he was weak as a result of not eating, having weight loss he was weak as a result of that. There were times when he would try to make it to the bathroom to go use the toilet and was unable to make it because he was weak and as such he would sometimes filth on himself on his way, so there were times when I had to come home and get him from outside and take him in".

The neighbours refused to help:

> Interviewer: So the neighbours would leave him lying in the yard?
>
> Interviewee: They wouldn't pay him no mind; they wouldn't pay him no mind.

So his caregiver, L, had to leave work to pick him up from where he is lying on the ground in his faeces, take him back into the house, clean his soiled body and clothes, and console him. Eventually, the strain of looking after his lover financially, physically and emotionally leads L to move in to the one room house where his lover has been trying to live alone with his deteriorating body:

> 'What made me decide to move in with him was I couldn't afford to see him in his filth not being able to go and use the bathroom as he would normally do. Not being able to prepare food and eat, and working within the field I know that those were also important.'

The need was great as his lover's body deteriorated in a familiar description that nevertheless repeats itself across the Commonwealth, as if nothing had changed since the advent of ART:

> 'He was throwing up, not eating, he lost a lot of weight, he was skin and bones. With that said I knew things were getting worst, his eyes were in a hole it was to the back of his head, his cheekbones were sunken so that in itself told me it was getting worst. He was having more frequent diarrhoea, he was dehydrated, I knew it was getting worst.'

L was determined to bring his lover solace and help him die with dignity. He took the few dollars he earned a month and used it to try and feed the two of them while they are living together, despite the fact that suffering from thrush meant the meal ended up being vomited again. Once that happened, the food was gone but not the hunger or the need for nutrition:

> 'So he starve because if you ain't eating what was available, when he did eat he throw up so there was nothing else to give him so he stayed hungry. I am sure that he might have been hungry many times and not share it with me because he didn't want me to be worried about what he would eat, and what was happening to him.'

This is Jamaica, however, and the community did not accept the couple's living arrangements, even though their neighbour was clearly dying:

> '...before he died I moved out because things had gotten real bad in terms of the community because this was in Spanish Town and because people were talking! And the neighbours were talking. I had to make the decision as to what, do I live with him and continue to take care of him and deal with the issues of the fear of being attack as well as being verbally attack or do I move out and do it on a visitation basis? ... [P]eople were [calling] us "batty man." "How is it that two men were living together?"'

L had already been physically attacked and then expelled from college for being gay. Moreover, like Hamida and K, he had contracted HIV from the partner for whom he was now caring. He realised he was looking at himself in the future and wondered who would look after him when his time came.

Finally, the pressure from the community and from his own fears of what might happen to him came to a head:

> 'What made me decide to move out was as a result of the external community pressure I couldn't deal with that. In addition to that I was also dealing with my own, for want of a better word, personal demons because I was probably saying, oh my gosh if I should test positive tomorrow is this how am I going to be living, and so it was complex.'

L began secretly sleeping at the office where he worked while doing his best to continue caring for his dying lover.

> 'I paid it [the rent] still but it was still difficult, it was just too much for me to be there looking at it, looking at him dying so I would pay, I would visit him now and then and sleep at my office – I would get into trouble for that – eventually I lost my job.'

Eventually his employers found out about his sleeping arrangements and, knowing nothing of what he was struggling with at home, fired him. Because of the double stigma of AIDS and homosexuality, he had nowhere to live:

> 'I was no longer able to live with him and take care of the emotional and health needs and I started sleeping at my office, it would be the office or the street and I was eventually fired. Protocol... office procedure... I was told on several occasions that I could not be sleeping at the office. Well I did not say why I was sleeping at the office, eventually I lost my job. So in losing my job it became practically that he was on his own too. How we managed, I had another friend in Kingston who I would take from him to give to him, and the reason why I paused, that friend died in November as well.'

L began squatting in an abandoned house with a group of gay men who were also homeless, until being homeless, HIV-positive and unemployed himself takes its toll and he can no longer be there for his lover as he once was. Three or four days after L's last visit he hears his lover is dead:

> 'I did not even know when he went into the hospital. I remember that … one day and someone called me and told me that my friend had died and I said, oh, and they said yes he was on Ward 9 and at that time at KPH Ward 9 was where persons with HIV were being kept or being bedded and I remember I was crying and people were being sympathetic but I was just crying, it was overwhelming.'

Because he was not family, his lover's mother reappeared and claimed the body, gave him a pauper's funeral, and took what little he had left behind. His lover now dead, L remained homeless and on the move:

> 'It [squatting in the derelict building with other homeless gay men] went on for a long time. A year and half or a year until, eventually I said, by this time my partner had died, I said to myself I can't live like this anymore, reflecting on the fact I might end up dying like him and being treated as how he was treated. I said I could not do that so I went back home to Duncans [in rural Jamaica], I spent another two or three months in Duncans. In the community people were talking about my sexuality, they were calling me names. I moved from one place to another … and then eventually I went to [another rural community] and started doing some yard work and then eventually I got the opportunity of coming to America to study.'

L subsequently successfully claimed asylum in the United States on the basis of his sexuality and lives in Massachusetts.

Notes

1. The literature is extensive. See, for example, Parker and Aggleton 2002; UNESCO 2003; or Cameron 2009.
2. The Stigma Index is a collaborative project between the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW), the International Planned Parenthood Federation (IPPF) and UNAIDS. The index is being used around the world to measure the stigma experienced by people living with HIV. To read more, see: www.stigmaindex.org/ In this research we highlight stigma for carers, which is different from that experienced by HIV-positive persons.
3. Court of Appeal for Ontario, Mcmurtry C.J.O., Macpherson and Gillese J. J .A. between: Hedy Halpern and Colleen Rogers, Michael Leshner and Michael Stark, Aloysius Pittman and Thomas Allworth, Dawn Onishenko and Julie Erbland, Carolyn Rowe and Carolyn Moffatt, Barbara Mcdowall

and Gail Donnelly, Alison Kemper and Joyce Barnett – and – Attorney General of Canada, the Attorney General of Ontario, and Novina Wong, the Clerk of the City of Toronto – and – Egale Canada Inc., Metropolitan Community Church of Toronto, the Interfaith Coalition on Marriage and Family, the Association for marriage and the family in Ontario, Canadian Coalition of liberal rabbis for same-sex marriage, and Canadian Human Rights Commission (date: 20030610; docket: c39172 and c39174)

4. For an analysis of the legal environment and HIV, see Commonwealth HIV and AIDS Action Group and International HIV/AIDS Alliance 2010.

5. The Duty of Care: The Right to Health in Hospital Settings

> *'1) The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*
> *2c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases.*
> *2d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness.'*
> – Article 12 of the International Covenant on Economic, Social and Cultural Rights

The role of the public hospital in the context of AIDS care is inarguably a State responsibility. National programmes traditionally acknowledge this by investing in staff training, including stigma reduction. This has not proven effective in many settings, as an examination of the narratives amply demonstrates.

L's experience in Jamaica as he nursed his partner are painful:

> 'At that time people used to be kept on specific wards. They were not looked on by the nurses, the doctors. They didn't want to touch them, they were scorned. They were basically like the Biblical days about people having leprosy, so persons were not treated well. It would have been stressing even to go to the hospital to disclose I am HIV-positive. People are still afraid of talking about their HIV status or disclosing to medical professionals.
>
> 'I think he was afraid if he got sick what would happen to him if he needed to go to the hospital. He wouldn't get better treatment at the hospital. Eventually when he got sick and went to the hospital he didn't get good treatment. As an individual living with the virus he had gone to the doctor's before. The treatment he received made him never want to go to the hospital again.
>
> 'I do not think he was in the hospital long because I had gone and visited him maybe three or four days earlier at home. I did not know he was in the hospital because apparently what happened is that he went to Spanish Town Hospital and they transferred him to Kingston Public Hospital. Someone from the yard, one of the neighbours, got him to Spanish Town Hospital. Then I did not even know when he went into the hospital. I was at work one day and someone called me and told me that my friend had died. He was on Ward 9. Ward 9 was where persons with HIV were being kept or bedded.'

In this case, the State failure to guarantee dignity, rights and freedoms equally to all citizens was violated because these were gay men. They lived in such fear with the stigma of both their sexuality and their HIV status that they were too afraid to seek the public health care and support to which other citizens were entitled for other illnesses as a matter of course. They constantly lived in a state of stress with the conditions of HIV, and could not enjoy equal human rights. Furthermore, Jamaica did not create the conditions that assured them of medical service and medical attention in the event of HIV.

In Papua New Guinea, Alice recounts taking her sister's husband (and later her sister) to the doctor:

> '...with what looked like scabies spread everywhere. Under his skin and into his body too. We went to the skin doctor at the hospital to get medicine and cream. It didn't get better. His skin was looking worse and then his joints locked up and he couldn't walk properly. Finally he couldn't walk at all. He was losing a lot of weight. We went to Three Mile and they admitted him to Port Moresby General Hospital. My sister looked after him and I watched the kids at home. The doctors discharged him and they came home. We returned to the village and he died there.
>
> 'My sister looked after her husband in the hospital. .... While caring for him she got the scabies. He passed it on to her and she started to get sick. The sores were spreading and she went to the skin doctor to get cream. ... The sores were getting bigger. This continued until I saw that she was really bad and there was nothing more I could do to help so I took her to the hospital. They said TB. But when I talked to the TB doctors they said "no, it's not TB". We were in emergency and she was very weak and said she couldn't hold on anymore. She died in the hospital. ... They did blood tests when they first went in and said that he was not sick. One doctor said TB and referred us to the TB clinic but the TB doctor said it was not TB. He said it was a different sickness. But they never told us what sickness it was.'

Ruth, B's mother recounts:

> 'My daughter was living at home with me when she got sick. I took her to the Barracks Clinic, which is about a mile from our house. They said she had malaria and pneumonia. It was only later I heard from others that she had HIV/AIDS. I took her to the AIDS clinic. I would go to the Barracks Clinic and ask for medicine. If they had none, I had to find money and go to the pharmacy to try and buy medicine. Medicine was expensive. Some were 20 kina, 30 kina, some were almost 45. When I didn't have enough money I would try to get the 30 kina packet. Some people who work with HIV patients came and told me that the best thing would be for me to take her and leave her with them at the AIDS Clinic at Six Mile. But I heard that they mistreat them. They shout and swear at them

> and treat them badly. I heard that they push them in the showers so they fall down. Because of these stories I said no to them. The sisters at Taurama Barracks Clinic also advised me to take her to the AIDS hospital. I don't treat my child badly. Why should I send her to where strangers might?
>
> 'I never found any support in the way of counselling. I didn't know where to go. When she got really sick we paid for the ambulance from fish money and took her to the hospital. After we went back to the village we didn't see anyone from the hospital again. They knew about us. But no one came to help us. After she died people from the AIDS clinic came and did a workshop here.'

When Papua New Guinea and any other State ratifies the ISESCR, they agree that everyone is entitled to the highest attainable standard of physical and mental health. In the stories of Alice and Ruth:

- HIV conditions were wilfully misdiagnosed by State agents who were members of the medical profession
- information was deliberately withheld from the patient and the carer
- there was no outreach support or information for the carer, and
- medicine was not provided, further impoverishing the household.

The final irony is the State arrives to discharge its duties after the patient has died.

M, who nursed her sister in a public hospital in Guyana tells her story:

> 'She was sitting in the chair and she said "you know, I can't make it. Carry me to the hospital". By the time we went to the hospital and to check her up and do the test they told me she was HIV-positive. She could not have walked. They were not admitting her at the hospital. They told me to take her back home. While we were trying to get her out of the hospital she collapsed. Her foot give out. And then they say to come back and they admit her. I was confused because hearing she was HIV-positive then they not wanting to keep her at the hospital.
>
> 'So when I left the hospital they say you have to bring things for the hospital. I used to go. The first day I went I cleaned her skin. And just like how I leave her, the nurse left her there. And for the two weeks that she spent in the hospital the nurses have never ever done anything for her. They just put her there to the last bed in the ward in the corner. At first they gave her some saline for the first two days. And then they took out the saline and if I don't go in time to clean her skin she would be left there until I go. So I had to be there three times a day to clean her skin. The nurses

> have done nothing for her in hospital. I have never seen a doctor because when I get there they would always say the doctor done run the ward and because of the fact that she wasn't seeing and she was not talking, I could not have asked her if the doctor was there. But I have never seen the doctor.
>
> 'I fed her, I used to feed her in the morning and at lunch time. Liquids. I used to have a straw but she had this thrush in her mouth. The diarrhoea it only happened for two days before she died.
>
> 'I am still wondering, sometimes I am being in denial, did my sister really die from HIV? With all the signs and symptoms she didn't have diarrhoea, she didn't have vomiting, she did not have sores, and I still can't come to grips with it. I think there is a lesson that people out there should learn. That the nurses would not do what a caregiver would do.'

It is common for hospitals not to want to admit people with AIDS and to want to discharge them, which breaches article 12 of the ICESCR. The need for carers to continue to care even when the patient is hospitalised because of the failure of the State to provide sufficient care is also in evidence. This too is not unusual. No carer is free from stress and the implications for their own mental health because the member of their family has been hospitalised. Full information, and access to anyone who might provide that, was also denied. As a consequence the carer worries after the death whether or not they did something wrong.

6. HIV and Gender-based Violence: The Rights of Unpaid Women and Girl Carers

> CEDAW General Recommendation 19 (1992) states that 'gender-based violence, which impairs or nullifies the enjoyment by women of human rights and fundamental freedoms under general international law or under human rights conventions, is discrimination within the meaning of article 1 of the Convention'.
>
> CEDAW General Recommendations on health say that States should ensure the removal of all barriers to women's access to health education and information in the area of sexual and reproductive health and allocate resources for programmes directed at adolescents for the prevention and treatment of sexually transmitted diseases, including HIV and AIDS. The General Recommendation on HIV/AIDS directs States parties to increase their efforts to disseminate information to increase public awareness of the risk of HIV infection and AIDS, especially in women and children.
>
> The Committee on the Rights of the Child, in its General Comment No. 3 (2003), while setting out that the right to health (article 24) is central to combating HIV among children, notes that HIV affects a child's civil, political, economic, social and cultural rights. It further notes that the right to life, survival and development (article 6) and the right to have his/her views respected (article 12) should be the guiding themes in the consideration of HIV and AIDS at all levels of prevention, treatment, care and support.

Situating rights

As noted earlier, the 1949 Universal Declaration of Human Rights (UDHR) sets out in Article 1 that 'All human beings are born free and equal in dignity and rights'. It emphasises the 'inherent dignity' and 'equal and inalienable rights' of all members of the human family as the foundation of freedom, justice and peace in the world. Therefore it has been asserted (Pulea 2010) that dignity provides the rationale for the requirement of respect of persons (Lebech 2004) and it has also been described as 'the shaping principle…' (Andorno 2009) that reinforces the intrinsic worth of human beings.

Following on from the above, women's rights are seen as an indivisible part of human rights, and the UN Conference on Human Rights in Vienna in 1993 recognised that women's rights in the personal sphere are as important as their rights in the public sphere. The CEDAW Committee issued Recommendation No. 19 in recognition of the pervasive and persistent violence against women in different forms and how this impairs or nullifies the enjoyment by women of human rights and fundamental freedoms. Violence against unpaid women carers is a violation of their rights to dignity, personal security and the enjoyment of all freedoms.

The Convention on the Rights of the Child (CRC) sets out the framework of rights that enable a child to live in dignity and enjoy her or his rights in various spheres of life (family, community, school, etc.). General Comment No. 3 asserts that the HIV epidemic 'impacts on the daily life of younger children, and increases the victimisation and marginalisation of children, especially those living in particularly difficult circumstances'. In the case of child carers – or indeed those children requiring care from older siblings – any form of violence against them and/or violation of their rights to health, education, food and adequate and safe housing is in breach of the CRC. Although child labour is a violation of a child's right to dignity and impinges on a her or his enjoyment of all other rights, the realities of impoverished and vulnerable households has meant that children continue to engage in unpaid household chores and often drop out of the school system to become full-time carers in households affected by HIV.

As rights holders, unpaid women and child HIV carers in households are entitled to social justice that ensures their access to resources, protects their person from any form of violence and accords them dignity in their daily lives.

Experiencing violence: examining the voices of women and young carers

In Bangladesh, when Hamida's husband becomes angry, '… then he becomes cruel to me. It is really painful for me.' As an HIV-positive injecting drug user, he is unable to continue work as a rickshaw puller and has resorted to picking up waste for recycling and selling to finance his drug addiction. She has had to step in with paid employment (care-giving and counselling with an NGO) and also provide the unpaid work required for the maintenance of the household. Living with violence at the hands of her husband is not only physically draining but also emotionally unbearable as she grapples with working out a future for her children.

Her children seem to offer some hope. However, her young 11-year-old son has had to stop education and begin waged employment.

> 'Nobody helps me in my daily household work ... I could not able to continue my son's education but my daughter is going to school by staying with my sister. My son is working too for helping the family. If don't work then where we get the food? ... I am being upset by thinking what will happen to my children in my absence. Who will take care of them and who will provide them with food?'

The children's situation – relocation and being with extended family for access to education in the case of the daughter (an example of a positive outcome of government policies on girls' education) and waged work for the son – reflects the difficult choices for vulnerable families as they try to balance development gains and benefits with financial demands and decisions. While the girl's access to education is an obvious gain, it needs to be understood in a context where she may not go on to pursue education beyond the primary level given cultural and economic constraints.

As domestic violence is often shrouded in a culture of silence, women not only rarely speak up but are also unable to defend themselves. Women's subordination and socialisation and the gender dynamics within a community often prevent or deter them from approaching the police or traditional authority. Even when legislation on domestic violence exists, enforcement is problematic. Given Hamida's HIV status and her many physical and emotional burdens, her socioeconomic rights are breached and her right to dignity is compromised.

In Uganda, Jessy also faces uncertainty and violence as she struggles with being the primary caregiver for her sero-positive mother and her younger siblings. Her father died in 2005, and her mother's health took a turn for the worse in 2007 after she tested positive. They live in a cramped settlement with Jessy constantly worrying about the future and struggling to provide full-time care without adult help or supervision. Her circumstances are not conducive to her personal safety as she attempts to also make some money to feed her family.

> '... [during free time] I am not resting but thinking of what is going to happen to my young ones when mother passes away. My mother's sickness is on and off, but the hardest time I have ever gone through was when she collapsed in the night and I was alone with her in the house, nobody to help me carry her to the bed. I wanted to call my uncle who was 5 km away from us but I did not have any airtime on mother's phone. I was forced to scream to draw

> the attention of the neighbours but unfortunate for me only one lady came out but she did not have a mobile phone. She remained in that condition until 5 am when I jumped on a Boda Boda [local bikes used to transport people] to go and call my uncle.'

> '... I used to wash clothes for some people to enable me to get some little income but I stopped after escaping rape from a man who deceived me to pick the clothes from the house and wanted to force me into sex.'

The intergenerational burden of HIV has placed a grandmother in Namibia in a vulnerable position as she struggles to cope with caring for her grandchildren, whose lives have been blighted by AIDS. Emily says:

> 'Five of us live in this house – the oldest child, a 16-year-old boy is somewhere on the street. His name is S. I don't even know if he went to school today. The girl, W, is only here for one year. Then there are the twins H and C. I take care of all the children. I have had the 16-year-old boy since he was 4 months old. His mother, my daughter, died. The twins belong to my neighbour, a woman who passed away. The girl, W, is staying here to study. She is my granddaughter. Her mother is not one of those infected. I have been looking after the children for over 10 years ... The 16-year-old has an attitude about him and it stresses me out ... He has not yet attacked me, but his attitude tells me that it is only a matter of time. I feel so emotional about it but only God can help.'

Hamida, Jessy and Emily are made vulnerable by their situations as carers in households severely affected by HIV, which leaves them open to the threat of violence. In Hamida's case, violence at the hands of her husband reflects the structural causes of gender-based violence, which are founded on patriarchal norms and perpetuated by cultural constructs of gender roles. The intersection of violence against women and girls and HIV has been highlighted by women activists, and HIV-positive women's experience of violence in its various forms was identified at the 2010 Vienna AIDS Conference. These range from non-consensual testing and disclosure of results to stigmatisation, isolation, disinheritance and ostracism by family and community, forced sterilisations and forced abortions. Because it is shrouded in a culture of silence and has taken a long time to be named, labelled and recognised as a violation of women's and girls' human rights, domestic violence often remains unchecked. Too often women have paid for this with their lives.

The challenge of addressing women's and girls' needs and interests as sero-positive persons and/or carers within the broader context of structural inequalities of sexual violence, economic dependency and unequal access to ART often poses problems when designing policy and programme solutions. An integrated approach to the elimination of violence against women and girls in the context of HIV would have to consider legislative measures, legal interventions, affirmative actions, training of the police and judiciary, improved reporting, data collection and monitoring, public education, programmes targeted at abusive men, support services, health measures and protective mechanisms, and the intervention of community and religious leaders. Such an approach would be women-centred and consider abused women's and girls' particular needs and interests within the framework of their daily realities and social relations.

7. A Case for Justice: The Rights of Prisoners with HIV

> *'All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.'*
> – Article 10 (1), International Covenant on Civil and Political Rights

The voices on HIV care reveal that prisoners with HIV struggle with dignity and rights as they grapple with systems that seem to emphasise control over care. The story of a woman prisoner in Canada bears this out:

> 'I was H's case worker while at PASAN (Prisoners with HIV/AIDS Support Action Network) and there are horror stories with regards to her case. Overall, the system did not look after her. Women prisoners were bathing her, feeding her, doing general care and emotional support. They would try to look after her, cooking, putting lotion on her sore body parts, doing make-up. Right before she was brought to the hospital, she was found lying in her own vomit with rotting food in her cell, cigarette butts everywhere and fruit flies all over. Her case management officer did an informal "sit in" and wouldn't leave the prison until someone went to see her and took her to the outside hospital. Women were yelling well wishes to H as she left the prison. I met with several women after the funeral service for her (at the prison) and they all told me similar horror stories about her not getting proper care.
>
> 'Compassionate release for people living with HIV/AIDS in prisons is a huge area of concern. PASAN has done a great deal of advocacy in this area because people are often days or moments away from dying before they are released (sent to hospital or home to be with family). People have died in the ambulance while on the way to the hospital so that there is no inquest into prisoners deaths. CSC (Correctional Service of Canada) does not have to do an inquest if a prisoner is no longer in custody.'

In accordance with the United Nations' Basic Principles for the Treatment of Prisoners (United Nations 1990), prisoners are in the custody of the State. Principle 1 of this document states that: 'All prisoners shall be treated with the respect due to their inherent dignity and value as human beings'. This is in alignment with article 10.1 of the ICCPR. Principle 9 states that: 'Prisoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation'.

These agreements designate the State as the primary carer for people in prison. This is critical for prisoners with HIV or AIDS because many do not have sustainable contact with family and others outside, who often provide emotional support, money for medication and food to sustain the health of those inside (Goyer 2003; Avert.org 2010). Some prisoners have no external supports at all. Compliance with article 10.1 of the ICCPR is therefore necessary for the provision of quality care for those incarcerated in respect of their dignity and humanity.

An interview between a PASAN caseworker and Carol, an inmate from a Canadian women's prison, shows the reality for prisoners with HIV.

> Carol: 'My friend H (referred to earlier) was more sick and she should have been in hospital. She should have at least been in the health-care centre because they did have a couple rooms there for inmates. You know, in the hospital, in their health-care system, but it was like they neglected her.'
>
> Caseworker: 'So what kind of care was she getting while she was in that centre?'
>
> Carol: 'None … they waited until the very end, until she was on her death bed to give her compassionate parole. They waited until she had, in fact, dementia, where she didn't know where she was anymore or what was going on … she couldn't feed herself anymore. She couldn't bathe herself anymore … she didn't know who you were. You know, she'd just go blank.'

While there were services provided by paid prison staff, chaplains, NGOs and other 'external' supporters, the interview notes show that a significant and valuable part of care-giving was provided by fellow inmates. These included bathing and providing moral and emotional support – functions willingly carried out despite institutional rules that barred prisoners from entering each other's 'houses' (cells) – and advocating on behalf of each other. Carol spoke of the closeness that developed between inmates in the care-giving process, reflecting respect for each other's dignity and humanity.

> 'I used to draw her (H) pictures and write her poems and all that ….'

Carol spoke of another inmate she helped care for who had HIV, and said this of prison authorities…'you know they had to wait until, you know, she couldn't hurt … like she wouldn't … she couldn't walk no more and she couldn't hurt anybody else. Like that's in my eyes, that's what, you know then they let her out…'

ICCPR reports: the Commonwealth picture

A review of the UN Human Rights Index[1] shows that, of the 53 Commonwealth nation members,[2] the following 17 nations submitted reports to the ICCPR between 2000 and 2010: Australia, Barbados, Botswana, Canada, The Gambia, Guyana, Kenya, Mauritius, Namibia, New Zealand, Rwanda, Sri Lanka, Trinidad and Tobago, Uganda, United Kingdom and Northern Ireland (and the associated States of the UK), United Republic of Tanzania and Zambia. A specific review of section 10 of the ICCPR was made of the submitted reports.

A few national reports indicated policies around general access and entitlements of citizens with HIV or AIDS to health care; some also mentioned policies for prisoner access to drugs and support through publicly funded services. Relevant NGO reports that accompanied the country reports showed concerns about legislative and attitudinal discrimination against non-heterosexual people, which had implications for the funding of preventative initiatives to address HIV (see, for example, BONELA et al. 2008).

Overall, there were no questions by the Human Rights Committee (HRC) on country reports that requested details of how prisoners with HIV or AIDS were being cared for and by whom. There was insufficient information in the reports or the HRC responses to enable an analysis of the humane and dignified treatment of prisoners with HIV. The HRC did from time to time – as with Botswana (HRC 2006), Namibia (HRC 2004a) and Uganda (HRC 2004b) – raise issues with nations about 'efforts to protect (their) populations from HIV/AIDS' and say that they should adopt comprehensive measures encouraging greater numbers of persons suffering to obtain adequate ART and facilitate such treatment.

Despite statements from countries that access to health services – in some places free care – was assured in policies, their reports did not illuminate how prisoners actually accessed such care, nor how resource-strapped prisons and State bodies accessed and then made available such resources (drugs, professionals, equipment, emotional support, NGO support, contact with family/significant others) to prisoners in facilities. The HRC's questions were often about the wider issues of overcrowding, prisoner safety and lack of basic hygiene, food and health care (HRC 2003). The Committee also expressed concern about the lack of guarantees in a few places of the separation of juveniles from adults while in detention (HRC 2009). Despite policies indicating that terminally ill prisoners can be granted compassionate leave, inmates with HIV in both developed and developing countries continue to die in prison before being released to their families and significant others (IRIN/Plus News 2009).

The length of time between reports to the HRC under the ICCPR, and the absence of reports for the majority of Commonwealth nations, made it difficult to assess breaches of ICCPR article 10.1 in the non-reporting countries or compliance in those who did report.

In the real world, glimpses obtained from NGO reports, articles and testimonies of individuals show severe and significant breaches of this article for prisoners with HIV and AIDS. The presence of well-intentioned policies in country reports masks the struggles to guarantee the upholding of people's rights and dignity and the realities for individual lives even in better-resourced nations. A survey of prisons received by the Prison Reform Trust (PRT) in the UK – with 63 completed surveys received from the 139 prisons in England and Wales, 11 from the 16 prisons in Scotland and 1 from the Northern Ireland Prison Service (NIPS) – found that over one third of prisons had no HIV policy; over half had no sexual health policy (PRT and NAT 2005).

The types of issues in relation to the care of prisoners with HIV varied between countries, although negative stigma against same sex relationships, drug use and ignorance about how HIV is spread appear to be the common barriers to the provision of any health care and support to inmates. Poor treatment includes inadequate and inappropriate supervision to protect from sexual abuse, unsafe needle sharing, limited access to condoms, inappropriate nutrition, ongoing negative stigma from officials including health professionals, inadequate staffing and unhelpful bureaucratic procedures that are administered regardless of their detrimental impacts on prisoner health, such as removal of medication from holders, delays in getting medication and gaps in continuity of care (UK AIDS and Human Rights Project 2008).

> 'One woman attending the group in Manchester needed to take her medication at a specific time on a full stomach. It was agreed she could have a sandwich at that time, but every day the guards grabbed it off her. Every day she had to explain that she was allowed it. When another detainee said that it was ridiculous that every day this woman had to fight for a sandwich she had to eat to take her medication, she was told that it was none of her business. There was no mechanism, no continuity. Every day there were different people on the wing. The detainees were told not to expect the guards to know their situations.' (PRT and NAT 2005, p.36)

Legislative barriers and state-promoted attitudes against homosexuality in sub-Saharan Africa (UNODC et al. 2007), the Caribbean (Day 2007) and India (Johari and Mansuri 2006) prevent the distribution of condoms in prisons and make inmates reluctant to go for HIV testing or other activities that could support their care as this would identify them and cause them to be subjected to inhumane and undignified treatment. The Prison Reform Trust report showed how stigma affected an HIV-positive female prisoner in the UK who reported experiencing discrimination from the prison officers, health-care staff and fellow inmates. The inmate said that she was not allowed in the kitchen because of her HIV status and that a nurse also refused to take a sputum sample. The prisoner reported being verbally and physically abused and had witnessed other prisoners being abused by fellow inmates and staff. Other inmates confirmed that an HIV-positive prisoner would be physically and/or verbally abused or isolated if his or her status were known (PRT and NAT 2005).

For resource-strapped nations – particularly in the Caribbean and sub-Saharan countries where there is severe overcrowding and multiple individuals are held in one space – issues of prisoner dignity, confidentiality, access to condoms and medication paled in comparison to prisoners basic needs such as food, water, sleep, sanitation, security from sexual assault and protection from exposure to other diseases such as tuberculosis and Hepatitis C. Uganda is even considering legislation that potentially assigns the death penalty to a prisoner with HIV (UN News Centre 2009). In both developed and developing Commonwealth nations, the negative stigma associated with homosexuality and the ignorance of professionals and others about HIV and AIDS are still strong barriers to the prevention of the spread of HIV and lead to negligence in the care for prisoners with HIV and AIDS.

A prisoner's story illustrates reality in a cell in the UK:

> 'I was 25 when I was banged up. I was also on combination therapy … before I went to jail … After months of regular beatings … [t]his big, mean, menacing bloke has summoned me to his cell. He said he'd decided to take me under his wing …. You can't say no - I wouldn't be here if I had. In the beginning we would have sex every day, sometimes three times a day …. Now condoms are hard to come by in prison. As I went down to the medical quarters twice a day (to get my medication), I used to ask there. But I was rationed to one a day … I was told that if I took the dirty condom back – to prove it had been used – they would give me more …. But even taking dirty condoms back didn't always guarantee fresh supplies … I doubt the authorities would admit it, but prisoners are constantly

> treated for sexually transmitted diseases. It goes on daily. If I hadn't gone in with HIV, I'd have been damned surprised if I hadn't come out with it.' (PRT and NAT 2005, p.17)

In Cameroon prisoners with HIV and other illnesses lacked access to health services and facilities to cater to their specific needs, particularly in rural areas (IRIN 2006). Budgetary constraints meant that inmates had to buy their own drugs – if they and their family could afford it – as prison facilities had limited funds to provide these. Staff and inmates assisted sick prisoners by supporting them on a day-to-day basis and engaging in fundraising activities for their needs. Consider this statement from a prison official:

> '"We are abandoned here in these bush prisons – all assistance stops at Douala and Yaounde [the capital]," Wantoh Francis Teih, prison director said, adding that there is no budget whatsoever for health care and medicines for the more than 300 detainees.' (Ibid.)

Stigma against homosexuality and HIV and AIDS hindered people from offering or consenting to be tested in prisons, affecting estimates of disease prevalence and health-care needs. This negative stigma became a barrier to inmates supporting each other.

The State is responsible for the 24/7 care of prisoners with HIV in ways that uphold their dignity and respect their humanity, in accordance with article 10.1 of the ICCPR and with the UN Basic Principles for the Treatment of Prisoners. Our research shows consistently lower thresholds of dignity accruing to these persons than to those cared for in their own homes and with no resources. At the World AIDS Conference in Vienna in July 2011, the United Nations Rapporteur on torture and punishment warned: 'that overcrowded prisons were breeding grounds for AIDS. Manfred Nowak, who has visited detention facilities around the world, said inmates were often held in inhumane conditions in which the HIV virus spread through the use of non-sterile drug injection equipment, sexual contacts, tattooing and sharing of razors. Nowak told the conference that governments should, among other things, inform prisoners of the risk of HIV infection, offer free HIV testing and counselling as well as provide needle and syringe programmes and opiate substitution therapy' (Jürgens et al. 2011).

On 21 August 1997, after statements by the Commissioner of Corrections in Jamaica that condoms would be distributed to inmates and warders to prevent the spread of HIV, the warders went on strike. The result was chaos and rioting in the two largest correctional institutions. Inmates with scores to settle used the opportunity and those perceived to be homosexual were targeted, with 16 prisoners killed and more than 50 injured (Human Rights Watch 2004). The Commissioner resigned and a separate section was created in correctional institutions to house inmates labelled as homosexual. HIV and AIDS and their association with male homosexuality became the scapegoat for the prison riot, and a culture of fear paralysed HIV prevention efforts in the correctional system.

After assurances from the Commissioner of Corrections that condoms would not be made available, the HIV testing and treatment services resumed, with a focus on clinical services for all inmates. This distancing technique allowed the programme to continue and provide needed medical support for inmates living with HIV and AIDS, but the ability to effectively reduce transmission was lost. It should be noted that half of the inmate population is released to the community each year (Government of Jamaica 2008). Inmates separated in the 'homosexual' section continue to face stigma and discrimination and suffer a disproportionate burden of infection without access to standard methods of HIV prevention.

Few correctional systems in low- and middle-income countries provide even the basic HIV testing and treatment services now available in Jamaica (Dolan, Kite and Black 2007; Andrinopoulos et al. 2010), and condom distribution in prisons is a contested issue world-wide (Júrgens 2007; Okie 2007).

Conclusion

Given the voice of the woman with HIV who recounted her experiences in prison and the analysis of the Commonwealth situation based on ICCPR reports and other publications, it is clear that the rights of prisoners with HIV are severely compromised.

Notes

1. United Nations Human Rights Index of Human Rights Documents http://www.universalhumanrightsindex.org/en/index.html
2. Fiji Islands is excluded as its membership is currently suspended.

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 breast-feeding, 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, believes 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/needy 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:

	Unconditional	*Conditional*
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.

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Annex: Methodology

The researchers met at the 8th Commonwealth Women's Affairs Ministers Meeting (8WAMM) in Kampala, Uganda and began discussions on the 24/7 involvement of caregivers with people living with HIV and those struggling with the symptoms of AIDS. Building on the discussions and recommendations at 8WAMM – and in the context of the theme for the 53rd Session of the UN Commission on the Status of Women (CSW), which focused on the 'Equal sharing of responsibilities between women and men including care-giving in the context of HIV/AIDS' – the Commonwealth Secretariat decided to work on the issue of women's role in HIV care and support, with a specific focus on their unpaid work.

The environment for the study

The public health sector is a major expenditure item for any government, whether costs are met from redistributing national revenues or from development assistance programmes. In more developed economies, the economic imperative of the last decade has been for health institutions to develop more 'efficiencies' and 'effectiveness'. Operationally these policy approaches have had rather more focus on outputs than outcomes.

One of the chief manifestations of this approach has been to discharge patients earlier from public care facilities. In many countries where HIV and AIDS are of epidemic proportions and hospitals cannot cope, they have just sent all patients 'home'. In making this policy choice, there is a presumption that there is a reserve army of unpaid labour available in the family or community to immediately resume responsibility for the discharged patient. Just who is it that the policy-makers are presuming will do this caring role?

In other growing economies there is increasing pressure on governments for the provision of ever more sophisticated and expensive secondary and tertiary care facilities, at a time when studies in health economics demonstrate that the best investments in health are those associated with prevention, early detection and treatment. The location of many activities that promote or hinder this initial investment in health care is the household. Assuming that providing family health care does not have personal, family and social consequences is unfair, unrealistic and dangerous for health policy.

There are economic costs in respect of the invisibility of unpaid household and community work. We know this from the growing number of national and other time use data sets, from surveys or pilot studies on unpaid work and health care, from decades of narrative captured in a wide range of social science literature and from our own observations and experience. Insufficient or inadequate care at the onset of illness can exacerbate its severity, with costs incurred across sectors. These include the loss of labour from the market sector, the loss or diminution of unpaid productive and reproductive activities when the woman of the house either is ill or has to forego other daily household tasks to carry out caring work, or the loss of education when a child is removed from school to assist in caring roles. The known outcomes of longer-term illness include increasing the possibilities of poverty, poor nutrition or hunger and a range of other vulnerabilities.

It is also important to remember that household work includes the daily maintenance of well-being, which tends to be even more invisible than caring for the sick. Household access to water, hygienic practices and a clean environment are all daily household routines that enable a healthy paid, informal or subsistence labour force to remain productive. This work is of significant economic importance.

Research design

The first study design consisted of three main phases: a literature review, qualitative research with women from households affected by HIV as well as with those involved in caring for family members living with HIV or AIDS, and finally an economic analysis of the cost estimates of the care-giving at the household level, including opportunity costs, a cost benefit analysis and State care costs not incurred.

To a large extent, the literature search supported by the results from the qualitative enquiry changed the direction of the third component from an economic to a rights-based analysis. An extensive search of Scopus yielded a large number of articles directly related to the research topic, and http://www.genderandaids.org/modules.php?name=News&new_topic=10 contained some further directly relevant articles. These are included in the bibliography.

There was a wide variation in local circumstances in the studies of unpaid care in households. Situational analyses were needed to ensure appropriateness to the local setting and to define specific support needs and the nature of the human rights breaches in each circumstance.

The strategic policy questions raised in the literature review were extensive; they were far beyond the scope of a simplistic approach that might evaluate whether a carer's role was being understood in budgeting processes or assess the implications for addressing women and girls' roles in the HIV care economy in terms of gender-responsive budgeting.

The issues included:

- Access to and ability to utilise information
- Interruption of schooling
- Diminution or loss of income-generating and subsistence activities
- Decrease in food/nutrition especially for children
- Invisibility of women carers; increased invisibility and increased work burden of young carers even when they are not the primary caregiver
- Threat or ceasing of loan repayments, damaging extended family and community relationships
- Increased impact on rural households generally with escalation in impact as a result of global recession and fuel crisis
- Violent households more likely to experience spread of infection
- Whole households subjected to community stigma
- No provision of disinfectant, gloves, soap, bandages, painkillers
- No access to clean water
- Creation of time poverty due to burden of care
- Access to and use of condoms
- No sanitation
- No hygienic living conditions
- No respite for carers
- Destruction of traditional safety nets
- No transport
- Little or no food
- No counselling
- Hopelessly inadequate infrastructure
- No labour-saving technology of the simple grating, threshing, milling, pounding, drying, cooking kind
- No fuel whether wood, dung, gas, kerosene, paraffin, charcoal
- Deteriorating health of caregiver(s)
- Female abandonment by males in the household
- Wives and daughters sent to care for HIV-positive relatives, who live elsewhere, of the males in their household
- Male carers seen as deviant and unmanly
- Orphans

The literature review made it obvious that the research focus in the field would be most usefully situated within a rights-based framework and in particular focused on the dignity of the caregiver in a capability approach analysis. It highlighted different impacts on carers by age, cultural expectations, religion, sexual orientation and gender, most of which are overlaid with stigma.

The second phase of the research involved primary qualitative research with women, men and girls from households affected by HIV as well as with those involved in caring for family members or partners living with HIV or AIDS. This phase consisted of key informant interviews.

Sampling was purposive as the objective of the primary research was to establish the dynamic of the inequality and indignity of women and girls in the HIV care economy where such a dynamic exists, not to establish statistics of the percentage of cases where this occurs in a national sample. Subjects for the interviews and focus groups were chosen directly by the researchers or through a researcher's networks, or brokered by civil society organizations providing support to women and girls in households affected by HIV. The general trend of the primary research was interviews with women involved in the HIV care economy, but this also included information on same sex partners and children involved in care.

The original list of countries was India, Jamaica, Papua New Guinea, South Africa/Namibia, Trinidad and Tobago and Uganda. However, members of the research team attending the World AIDS Conference 2008 were further struck by the invisibility in the vast agenda of unpaid care workers as an issue.[1] With this in mind, and in recognition of the desire of the Secretariat to be able to report early findings to the CSW meeting in New York in March 2009, an extended group of countries and purposive fieldwork criteria were agreed to. An early point made was that not only developing countries of the Commonwealth had exploited the human rights of caregivers: it did not seem that Australia, Canada, New Zealand or the United Kingdom had dealt with the rights of these people either. A further detail was an effort to locate male caregivers. As a first choice, the respondents were to be from the following countries and caring for individuals in the following categories:

- Bangladesh: intravenous drug user in an Islamic household
- Botswana: a nuclear family in receipt of food aid
- Canada: woman prisoner or woman living on the street or child with HIV
- Guyana: woman-headed household/violence

- India: sex worker/semi-rural
- Jamaica: gay man/violence, or stigma and baby mother
- Namibia: a grandmother in the care role
- New Zealand: transgender
- Nigeria: Muslim woman in the compound caring for relatives
- Papua New Guinea: subsistence/rural
- Uganda: a child carer in one of the Christian community care schemes

Ethical assumptions

A list was prepared of persons who might be able to assist with the selection of possible research participants. Ethical guidelines for the researchers were also drafted.

Participant carers would remain anonymous unless they wished to be identified. They would be given a pseudonym in the final report. The carer would be well known to the interviewer, preferably over a number of years, so that her or his story could be checked for internal consistency. The interviewer might also be able to provide prompts if changes in the circumstances of the participant carer had been observed.

The interview would be conducted in the language of choice of the participant, who would have chosen the venue for the interview. The participant should be the principal caregiver living in the same household as the patient, or otherwise the person on whom the patient was completely dependent to meet her or his needs.

The participant/household might be 'rewarded' by the provision of prepared food or another item that saved labour (e.g. water, fuel) for the time the interview took in the carer's day. Arrangements had to be made by the interviewer for any necessary supervision of the patient at this time. If possible, the interview should be recorded for transcription and the transcript checked thoroughly for accuracy with the participant, who might also remember more things – and possibly more rights-based characteristics – after the interview so it would provide an opportunity to add material.

The data received from the fieldwork varied considerably with respect to the management of these particular processes.

A photo was good if possible, but not necessary. No photo needed to be provided if the carer chose anonymity. The patient should not be in attendance at the interview and did not have to know that it was even taking place. The focus of the interview was on the carer

Based on the literature review and reflecting a shift from an economic replacement value focus to the inclusion of a capability and strategic policy intervention approach, a semi-structured interview format was drafted, piloted, reviewed and finalised for distribution.

Interview format

The interviewer was to record as much as possible about the carer before the beginning of the interview:

Name:

Age:

Education:

Distance from hospital or clinic or health centre:

Distance from closest basic shop for supplies:

Number in household:

Access to transport:

Access to drinking water:

Type of fuel used for cooking:

The following questions were to be asked in the interview:

- What is the relationship between you (the carer) and the HIV patient?
- How long have you lived in the same household?
- How long have you been providing care?
- How many of you live here regularly or from time to time? (i.e., who else sometimes lives here?)
- Can you describe a typical day in your life before X became so sick? *This needs to take a lot of time. Go through it carefully. What did you do when you woke up – right through to when did you go to bed?*
- Did you feel you had any choice about becoming the primary caregiver?
- What are the nearest public health services?
- Does anyone come to visit to provide help?
- Does anyone ever come to give you some rest?
- Have you had any advice or training to help you with this work?
- How is your own health?

- Can you describe the hardest physical tasks you have as a carer.
- Are you able to get any free exercise time?
- Can you describe the toughest emotional tasks you have as a carer?
- Have you felt depressed or stressed?
- Can you describe the meals you prepare in a day?
- Are you able to do any work outside the home? E.g. – one at a time – gardening, cooking, petty marketing, paid employment, fetching firewood / water (in case it is applicable)? How has this affected the other adults and children who live in this household?
- What has happened to your finances or savings since you have been a full-time carer?
- Can you go to any community meetings or political meetings?
- Did you ever do any of that – or want to do that?
- Have you ever had a holiday? When was that? What did you do?

Analysis

In the original concept note the third phase of the research was to involve economic analyses, including producing costing estimates of the time expended by women and girls as well as opportunity costs for women and girls for expending labour in the HIV care economy. The costs would be compared to the expenditures, where available, on line items for care, support and treatment in national programming. However, the literature review and the decision taken to work with the capability approach, at the interface of economics and human rights, led to a different analytical framework.

The research team met together in a four-day workshop at the completion of the fieldwork. Each member had read all the fieldwork data. The team wrote the research introduction and one of the 'capability' chapters together, so that a pattern was established for the individual pieces of work that would follow.

The research was peer-reviewed by an expert with substantial experience in the field of gender, sexual and reproductive health and population studies, HIV programming and economic analyses of hidden phenomena.

The research report makes visible core dynamics of the role, costs and benefits of mostly women's and girls' involvement in the HIV care economy, but with interesting and diverse roles played by men. As the national response moves to a greater emphasis on community care and home-based care for both people living with HIV and orphans and other children affected by HIV, a cross-cultural gender analysis will greatly strengthen the ability of governments, citizens' groups and international partners to participate in cost effective rights-based care, prevention and treatment programmes in the Commonwealth. The study contributes significantly to economic and human rights policy implications for understanding unpaid 24/7 carers of people living with HIV and AIDS.

Note

1. With the exception of a panel supported by the Stephen Lewis Foundation.

At the heart of this wonderful volume are the voices of the carers of people living with HIV, the voices of so many women and girls, but there are also the voices of men: gay men, transsexuals, friends. And woven around their stories are the international instruments within which their rights can be located, the economic analysis of their plight, and the assertions that they too, like all of us, must have the freedom to make choices and the wherewithal, the agency, to live the lives that they have the capabilities to live. This is groundbreaking work. Too long overdue. May it lead to the needed changes, in policies and in the care we give to the carers.

Dr Elizabeth Reid, carer, development worker, feminist, and Visiting Fellow, Australian National University

At the centre of the HIV and AIDS response are the 12 million people who need care and treatment. Those who are ill require support from carers who provide physical, social and psychological support. Yet these carers – essential actors in the response – are often invisible to the system that relies on them.

The writers argue that focusing on the carer, at the household level, directs assistance where it is most effective and most needed, will respect human rights, and will help achieve the millennium development goals in health.

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