
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 Review² 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 report³ 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 health. 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.

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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.