INTER-AMERICAN COURT OF HUMAN RIGHTS

TGGL and Family v. Ecuador

Case No. 12.723

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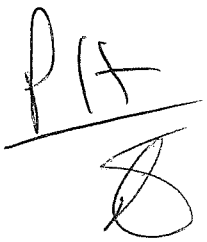

Introduction

1. Nominated by the Government of New Zealand, I served as a member of the United Nations Committee on Economic, Social and Cultural Rights (CESCR) between 1999-2002, and was appointed the Committee's Rapporteur. Between 2002-2008, I was the first United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and submitted some 30 reports to the United Nations General Assembly, Commission on Human Rights and Human Rights Council. Between 2011-2013, I advised Dr. Flavia Bustreo, Assistant Director-General of the World Health Organization (WHO), on human rights issues.

2. The Inter-American Court on Human Rights has invited me to submit testimony on: "the obligations that the American Convention of Human Rights, as interpreted in light of the applicable international standards, impose on the State with respect to persons who live with HIV. The expert will specifically refer to State obligations with respect to persons who were infected as a consequence of State actions or omissions. The expert will also refer to State obligations with respect to persons who live with HIV facing multiple situations of vulnerability."

3. A second expert is invited to provide testimony on "the scope and content of the obligations of supervision and control of private entities providing health services" and a third is invited to provide testimony "on the international standards that determine the State obligations regarding the health of children". Accordingly, for the most part, I will not specifically address these issues in this affidavit.

4. Sometimes I use the shorthand 'the right to health', or 'the right to the highest attainable standard of health', instead of the fuller formulation used in article 12, International Covenant on Economic, Social and Cultural Rights (ICESCR): 'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.[1]

5. In this affidavit I give particular attention to State obligations, with respect to persons living with HIV, arising from the international right to the highest attainable standard of health. However, I sometimes refer to other human rights. In keeping with my instructions, I focus on international standards; from time to time, I refer to illustrative regional and national case law.[2]

6. The Government of Ecuador helpfully provided me with some questions and I have answered them to the best of my ability in appropriate places in the affidavit.

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[1] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (ICESCR).

[2] While preparing this affidavit, I have greatly benefited from the advice and industry of many colleagues. I am grateful to them all. I would especially like to record my debt of gratitude to Luisa Cabal, Emeline Dupuis, Patrick Eba, Richard Elliott, Lisa Forman, Nancy Carmina Garcia Fregoso, Anand Grover, Giulia Giannuzzi, Diana Guarnizo, Sheldon Leader, Joo-Young Lee, Gen Sander, Clara Sandoval, Nina Sun, Giulia Virdis and Jane Wright. However, this document reflects my understanding of international human rights law: it does not necessarily reflect theirs.

Some preliminary remarks about the international right to the highest attainable standard of health

7. In the context of those living with HIV, this affidavit considers the international right to the highest attainable standard of health. It briefly outlines some of the international and regional sources, and then sketches the contours and content, of this fundamental human right. The affidavit suggests that the international right to health can be understood as a right to an equitable, responsive, integrated and effective health system for all. Drawing on work undertaken by many in recent years, the affidavit introduces a 'right-to-health analytical framework', which provides an elementary map for those wishing to navigate the right to health. Because of the issues raised by the present case, the affidavit looks more closely at two dimensions of the right to health: discrimination on the grounds of HIV-status, and access to medicines, including antiretroviral therapies. Drawing from the concurring opinion delivered by Judge Ferrer MacGregor Poisot in *Suárez Peralta v Ecuador*, I also consider the place of the right to the highest attainable standard of health within the American Convention on Human Rights.[3]

8. Twin global right-to-health challenges are to clarify, with a reasonable degree of particularity, the scope of States' obligations and how those obligations can be operationalised in practice. What, precisely, does the right to health oblige a State to do and refrain from doing? It is difficult to answer that question when looking at the right to health in its entirety because the terrain is extensive and complex. It is more manageable to consider what a State has to do, and not do, in relation to one part of the right to health: a degree of specificity assists. For example, the UN Human Rights Council has adopted guidelines on maternal mortality and morbidity (2012)[4] and mortality and morbidity of children under-5 years of age (2014),[5] while WHO has published human rights guidance on contraceptive information and services (2013).[6] The forerunner, however, was the OHCHR/UNAIDS *International Guidelines on HIV/AIDS and Human Rights* (1996 and 2006).[7] Thus, the affidavit introduces these *Guidelines* because, with their specificity, they help to clarify what a State is obliged to do, and refrain from doing, for those living with HIV. In other words, the *Guidelines* help to apply article 12 of ICESCR, in tandem with other human rights, to those living with HIV.

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[3] Concurring Opinion of Judge Ferrer MacGregor Poisot, IACtHR, *Case of Suárez Peralta v. Ecuador Preliminary objections merits, reparations and costs.* Judgment 21 May 2013 Series C No. 261.

[4] UNHRC, Twentieth session, 'Technical guidance on the application of a human rights- based approach to the implementation of policies and programmes to reduce preventable maternal morbidity and mortality' (2 July 2012) A/HRC/21/22.

[5] UNHRC, Twenty-seventh session, 'Technical guidance on the application of a human rights-based approach to the implementation of policies and programmes to reduce and eliminate preventable mortality and morbidity of children under 5 years of age' (30 June 2014) A/HRC/27/31.

[6] WHO, 'Ensuring human rights in the provision of contraceptive information and services: guidance and recommendations' (Geneva 2013).

[7] Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), 'International Guidelines on HIV/AIDS and Human Rights (consolidated version 2006)' (Geneva 2006).

9. In brief, recognition – and our understanding – of the right to the highest attainable standard of health has been transformed in the last two decades thanks to the work of countless individuals, organisations and bodies, including States, inter-governmental organisations, judges, human rights bodies, health professionals, scholars, civil society and committed members of the public. All the implications of this profound transformation will take time to emerge. Those working on human rights and HIV/AIDS have played a key role in this promising – and challenging – process.

Summary of some key points in the affidavit

What are the obligations imposed on a State "with respect to persons who live with HIV"?

10. Persons living with HIV:

- are entitled to all the human rights to which everyone is entitled;
- without discrimination across the full spectrum of human rights;
- arising from these human rights, persons living with HIV are entitled to prevention, care, treatment and support;
- in relation to this prevention, care, treatment and support, some of the key entitlements and corresponding obligations are elaborated upon in the OHCHR/UNAIDS *International Guidelines on HIV/AIDS and Human Rights* (consolidated version 2006) (hereinafter *International Guidelines*), especially Guideline 6 and its commentary in paragraph 26.[8]

What are the obligations imposed on a State "with respect to persons who were infected as a consequence of State actions or omissions"?

11. A State has a human rights obligation at least to provide those living with HIV with a level of prevention, treatment, care and support consistent with the country's resource capacity. For short, I will call this level-A care (although it encompasses prevention, treatment, care and support). However, if a person is HIV-positive as a direct consequence of the State's acts or omissions, it would be unjust if the State's obligation was limited to providing them with level-A care. Instead, the State has an obligation to return them, so far as possible, to their *status quo ante* and this includes the provision of prevention, treatment, care and support which is not limited by considerations of the country's resource capacity. They should be provided with level-A-*plus* care, equivalent to the highest level of prevention, treatment, care and support available to anyone using the country's public or private health-related services. This is discussed later in the affidavit.

The right to health and the American Convention on Human Rights

12. I agree with Judge Ferrer that the right to the highest attainable standard of health is directly justiciable under the American Convention on Human Rights. If the Court were to adopt this interpretation of the Convention, it would have at its disposal for its consideration the extensive

[8] Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), 'International Guidelines on HIV/AIDS and Human Rights (consolidated version 2006)' (Geneva 2006).

and deepening jurisprudence on the right to health. This affidavit endeavours to introduce some of these jurisprudential insights in the specific context of those living with HIV.

Persons living with HIV are entitled to all the human rights to which everyone is entitled

13. The *International Guidelines on HIV/AIDS and Human Rights*, which I discuss later in this affidavit, includes a chapter summarising the international human rights obligations in relation to HIV.[9] The chapter observes that the human rights relevant to HIV/AIDS include:

    - The right to non-discrimination, equal protection and equality before the law;
    - The right to life;
    - The right to the highest attainable standard of physical and mental health
    - The right to liberty and security of person;
    - The right to freedom of movement;
    - The right to seek and enjoy asylum;
    - The right to privacy;
    - The right to freedom of opinion and expression and the right to freely receive and impart information;
    - The right to freedom of association;
    - The right to work;
    - The right to marry and to found a family;
    - The right to equal access to education;
    - The right to an adequate standard of living;
    - The right to social security, assistance and welfare;
    - The right to share in scientific advancement and its benefits;
    - The right to participate in public and cultural life;
    - The right to be free from torture and cruel, inhuman or degrading treatment or punishment.

    The *International Guidelines* close this list with: "Particular attention should be paid to human rights of children and women."[10]

    The authority for this proposition – that persons living with HIV are entitled to all the human rights to which everyone is entitled – is the entire corpus of international human rights law which is constructed on the foundational principles signalled in the opening preambular paragraph of the Universal Declaration of Human Rights (UDHR): "*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".[11]

14. International human rights law – and its foundational principles of dignity, equality, the inalienability of rights, freedom, justice and peace, as identified in UDHR – apply to all human beings. This law and these principles are especially important and meaningful to vulnerable and

[9] International Guidelines on HIV/AIDS and Human Rights, 77.

[10] International Guidelines on HIV/AIDS and Human Rights, 81.

[11] Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Res 217 A(III) (UDHR).

disadvantaged "members of the human family". Over many years, international human rights law has developed precisely to protect and empower vulnerable and disadvantaged individuals and communities, *such as those living with HIV*. This is an emblematic example of the historic mission of international human rights law and its institutions.

The right to health: some international sources

15. Adopted in 1946, the Constitution of WHO states: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."[12] Two years later, article 25(1) UDHR laid the foundations for the international legal framework for the right to health.[13] Since then, the right to health has been codified in numerous legally binding international and regional human rights treaties. The following provides a brief overview of selected legal sources of the right to health.

16. Article 12 of ICESCR provides the cornerstone protection of the right to health in international law: the Covenant introduces legally binding provisions that apply to all individuals in the 163 ratifying States.[14] Additional right-to-health protections for marginalized groups are contained in group-specific international treaties. Article 5(e)(iv) of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) provides protections for racial and ethnic groups in relation to "the right to public health (and) medical care".[15] The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) provides several provisions for the protection of women's right to health, in particular articles 11(1)f, 12 and 14(2)b. The Convention on the Rights of the Child (CRC) contains extensive and elaborate provisions on the child's right to health, including article 24, which is fully dedicated to the right to the health of the child, and articles 3(3), 17, 23, 25, 32 and 28, which contain protections for especially vulnerable groups of children. The "guiding principles" of CRC, contained in articles 2, 3, 6 and 12, guide implementation of all Convention rights. Entering into force in 2008, the Convention on the Rights of Persons with Disabilities (CRPD) includes several provisions bearing closely upon the right to health. Of particular importance is the lengthy article 25 which begins: "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."[16] Further standards relating to specific groups are set out in other instruments, such as the Principles for the Protection of Persons with Mental Illness and the

[12] Constitution of the World Health Organization (adopted 22 July 1946, entered into force 7 April 1948) 14 UNTS 185, preamble.

[13] UDHR art 25(1).

[14] At 13th February, 2015.

[15] International Convention on the Elimination of All Forms of Racial Discrimination (adopted 7 March 1966, entered into force 4 January 1969) 660 UNTS 195 (ICERD).

[16] Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force 3 May 2008) 2515 UNTS 3 (CRPD).

Improvement of Mental Healthcare and the Declaration on the Elimination of Violence against Women.[17]

17. The Commission on Human Rights, and its successor the Human Rights Council, have adopted resolutions reaffirming the importance of the right to health. The year 2002 was a turning point with Commission resolutions on access to medicines (2002/32), disabilities (2002/61) and establishing a UN 'special procedure' on the right to health (2002/31). The outcome documents of United Nations world conferences, such as the Declaration of Commitment on HIV/AIDS, adopted by the General Assembly in 2001,[18] and the Political Declaration on HIV/AIDS of 2006,[19] include right-to-health commitments. In the course of this affidavit, I refer to some of these Commission and Council resolutions, as well as world conference outcome documents.[20]

The right to health: some regional sources

18. This section provides some brief introductory remarks about health-rights in regional human rights systems. A later section makes some additional comments about the right to the highest attainable standard of health in the Inter-American system of human rights.

19. In addition to international standards, the right to health (or a similar formulation) is explicitly recognized in regional human rights treaties and instruments, including the American Declaration on the Rights and Duties of Man; the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (art. 10)[21]; the European Social Charter (art. 11)[22]; the African Charter on Human and Peoples' Rights (art. 16)[23]; and the African Charter on the Rights and Welfare of the Child (art.14).[24] In this context, I discuss the American Convention on Human Rights below (paragraphs 83-91).

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[17] For an additional list of group-specific international standards on the right to health, see E/CN.4/2003/58, Annex I.

[18] Declaration of Commitment on HIV/AIDS, UNGA Res S-26/2 (2 Aug 2001) UN Doc A/RES/S-26/2.

[19] Political Declaration on HIV/AIDS, UNGA Res 60/626 (15 June 2006) UN Doc A/RES/60/626.

[20] For additional information see e.g. see E/CN.4/2003/58, Annexes I and II.

[21] Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) (entered into force 16 November 1999) OAS Treaty Series No 69 (1988) reprinted in Basic Documents Pertaining to Human Rights in the Inter-American System OEA/Ser L V/II.82 Doc 6 Rev 1 at 67 (1992).

[22] European Social Charter (adopted 18 October 1961, entered into force 26 February 1965, revised 1996) ETS 163.

[23] African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 (African Charter).

[24] African Charter on the Rights and Welfare of the Child (entered into force 29 November 1999) OAU Doc. CAB/LEG/24.9/49 (1990).

20. Other regional instruments, which do not explicitly recognize the right to health but which offer indirect protections through other health-related rights, include the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women, and the European Convention for the Protection of Human Rights and Fundamental Freedoms and its protocols.

21. Regional human rights mechanisms adjudicate cases on the right to health. A notable case in 2002 was the finding by the African Commission on Human and Peoples' Rights of a violation of the right to enjoy the best attainable standard of physical and mental health by the Federal Republic of Nigeria, on account of violations against the Ogoni people in relation to the activities of oil companies in the Niger Delta.[25] In *Defence for Children International v Belgium*, the European Social Rights Committee considered the situation of a number of migrant and asylum-seeking children and held Belgium was in breach of "the right to protection of health" in article 11(1) and (3) of the European Social Charter.[26]

22. In other cases, regional mechanisms have found breaches of other health-related rights. For example, in *López Ostra v. Spain*, the European Court of Human Rights found that environmental harm to human health may amount to a violation of the right to a home and family and private life.[27]

23. In its admissibility decision in *Jorge Odir Miranda Cortez et al. v. El Salvador*, the Inter-American Commission on Human Rights held that while it was not competent to determine violations of article 10 (the right to health) of the Protocol of San Salvador, it would "take into account the provisions related to the right to health in its analysis of the merits of the case, pursuant to the provisions of articles 26 and 29 of the American Convention".[28] Later in this affidavit I return to the Inter-American human rights system.

The contours and content of the international right to health

24. The international right to health is not a right to be healthy. It is a right to facilities, goods, services and conditions that are conducive to the realization of the highest attainable standard of physical and mental health. The right encompasses timely and appropriate medical care, as well as underlying determinants of health, such as healthy occupational and environmental conditions, and access to health-related education and information.[29]

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[25] Social and Economic Rights Action Center & the Center for Economic and Social Rights v. Nigeria Communication No. 155/96 (African Commission on Human and Peoples' Rights, 27 May 2002).

[26] European Committee of Social Rights, *Defence for Children International v Belgium*, Complaint No 69-2011, 23 October 2012

[27] ECtHR, *López Ostra v. Spain*, 9 December 1994, Series A no. 303-C.

[28] IACHR, *Jorge Odir Miranda Cortez et al. v. El Salvador*, admissibility decision, Report no 29/01, Case 12.249, 7 March 2001, para 47.

[29] UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health' (11 August 2000) UN Doc E/C.12/2000/4, para 8.

25. The right to health can also be conceptualised as a right to an effective and integrated health system, encompassing healthcare and the underlying determinants of health, responsive to national and local priorities, and accessible to all.

26. As with a fair court system, an effective health system is a core social institution.[30] Although many human rights are important to a well-functioning court system, a key is the right to a fair trial. Through human rights treaties, national laws and policies, judicial decisions, and so on, the right to a fair trial has helped to identify the key features of a fair court system, such as an independent judiciary and trials without undue delay. The right to a fair trial has not only identified unfair judicial processes but also led to welcome reforms in many countries.

27. By analogy, the right to the highest attainable standard of health can help to establish health systems that are equitable. To make this happen, the right-to-health features of health systems need to be identified. Once identified, these features will not provide a neat blueprint or formula for a health system. There will be grey areas, just as there are in relation to the right to a fair trial and court systems. The right to a fair trial insists upon key principles, such as fairness, independence and impartiality, and several important features that a court system must have if it is to be fair. The right to health has a similar role in relation to the development of an equitable, responsive, integrated and effective health system for all.

28. At the heart of this understanding of the right to health (i.e. a right to a health system with certain features) is a package of health services, facilities, and goods, extending to healthcare and the underlying determinants of health, such as access to evidence-based health-related information. This package must be available, accessible, and of good quality. Also, it must be sensitive to different cultures. While this package will have many features that are common to all countries, there will also be differences between one country and another, reflective of different disease burdens, cultural contexts, resource availability, and so on.

29. The right to health can also be broken down into more specific entitlements, such as the rights to: maternal, child, and reproductive health; healthy workplace and natural environments; access to safe and potable water; and prevention, treatment, care and support for those living with HIV.

30. The remainder of this affidavit is designed to address one of these more specific entitlements: the right to prevention, treatment, care and support for those living with HIV.

The right-to-health analytical framework[31]

31. In recent years, CESCR, Pan American Health Organization (PAHO), civil society organizations, academics and many others, have developed a way of 'unpacking' or analysing the right to health. The analytical framework that has been developed is made up of a number

[30] Lynn Freedman, 'Achieving the MDGs: Health Systems as core social institutions' (2005) 48 Development 19.

[31] Grounded in article 12, ICESCR, and CESCR's General Comment No. 14, this framework is set out in numerous places, for example, Paul Hunt and Sheldon Leader, "Developing and applying the right to the highest attainable standard of health: the role of the UN Special Rapporteur (2002-2008), in John Harrington and Maria Stuttaford (eds), *Global Health and Human Rights: Legal and Philosophical Perspectives*, Routledge, 2010. This sub-section draws from this publication.

of key elements with general application to all aspects of the right to health, including the right to prevention, treatment, care and support for people living with HIV. Here is a summary of some of the key elements of the right-to-health analytical framework:

♦ *Freedoms and entitlements*
The right to health includes both freedoms (e.g. the freedom from discrimination or non-consensual medical treatment and experimentation) and entitlements (e.g. the provision of essential primary health care). For the most part, freedoms do not have budgetary implications, while entitlements do.

♦ *Available, accessible, acceptable and good quality*
All health services, goods, and facilities should comply with each of these four requirements. For example, an essential medicine, such as an antiretroviral therapy, should be *available* within the country. Additionally, the medicine should be *accessible*. Accessibility has four dimensions: accessible without discrimination, physically accessible, economically accessible (i.e. affordable), and accessible health-related information. As well as being available and accessible, health services should be provided in a culturally *acceptable* manner. This requires, for example, effective coordination and referral with traditional health systems. Lastly, all health services, goods, and services should be of *good quality*; a medicine, for example, must not be beyond its expiry date.

♦ *Respect, protect, fulfil*
This subsidiary framework relates to the tripartite obligations of States to respect, protect, and fulfil the right to the highest attainable standard of health, as explained and used by CESCR, the Committee on the Elimination of Discrimination Against Women (CEDAW) and others. A version of this subsidiary framework is also enshrined in the Constitution of South Africa.

For example, the obligation to *respect* places a duty on States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to *protect* means that States must prevent third parties from interfering with the enjoyment of the right to health. The obligation to *fulfil* requires States to adopt necessary measures, including legislative, administrative and budgetary measures, to ensure the full realization of human rights, including the right to the highest attainable standard of health.

♦ *Non-discrimination, equality and vulnerability*
Because of their crucial importance, the analytical framework demands that special attention be given to issues of non-discrimination, equality and vulnerability in relation to all elements of the right to the highest attainable standard of health. Discrimination on the ground of HIV-positive status is discussed further below.

♦ *Resource constraints and progressive realization*
International human rights law recognizes that the realization of the right to health is subject to resource availability. Thus, what is required of a high-income State today is of a higher standard than what is required of a low-income State today. However, a

State is obliged—whatever its resource constraints and level of economic development—to realize progressively the right to the highest attainable standard of health.[32] In essence, this means that a State is required to be doing better in two or three years time than it is doing today; if it is not, the State has the burden of justifying the lack of progress. In order to measure progress (or the lack of it) over time, indicators and benchmarks are needed.

♦ *Core obligations of immediate effect*

Despite resource constraints and progressive realization, the right to health also gives rise to some core obligations of immediate effect, such as the duty to avoid discrimination.[33] These are obligations without which the right would be deprived of its *raison d'être* and as such they are not subject to progressive realization, even in the presence of resource constraints.[34] Core obligations are discussed further below in the specific context of access to essential medicines, such as antiretroviral therapies.

♦ *Active and informed participation*

Participation is grounded in internationally recognized human rights, such as the rights to participate in the formulation and implementation of government policy (CEDAW, Article 7(b)), to take part in the conduct of public affairs (ICCPR, Article 25(a)),[35] and to freedom of expression and association (ICCPR, Articles 19 and 22). The right to health requires that there be an opportunity for individuals and groups to participate actively and in an informed manner in health decision-making that affects them.[36]

♦ *Monitoring and accountability*

The international right to health introduces globally legitimized norms or standards from which obligations arise. These obligations have to be monitored and those responsible held accountable. Without effective monitoring and accountability, the norms and obligations are likely to become empty promises. In some health sectors, the *same* body is responsible for delivering and regulating health-related services, as well as holding accountable those responsible. From the right to health perspective, this is deeply problematic. In some health sectors, it is not understood that accountability mechanisms provide rights-holders (e.g. individuals and groups) with an opportunity to understand how duty-bearers have discharged their obligations, and it also provides duty-bearers (e.g. ministers and officials) with an opportunity to explain their conduct.

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[32] ICESCR art 2(1).

[33] UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health' (11 August 2000) UN Doc E/C.12/2000/4, para 43.

[34] UN Committee on Economic, Social and Cultural Rights, 'General comment No. 3: The nature of States parties' obligations' (1 January 1991) UN Doc E/1991/23, para 10.

[35] International Covenant on Civil and Political Rights (adopted 16 Decemebr 1966, entered into force 23 March 1976) 999 U.NTS 171 (ICCPR).

[36] UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health' (11 August 2000) UN Doc E/C.12/2000/4, para 54.

> In this way, accountability mechanisms help to identify when—and what—policy or other adjustments are necessary. Accountability tends to encourage the most effective use of limited resources, as well as a shared responsibility among all parties. Transparent, effective, accessible and independent accountability mechanisms are among the most crucial – and elusive – characteristics of the right to the highest attainable standard of health.[37]

32. These key elements of the right-to-health analytical framework signal the contribution of the right to health to health-justice. For example, the pre-occupation with non-discrimination, equality and vulnerability requires a State to take effective measures to address the health inequities that characterize some populations, such as those living with HIV. The focus on active and informed participation requires a State to adopt, so far as possible, a 'bottom-up' participatory approach in health-related sectors. The requirement of monitoring and accountability can help to ensure that health policies, programmes and practices are effective, meaningful to those living in poverty, and free from waste and corruption.

33. The next two sections look more closely at two elements of the right-to-health framework that have particular relevance to those living with HIV: discrimination and access to medicines.

Discrimination and HIV-status

Irrational fear and multiple adverse impacts

34. In *Judging the epidemic: A judicial handbook on HIV, human rights and the law*, Edwin Cameron, Justice of the Constitutional Court of South Africa, observes:

> HIV is a fragile virus. It is extremely difficult to transmit. It is non-contagious. It can be transmitted only through a significant injection of virally active material; this can occur only through sexual intercourse, blood transfusion or shared syringes. In addition, a young infant may get HIV from a mother during birth or breast-feeding. But these circumstances rarely occur during the casual engagements of everyday life.
>
> So, irrational fear about contamination with HIV is entirely unjustified. What is more, AIDS is now a fully medically manageable condition. When I was desperately sick with AIDS in 1997, I thought I would certainly die. I thought I would die soon. But I did not die. My life and energies and vitality were restored to me. And I have been living a full, vigorous and joyful life for 15 years because of successful ARV treatment.[38]

35. Chapter 4 of *Judging the epidemic* is devoted to discrimination on the basis of actual or presumed HIV-positive status, and it begins:

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[37] Paul Hunt and Tony Gray (eds), *Maternal mortality, human rights and accountability*, Routledge, 2013.

[38] UNAIDS, 'Judging the epidemic: A judicial handbook on HIV, human rights and the law' (Geneva 2013), xv.

> People living with or presumed to be living with HIV experience stigma, exclusion, abandonment and even physical violence. They are excluded from access to housing, employment, health-care services, immigration and education (among other things).
>
> HIV-related stigma affects all people living with HIV in some fashion, but the experience and impact is not homogeneous. People who belong to groups that are already marginalised tend to experience the most severe forms of stigma, and they also are most likely to experience discrimination when diagnosed with HIV. [...]
>
> Redressing HIV-related discrimination promotes equal access of people living with HIV to opportunities and services, and it reduces barriers to HIV prevention, testing and treatment[39]

36. In *Jorge Odir Miranda Cortez et al v El Salvador*, the Inter-American Commission on Human Rights emphasised that the persistent stigma and discrimination suffered by people living with HIV has multiple adverse impacts:

> Generally speaking, it should be mentioned that persons living with HIV/AIDS very often suffer discrimination in a variety of forms. This circumstance magnifies the negative impact of the disease on their lives and leads to other problems, such as restrictions on access to employment, housing, healthcare, and social support systems. There can be no doubt that the principle of non-discrimination must be very strictly observed to ensure the human rights of persons affected by HIV/AIDS. Public health considerations must also be taken into account since the stigmatization of, or discrimination against, a person who carries the virus can lead to reluctance to go for medical controls, which creates difficulties for preventing infection.[40]

37. The Commission's words highlight the public health impact of stigmatization and discrimination, a theme that is addressed in the UNAIDS *Protocol for the identification of discrimination against people living with HIV*. The Protocol explains that discrimination against people living with HIV, or suspected of it, can have "three devastating public health consequences:

    1. Arbitrary discrimination tends to instil fear and intolerance. It creates a climate that interferes with effective prevention by discouraging individuals from coming forward for testing and from seeking information on how to protect themselves and others, thus deepening the adverse impact of living with HIV. Since the effectiveness of a prevention policy depends on reaching those who are at risk and encouraging them to adopt safe behaviour, it is essential to combat the discrimination that drives people away from these types of programmes.

    2. Arbitrary discrimination may engender a dangerous complacency in individuals and groups who are not targeted, and who therefore assume that they are not at risk. For

[39] UNAIDS, 'Judging the epidemic: A judicial handbook on HIV, human rights and the law' (Geneva 2013), 23.

[40] IACHR, *Jorge Odir Miranda Cortez et al. v. El Salvador*, Report No. 29/01, Case 12.249 (2001), para 70.

example, if a State treats HIV and AIDS as a problem related to foreigners visiting or residing in the country, it may increase the vulnerability of its own citizens.

3. Arbitrary discrimination against people living with HIV, or suspected of it, tends to exacerbate existing forms of marginalisation, such as racism, gender-based discrimination, homelessness, and discrimination against children. It deepens the already-increased vulnerability of marginalised groups to HIV infection, and obstructs their ability to deal with the impact of their own infection and/or infection in their family or associates."[41]

International human rights law, discrimination and HIV-status[42]

38. Major international human rights treaties have been interpreted to include HIV as a ground on which discrimination is prohibited. For example, ICESCR prohibits discrimination on various grounds, including "other status", and CESCR has confirmed that "health status (including HIV/AIDS)" is a prohibited ground of discrimination.[43] The Committee on the Rights of the Child has come to the same conclusion in relation to article 2 of the Convention on the Rights of the Child.[44] As UN Special Rapporteur on the right to health I adopted this position, without contradiction. [45] My successor, Anand Grover, wrote: "The right to health seeks, *inter alia*, to ensure access to quality health facilities, goods and services without discrimination, including on the grounds of physical or mental disability, or health status."[46] The *International Guidelines on HIV/AIDS and Human Rights* highlight that "States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV and people with disabilities from discrimination in both the public and private sectors".[47]

39. In 2001, the UN General Assembly adopted the Declaration of Commitment on HIV/AIDS, in which states committed to enacting, strengthening and enforcing legislation, regulations and other measures to eliminate all forms of discrimination against people living with HIV/AIDS

[41] UNAIDS, 'Protocol for the identification of discrimination against people living with HIV' (Geneva 2000), 6.

[42] Richard Elliott, Leah Utyasheva and Elisse Zack, 'HIV, disability and discrimination: making the links in international and domestic human rights law', [2009] Journal of the International AIDS Society, 12.

[43] UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health' (11 August 2000) UN Doc E/C.12/2000/4, para 18.

[44] UN Committee on the Right of the Child, 'General comment No. 3: HIV/AIDS and the right of the child' (17 March 2003) UN Doc CRC/GC/2003/3, para 9.

[45] UNCHR 'Report of the Special Rapporteur on The right of everyone to the enjoyment of the highest attainable standard of physical and mental health' (2003) UN Doc E/CN.4/2003/58 15, paras 64-75.

[46] UNGA, 'Report of the Special Rapporteur on The right of everyone to the enjoyment of the highest attainable standard of physical and mental health' (2010) UN Doc A/65/255, para 8.

[47] International Guidelines on HIV/AIDS and Human Rights, Guideline 5.

and members of vulnerable groups.[48] In 2006, they reaffirmed this commitment in the Political Declaration on HIV/AIDS.[49]

Four illustrative cases

40. There are numerous cases in which courts have held that differential treatment on the grounds of HIV-status is discriminatory. Some of these cases are set out in *Courting rights: Case studies in litigating the human rights of people living with HIV*[50] and *Judging the epidemic: A judicial handbook on HIV, human rights and the law.*[51] Here I refer to four illustrative examples.

41. In *Hoffmann v South Africa Airways*, the Constitutional Court of South Africa held that the blanket exclusion of people living with HIV from employment infringes the constitutional guarantee of equality.[52]

42. In *XX v Ministry of National Defence*, the plaintiff challenged the legality of a Colombian cadet school's decision to expel him following a HIV-positive test result, alleging that his rights to equality, life, work, privacy, health and freedom to choose his profession or occupation had been violated.[53] The Colombian Constitutional Court held that different and prejudicial treatment of those living with HIV was discriminatory and in breach of the Constitution. The Court cited a previous case in which it held: "[I]t is necessary to remember that the person ill with AIDS or the person who is HIV-positive is a human being and, as such enjoys, in accordance with Article 2 of the Universal Declaration of Human Rights, all the rights proclaimed in the international human rights instruments, without the possibility of being the object of discrimination, nor of arbitrary decisions, by reason of their status. It would be illogical for a person who has an illness to be treated in a manner harmful for their physical, moral or personal integrity."[54]

43. The Supreme Court of Mexico held that dismissal from the armed forces for being HIV-positive was unlawful because it violated the constitutional principle of non-discrimination on the ground of health-status.[55]

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[48] Declaration of Commitment on HIV/AIDS, UNGA Res S-26/2 (2 Aug 2001) UN Doc A/RES/S-26/2.

[49] Political Declaration on HIV/AIDS, UNGA Res 60/626 (15 June 2006) UN Doc A/RES/60/626.

[50] UNAIDS, 'Courting Rights: Case Studies in Litigating the Human Rights of People Living with HIV' (Geneva 2006).

[51] UNAIDS, 'Judging the epidemic: A judicial handbook on HIV, human rights and the law' (Geneva 2013).

[52] *Hoffmann v. South African Airways,* Constitutional Court of South Africa, Case CCT 17/00 (2000).

[53] *XX v Ministry of Defence* ("General Jose Maria Cordova" Cadet School), Constitutional Court of Colombia, Judgement No.T-707205, Third Appeal Bench of the Constitutional Court (2003).

[54] *XX v. Gun Club Corporation et al.*, Constitutional Court of Colombia, Decision SU-256 (1996).

[55] Ruling of the Supreme Court of Mexico in plenary 131/2007, entitled: "Social security for the Mexican Armed Forces. Article 226, second category, fraction 45 of the law of the related Institute that foresees the legal causes of retirement on the grounds of incapacity for work of HIV-positive persons, violates Article 1 of the Federal

44. In *Kiyutin v Russia*, the European Court of Human Rights held that the refusal to grant a residence permit because of HIV-status is a breach of article 14 (non-discrimination) taken together with article 8 (respect for private and family life) of the European Convention on Human Rights. The Court acknowledged that people living with HIV have suffered a history of stigma and discrimination.[56]

Access to medicines

Medicines as part of the international right to health

45. There is overwhelming authority for the proposition that access to medicines, including antiretrovirals, is an integral element of the international right to the highest attainable standard of health.

46. Under article 12(1) ICESCR, "States Parties recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". Article 12(2) identifies "steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right". These steps "shall include those necessary for ... (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness." An ordinary interpretation of these provisions places access to medicines within article 12(2)(c) and (d), as confirmed by CESCR in General Comment 14 on article 12. According to paragraph 43 of General Comment 14, the right to the highest attainable standard of health gives rise to some "core obligations", including to "provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs".[57] Shortly I will return to the concept of "core obligations" but, in any event, paragraph 43 confirms that access to medicines falls within the States Parties' obligations arising from article 12.

47. This was the position I took when serving as UN Special Rapporteur on the right to health. In 2006, for example, I presented a report to the UN General Assembly which examined States' obligations in relation to medicines. The analysis was based on the proposition that "access to medicines forms an indispensable part of the right to the highest attainable standard of health."[58] Throughout my term as UN Special Rapporteur, I cannot recall any State, or other actor, objecting to this interpretation of article 12. Anand Grover, UN Special Rapporteur from 2008-2014, also took this position. In 2013, for example, he presented a report to the UN

Constitution." (Semanario Judicial de la Federación y su Gaceta, Ninth period, Volume XXVI, December 2007, p. 12). Amparo under review 307/2007. Rapporteur: Justice Juan N. Silva Meza. Secretary: Manuel Gonzalez Diaz.

[56] ECtHR, *Kiyutin v. Russia*, no. 2700/10, 10 March 2011, paras 59-74.

[57] UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health' (11 August 2000) UN Doc E/C.12/2000/4 para 43(d).

[58] UNGA 'Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt' (13 September 2006) UN Doc A/61/338 para 40.

Human Rights Council on access to medicines in which he begins: "Access to medicines is an integral component of the right to health".[59]

48. Numerous resolutions of the UN Human Rights Council (and the Commission on Human Rights) also confirm that "access to medicines is one of the fundamental elements in achieving progressively the full realization of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[60] There are also numerous resolutions of the Council (and Commission) recognising that "access to medication in the context of pandemics such as HIV/AIDS is one fundamental element for achieving progressively the full realization of the right of everyone to the highest attainable standard of physical and mental health."[61]

49. Further, there are many cases in numerous jurisdictions confirming that access to medicines is a fundamental element of the right to health. These are discussed, for example, by Alicia Yamin in her seminal article "Not just a tragedy: Access to medications as a right under international law",[62] the *Lancet* article "Is access to essential medicines as part of the fulfilment of the right to health enforceable through the courts" by Hans Hogerzeil and others,[63] and more recently by Noah Novogrodsky in 'The Duty of treatment: Human rights and the HIV/AIDS pandemic".[64] Published in 2006, the article by Hogerzeil and others concludes: "In 59 cases, access to essential medicines as part of the fulfilment of the right to health could indeed be enforced through the courts, with most coming from Central and Latin America."[65] Today, the number of cases is very much higher.

Essential medicines as a core obligation

50. Article 2(1) governs the obligations of States Parties to ICESCR. Thus, a State Party "undertakes to take steps [...] to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognized in the present Covenant by

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[59] UNHRC 'Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover, on access to medicines' (1 May 2013) UN Doc A/HRC/23/42 para 3.

[60] UNHRC 'Access to medicines in the context of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health' (11 June 2013) UN Doc A/HRC/23/L.10/Rev.1 para 2.

[61] For example, UN Commission on Human Rights, 'Access to medication in the context of pandemics such as HIV/AIDS, tuberculosis and malaria', Resolutions 2001/33, 2002/32, 2004/26 and 2005/23.

[62] Alicia Yamin, 'Not Just a Tragedy: Access to Medications as a Right under International Law' (2003) 21 Boston University International Law Journal 325.

[63] Hans Hogerzeil and others, 'Is access to essential medicines as part of the fulfilment of the right to health enforceable through the courts?' (2006) 368 (9532) Lancet 305.

[64] Noah Novogrodsky, 'The Duty of Treatment: Human Rights and the HIV/AIDS Pandemic' (2009) 12 (1) Yale Human Rights and Development Journal 1.

[65] Hans Hogerzeil and others, 'Is access to essential medicines as part of the fulfilment of the right to health enforceable through the courts?' (2006) 368 (9532) Lancet 305, at 305.

all appropriate means [...]." In 1990, CESCR adopted General Comment 3 on the meaning of article 2(1). General Comment 3 includes this passage:

> On the basis of the extensive experience gained by the Committee, as well as by the body that preceded it, over a period of more than a decade of examining States parties' reports, the Committee is of the view that a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, prima facie, failing to discharge its obligations under the Covenant. If the Covenant were to be read in such a way as not to establish such a minimum core obligation, it would be largely deprived of its *raison d'être*.[66]

51. In 2000, General Comment 14 elaborated upon the minimum core obligations arising from article 12. According to paragraph 43 of this General Comment, "in the Committee's view, these core obligations include at least the following", as then set out in paragraph 43(a)-(f). I will quote the two core obligations of particular relevance to the present case:

> Paragraph 43(a): "To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups;"
>
> Paragraph 43(d): "To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs".

52. Antiretrovirals were added to the WHO Model List of Essential Medicines in 2002 and updated in the WHO List of 2013.[67] Ecuador published its updated National List in 2013[68] and there appear to be two antiretrovirals in the WHO List of 2013 that are not in the Ecuador List of the same year.[69] This appears to be inconsistent with article 12 as interpreted in paragraph 43(d), General Comment 14.

53. The concept of core obligations, as well as its application in practice, remains work in progress. In the present case, I do not think it is necessary to explore in detail either the concept or its practical application. Instead, I confine myself to four points.[70]

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[66] UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 3: The Nature of States Parties' Obligations' (14 December 1990) UN Doc E/1991/23 para 10.

[67] WHO Model List of Essential Medicines (18th List, April 2013), see 6.4.2.

[68] *National List of Basic Medicines*, 9th revision, National Commission of Medicines and Supplies, Republic of Ecuador, 2013.

[69] The missing antiretrovirals are stavudine and lamivudine+nevirapine+stavudine.

[70] For a discussion of access to essential medicines as a core obligation, see Joo-Young Lee, *A human rights framework for intellectual property, innovation and access to medicines,* Ashgate, 2015 (forthcoming).

54. First, CESCR identified and articulated the concept of core obligations in 1990 because, without this idea, the Covenant "would be largely deprived of its raison d'être". In other words, core obligations were embedded in the Covenant since its adoption by the UN General Assembly in 1966. CESCR was established in 1985. In 1990, the Committee began to explore the core obligations concept and provide illustrative examples. Since then CESCR has gradually added to the list of illustrations in relation to different economic, social and cultural rights. For example, the Committee provided some illustrative right-to-health core obligations in 2000. For present purposes, the important point is that right-to-health core obligations predated both 2000 and 1990.

55. Second, as CESCR emphasises in General Comments 3 and 14, the core obligations identified in those Comments are only illustrative.

56. Third, although the concept of core obligations, as well as its practical application, remains work in progress, it appears to be common ground that the core obligation to ensure access to essential medicines must *at least* be accorded a very high priority by States Parties.

57. Fourth, accordingly, I respectfully suggest that when TGGL was infected with HIV in 1998, there was at that time an obligation on the Government of Ecuador to accord *at least* a very high priority to the equitable access of good quality essential medicines for all, otherwise article 12 "would be largely deprived of its *raison d'être*".

International Guidelines on HIV/AIDS and Human Rights

58. The preceding sections have introduced the international right to health law that applies to those living with HIV. For many years, OHCHR and UNAIDS have examined the relationship between HIV/AIDS and human rights. One of their key texts is the *International Guidelines on HIV/AIDS and Human Rights* (consolidated version of 2006).[71] One component of these *Guidelines* is the right to prevention, treatment, care and support for those living with HIV.

59. The *Guidelines* are authoritative, instructive and highly relevant to the present case. Although not legally binding, they are deeply rooted in, and reflective of, a range of widely recognised human rights standards. They are designed to help States, and others, move from open-textured human rights law to more specific human rights practice in the domain of HIV. In their Foreword to the *Guidelines*, the UN High Commissioner for Human Rights and Executive Director of UNAIDS "urge governments, non-governmental organizations, the UN human rights system, and regional bodies to benefit from and build upon these *Guidelines*, and continue to find ways to operationalise their commitment to protect human rights in the response to HIV."[72] The Introduction to the *Guidelines* reports that the "Commission on Human Rights has asked States to take all necessary steps to ensure the respect, protection and fulfilment of HIV-related human rights as contained in the *Guidelines*, and has urged States to ensure their laws, policies and practices comply with the *Guidelines*."[73] Moreover, the

[71] This section draws extensively from this OHCHR/UNAIDS publication.

[72] International Guidelines on HIV/AIDS and Human Rights, 7.

[73] International Guidelines on HIV/AIDS and Human Rights, 12.

Guidelines are being relied upon by courts when adjudicating cases involving people living with HIV e.g. the European Court of Human Rights in *Kiyutin v Russia*;[74] UN human rights treaty-bodies in their General Comments e.g. CESCR's General Comment 20;[75] and UN Special Rapporteurs in their reports e.g. Rapporteur on the sale of children, child prostitution and child pornography (Juan Petit), Rapporteur on the right to freedom of opinion and expression (Ambeyi Ligabo), and Rapporteur on the right to the highest attainable standard of health (Anand Grover).[76]

60. For these reasons, I introduce the *Guidelines* and also highlight some of the passages that have particular relevance to the present case.

61. In 1989, the UN Centre for Human Rights, in cooperation with WHO, organised the first International Consultation on AIDS and Human Rights. Participants discussed the possible elaboration of guidelines to assist policymakers and others in complying with international human rights standards regarding law, policy and practice. In 1995, the UN Secretary-General, in his report to the UN Commission on Human Rights, gave his support for this proposal: "In particular, Governments could benefit from guidelines that outline clearly how human rights standards apply in the area of HIV/AIDS and indicate concrete and specific measures, both in terms of legislation and practice, that should be undertaken."[77] In 1996, the Commission on Human Rights adopted a resolution which requested the UN High Commissioner for Human Rights, in cooperation with UNAIDS and others, to work "towards the elaboration of guidelines on promoting and protecting respect for human rights in the context of HIV/AIDS."[78]

62. Accordingly, in 1996, OHCHR and UNAIDS convened the Second International Consultation on HIV/AIDS. Chaired by Michael Kirby, Judge of the High Court of Australia, the consultation brought together experts in the field of HIV/AIDS and human rights, including Government officials and staff of national AIDS programmes. Participants discussed the most important human rights principles and concerns in the context of HIV and AIDS, as well as concrete measures that States could take to protect HIV-related human rights. The result was the ground-breaking *International Guidelines on HIV/AIDS and Human Rights (1996).*

63. In the next few years, there were major developments with regard to the right to health and access to HIV-related prevention, treatment, care and support, such as advances in the

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[74] ECtHR, *Kiyutin v. Russia*, no. 2700/10, 10 March 2011, para 34.

[75] UN Committee on Economic, Social and Cultural Rights 'General Comment 20: Non-discrimination in Economic, Social and Cultural Rights' (2 July 2009) UN Doc E/C.12/GC/20.

[76] UNGA 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (6 August 2010) UN Doc A/65/255 para 21; UNGA 'Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health' (10 August 2009) UN Doc A/64/272 paras 33 and 77; ECOSOC 'Report of the Special Rapporteur on the Right to Freedom of Opinion and Expression Mr. Ambeyi Ligabo' (30 December 2002) UN Doc E/CN.4/2003/67 para 39; ECOSOC 'Report submitted by Mr. Juan Miguel Petit, Special Rapporteur on the Sale of Children, Child Prostitution and Child Pornography' (9 January 2003) UN Doc E/CN.4/2003/79/Add.1 para 53.

[77] International Guidelines on HIV/AIDS and Human Rights, 9.

[78] International Guidelines on HIV/AIDS and Human Rights, 10.

availability of diagnostic tests and HIV-related treatments, including antiretroviral therapies. Also, there were increased international, regional and national commitments and other developments towards the full realisation of all human rights related to HIV, including improved access to health services for people living with HIV. These included the Declaration of Commitment on HIV/AIDS; the Millennium Development Goals; General Comment 14 of the UN Committee on Economic, Social and Cultural Rights; and the UN Commission on Human Rights resolutions on the right to health and access to medication.

64. Consequently, in 2002, the UN High Commissioner for Human Rights and Executive Director of UNAIDS convened the Third International Consultation on HIV/AIDS and Human Rights. This, too, was chaired by Judge Kirby. The Third Consultation agreed a revised Guideline 6 on access to prevention, treatment, care and support, together with a new commentary and recommendations in relation to Guideline 6. These were the only substantive changes to the *Guidelines* adopted in 1996.

65. In 2006, OHCHR and UNAIDS published the *International Guidelines on HIV/AIDS and Human Rights* which consolidates the 1996 version with the revisions agreed in 2002. In the following remarks, I refer to this consolidated version of 2006.

66. The consolidated version includes a brief history of the recognition of the importance of human rights in the context of HIV and lists the numerous charters and declarations, adopted at national and international conferences and meetings, which recognise the human rights of people living with HIV. This historical overview concludes: "The formulation of the present Guidelines is a culmination of these international, regional and national activities and an attempt to draw on the best features of the documents described above, whilst also focusing on strategic action plans to implement them. It has been noted that, although some positive measures at the national level to promote and protect human rights in the context of HIV/AIDS are in place, a dramatic gap exists between professed policy and implementation on the ground. It is hoped that these *Guidelines*, as a practical tool for States in designing, coordinating and implementing their national HIV policies and strategies, will assist in closing the gap between principles and practice and be instrumental in creating a rights-based and effective response to HIV."[79]

67. The consolidated version also includes a chapter summarising the international human rights obligations in relation to HIV, a list of the relevant human rights (set out earlier in this affidavit), and a 20-side narrative on 'The application of specific human rights in the context of the HIV epidemic'.[80]

68. The consolidated version confirms that the "purpose of these Guidelines is to assist States in translating international human rights norms into practical observance in the context of HIV".[81] The "principal users of the Guidelines will be States, in the persons of legislators and Government policymakers, including officials involved in national AIDS programmes and

[79] International Guidelines on HIV/AIDS and Human Rights, 111.

[80] International Guidelines on HIV/AIDS and Human Rights, 77-103.

[81] International Guidelines on HIV/AIDS and Human Rights, 13.

relevant departments and ministries, such as health, foreign affairs, justice, interior, employment, welfare and education."[82]

69. The heart of the consolidated text is the 12 *Guidelines* arranged in three groups:

A. Institutional responsibilities and processes

«*Guideline 1*: States should establish an effective national framework for their response to HIV which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV policy and programme responsibilities across all branches of government.

Guideline 2: States should ensure, through political and financial support, that community consultation occurs in all phases of HIV policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.»

B. Law review, reform and support services

«*Guideline 3*: States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV and that they are consistent with international human rights obligations.

Guideline 4: States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV or targeted against vulnerable groups.

Guideline 5: States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies.

Guideline 6 (as revised in 2002): States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of quality prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price. States should also take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV prevention, treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventive, curative and palliative care of HIV and related opportunistic infections and conditions.

States should take such measures at both the domestic and international levels, with particular attention to vulnerable individuals and populations.

[82] International Guidelines on HIV/AIDS and Human Rights, 14.

Guideline 7: States should implement and support legal support services that will educate people affected by HIV about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudsmen, health complaint units and human rights commissions.»

C. Promotion of a supportive and enabling environment

«*Guideline 8*: States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

Guideline 9: States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV/AIDS to understanding and acceptance.

Guideline 10: States should ensure that government and private sectors develop codes of conduct regarding HIV issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce those codes.

Guideline 11: States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV, their families and communities.

Guideline 12: States should cooperate through all relevant programmes and agencies of the United Nations system, including the UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV at the international level.»

70. While all 12 Guidelines are very important, in the present context I respectfully invite the Court to give particular attention to Guidelines 5, 6 and 8.

71. Each Guideline is accompanied by a commentary and recommendations for implementation. The commentary and recommendations accompanying Guideline 6 are the longest and consist of 10-sides. While it is not necessary to summarise or repeat this guidance, I underscore a few passages from Guideline 6's commentary and recommendations which have particular relevance to the present case.

72. Paragraph 26 emphasises that an effective response to HIV requires a comprehensive approach encompassing a continuum of prevention, treatment, care and support:

> Prevention, treatment, care and support are mutually reinforcing elements and a continuum of an effective response to HIV. They must be integrated into a comprehensive approach, and a multifaceted response is needed. Comprehensive treatment, care and support include antiretroviral and other medicines, diagnostics and related technologies for the care of HIV and AIDS, related opportunistic infections and other conditions, good nutrition, and social, spiritual and psychological support, as well as family, community and home-based care. HIV-prevention technologies include condoms, lubricants, sterile injection equipment, anti-retroviral medicines (e.g. to

prevent mother-to-child transmission or as post-exposure prophylaxis) and, once developed, safe and effective microbicides and vaccines. Based on human rights principles, universal access requires that these goods, services and information not only be available, acceptable and of good quality, but also within physical reach and affordable for all.

73. Some vital features of paragraph 26 merit emphasis. Access to antiretrovirals is only one element of an effective response to those living with HIV. People living with HIV require a comprehensive approach encompassing a continuum of prevention, treatment, care and support e.g. medicines, diagnostics, good nutrition, and social and psychological support, as well as family, community and home-based care. They require prevention services, as well as treatment, care and support, for at least two reasons. First, they need HIV prevention services to avoid onward transmission to others. For example, pregnant women living with HIV need services to prevent HIV transmission to their infants, and a HIV-positive person who is in a sero-discordant relationship needs HIV prevention to avoid transmission to his or her HIV-negative partner. Second, people living with HIV also need prevention services to avoid re-infection with a different strain of HIV virus and to avoid infection with other sexually transmitted infections that may affect their health. As set out in paragraph 26, these prevention services include condoms, lubricants and sterile injection equipment (for people who inject drugs).

74. In summary, a governmental response to those living with HIV which is confined to access to antiretrovirals and other medicines is not in conformity with the obligations of prevention, treatment, care and support arising from the right to the highest attainable standard of health.

75. Paragraph 28 is notable, not least for adopting language from CESCR's General Comment 14 and applying it to prevention, treatment, care and support:

> Universal access to HIV prevention, treatment, care and support is necessary to respect, protect and fulfil human rights related to health, including the right to enjoy the highest attainable standard of health. Universal access will be achieved progressively over time. However, States have an immediate obligation to take steps, and to move as quickly and effectively as possible, towards realizing access for all to HIV prevention, treatment, care and support at both the domestic and global levels. This requires, among other things, setting benchmarks and targets for measuring progress.

76. Paragraphs 30, 31 and 32 highlight the obligation to avoid stigmatization and discrimination, and to address the multiple disadvantages of some individuals and populations, such as girls and women. These passages need to be read with Guideline 5 and its accompanying text.

77. Paragraph 30:

> States should ensure that their laws, policies, programmes and practices do not exclude, stigmatize or discriminate against people living with HIV or their families, either on the basis of their HIV status or on other grounds contrary to international or domestic human rights norms, with respect to their entitlement or access to health-care goods, services and information.

78. Paragraph 31:

States' legislation, policies, programmes, plans and practices should include positive measures to address factors that hinder the equal access of vulnerable individuals and populations to prevention, treatment, care and support, such as poverty, migration, rural location or discrimination of various kinds. These factors may have a cumulative effect. For example, children (particularly girls) and women may be the last to receive access even if treatment is otherwise available in their communities.

79. Paragraph 32: " ... Particular attention must be paid to gender inequalities, with respect to access to care in the community for women and girls, as well as the burdens that delivering care at the community level may impose on them."

80. Paragraph 34 highlights that the health-care needs of persons living with HIV are unlikely to be static, as well as the particular vulnerability of individuals outside the formal employment sector:

> Legislation, policies and programmes should take into account the fact that persons living with HIV may recurrently and progressively experience ill-health and greater health-care needs, which should be accommodated accordingly within benefit schemes in both the public and private sectors. States should work with employers, and employers' and workers' organizations, to adopt or adapt benefit schemes, where necessary, to ensure universal and equal access to benefits for workers living with HIV. Particular attention must also be paid to ensuring access to health care for individuals outside the formal employment sector, who lack work-related health-care benefits.

81. The consolidated version includes recommendations for dissemination, including paragraph 89:

> Regional bodies (such as the Inter-American Commission on Human Rights [and] the Organization of American States [...]) should receive the Guidelines and make them available to the largest possible number of members and relevant divisions with a view to assessing how their activities might be made consistent with the Guidelines and promote their implementation.

82. In conclusion, the *Guidelines* address the twin global right-to-health challenges that I identify in paragraph 8 of this affidavit. They clarify, with a reasonable degree of particularity, the scope of States' obligations and how those obligations can be operationalised in practice. In effect, they apply article 12 of ICESCR, in tandem with other human rights, to those living with HIV.

State obligations arising from American Convention on Human Rights in light of applicable international standards

83. I am asked by the Court, in light of applicable international standards, to consider the State obligations arising from the American Convention on Human Rights. So I have to reflect on the place of the right to the highest attainable standard of health within the American Convention. Fortunately, this daunting task is made infinitely easier by the magisterial concurring opinion

delivered by Judge Ferrer MacGregor Poisot in *Suárez Peralta v Ecuador*.[83] I strongly support and warmly welcome Judge Ferrer's learned analysis which includes an examination of the American Convention, existing case law of the Inter-American Court, and the right to the highest attainable standard of health.

84. There is little merit in rehearsing all the compelling points made by Judge Ferrer. Instead, I confine myself to the following.

85. The Inter-American Court has affirmed the interdependence and indivisibility of civil, political, economic, social and cultural rights.[84] Without directly applying the right to health, the Court has decided a number of cases that help to promote and protect aspects of the right to health. This has been achieved by relying upon, for example, the rights to life and personal integrity, and the concept of a "decent life".[85] Occasionally, but rarely, the Court has referred to, and analysed, chapter III (i.e. article 26) of the American Convention.[86]

86. As a friend of the Court, I am sometimes puzzled that more weight is not attached to the fact that articles 1 and 2 clearly apply to *all* the rights and freedoms in the Convention, both the "civil and political rights" in chapter II and "economic, social and cultural rights" in chapter III, all of which have to be read in light of article 29 (restrictions regarding interpretation). Moreover, all these provisions are in the Convention's Part I, headed "State obligations and rights protected".

87. In his concurring opinion, Judge Ferrer identifies twenty States Parties to the American Convention that have constitutional provisions "that refer in some way to the protection of the right to health".[87] As he explains, with illustrations, these provisions have generated many cases in numerous national courts.[88] Also, many countries beyond the OAS constitutionally protect health-related human rights, which generate significant national case law, as amply demonstrated by the *Global Health and Human Rights Database*.[89]

88. In an important passage, Judge Ferrer emphasises:

> It is important to underscore that this understanding of the right to health as directly fundamental in the national States, or of the direct justiciability of the right to health within the framework of the American Convention, does not imply understanding the right to health as an absolute right, as a right that has no limits, or that it must be

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[83] Concurring Opinion of Judge Ferrer MacGregor Poisot, IACtHR, *Case of Suárez Peralta v. Ecuador Preliminary objections merits, reparations and costs.* Judgment 21 May 2013 Series C No. 261.

[84] Ferrer, paras 15-27.

[85] Ferrer, para 13.

[86] Ferrer, para 14.

[87] Ferrer, para 75.

[88] Ferrer, paras 76-84.

[89] http://www.globalhealthrights.org/ Developed by the O'Neill Institute for National and Global Health Law and the Lawyers Collective, in collaboration with a wide network of partners.

protected every time it is invoked. The absolute protection of a civil or social right in any litigation is not derived from its justiciability. Every case, whether it relates to a civil or social right, must be decided making an analysis of imputation and to verify how the obligations of respect and guarantee function in relation to each situation that is alleged to have violated a specific right.[90]

89. Perhaps one reason why the Court has hesitated to explicitly base relevant decisions on articles 1, 2, 26 and 29 and the right to health, buttressed by suitable civil and political rights from chapter II, was because the right to health was jurisprudentially immature and not well-understood. In the past, these hesitations were not without some justification. However, this affidavit has endeavoured to signal that times have changed. Today, national and international laws and case law, 'soft-law' (e.g. guidance of the UN Human Rights Council, human rights treaty-bodies, WHO/PAHO, OHCHR/UNAIDS, and others), and academic scholarship on the right to health, is rich and deep. Of course, the jurisprudential and operational challenges remain formidable. The Inter-American Court can play a formative role in addressing them, just as it has in relation to other vital human rights issues.

90. May I respectfully suggest that when the Court is called upon to decide contemporary, crucial, complex, multi-faceted cases, it may benefit from the norms in chapter III. In some cases, relying upon civil and political rights in chapter II, and not using economic, social and cultural rights in chapter III, is like trying to do a difficult manual task with one hand behind your back.

91. In conclusion, I agree with Judge Ferrer that the right to the highest attainable standard of health is directly justiciable under the American Convention on Human Rights. If the Court were to adopt this interpretation of the Convention, it would have at its disposal for its consideration the extensive and deepening jurisprudence on the right to health. Other sections in this affidavit endeavour to introduce these jurisprudential insights in the specific context of those living with HIV.

What are the obligations imposed on a State "with respect to persons who were infected as a consequence of State actions or omissions"?

92. This affidavit summarises the human rights entitlements of persons living with HIV. Some of the State obligations arising from these entitlements are immediate: they are subject to neither resource capacity nor progressive realisation. For example, the prohibition of discrimination on the grounds of health-status is an immediate obligation. However, some of the State obligations in relation to those living with HIV are subject to resource availability and progressive realisation. For example, people living with HIV require a comprehensive continuum of prevention, treatment, care and support, such as medicines, diagnostics, good nutrition, social and psychological support, as well as family, community and home-based care. Consistent with article 2(1) of the ICESCR ("with a view to achieving progressively"), and article 26 of the American Convention on Human Rights (again, "with a view to achieving progressively"), some elements of this comprehensive continuum are subject to resource capacity and progressive realisation. This is reflected in the *Guidelines*: commenting on Guideline 6, paragraph 28 confirms that "(u)niversal access will be achieved progressively over time." Accordingly, in relation to some elements of the comprehensive continuum, the current human

[90] Ferrer, para. 87.

rights obligations of a high-income State are more demanding that the current human rights obligations of a low-income State.

93. In Ecuador, there are estimated to be 11,000 women, aged 15 and over, living with HIV.[91] The Government of Ecuador has a human rights obligation at least to provide them with a level of prevention, treatment, care and support consistent with the country's resource capacity. For short, I will call this level-A care (although it encompasses prevention, treatment, care and support). Given the requirement of progressive realisation, level-A care should improve over time. If it does not, the Government has the burden of explaining why progressive realisation has not occurred.[92]

94. However, I respectfully suggest that if a woman in Ecuador is HIV-positive as a direct consequence of the State's acts or omissions, it would be unjust if the State's obligation was limited to providing her with level-A care. Instead, the State has an obligation to return her, so far as possible, to her *status quo ante* and this includes the provision of prevention, treatment, care and support which is not limited by considerations of Ecuador's resource capacity. She should be provided with level-A-*plus* care, equivalent to the highest level of prevention, treatment, care and support available to anyone using Ecuador's public or private health-related services.

95. Moreover, the State's obligation to return the woman, so far as possible, to her *status quo ante* should not be confined to matters of health. For example, as a consequence of the State's acts or omissions, her education might have suffered and her capacity to earn a livelihood might have diminished. Thus, the State's obligation is to return her, so far as possible, to her *status quo ante* in relation to health and other foreseeable matters.

96. Finally, given the facts of the present case: if the person who is HIV-positive as a direct consequence of the State's acts or omissions is a child, the State's obligation to restore, as far as possible, the *status quo ante* should extend to the child's family, so far as foreseeable that family members would be affected by the child's infection. For example, additional child care responsibilities may adversely impact upon the family's income-earning capacity.

Oyal v Turkey[93]

97. This decision of the European Court of Human Rights merits particular attention because its facts have some similarity to the present case. Also, in light to the *Guidelines*, it raises a query about remedies.

98. The primary applicant, the child of the second two applicants, was born prematurely and diagnosed with an "inguinal and umbilical hernia." The child required a number of blood and plasma transfusions during the first two months of life, and the applicant parents purchased the required blood and plasma from the Turkish Red Cross. Four months after hospital staff carried

[91] UNAIDS, Ecuador: HIV and AIDS estimates (2013).

[92] See UN Committee on Economic, Social and Cultural Rights, 'General Comment No. 14: The right to the highest attainable standard of health' (11 August 2000) UN Doc E/C.12/2000/4 especially paragraphs 30-33.

[93] ECtHR, *Oyal v. Turkey*, no. 4864/05, 23 March 2010.

out the blood transfusions, the parent applicants learned that their child had been infected with HIV. Later, the Government of Turkey discovered that a blood donor to the Turkish Red Cross was HIV positive and that the particular donor had previously given quantities of blood and plasma. It then became apparent that a unit of plasma given to the child had come from the same HIV-positive donor.

99. After a series of administrative proceedings, which lasted over twelve years, against the Ministry of Health, the Administrative Court found that Ministry of Health personnel had negligently performed their duties. However, the Administrative Court awarded the family, which had fallen into economic hardship, only one year of medical treatment expenses.

100. Dissatisfied with the duration of the administrative proceedings, as well as the compensation awarded, the applicants filed an action with the European Court of Human Rights. In particular, the applicants claimed that insufficient training and poor supervision of staff at the Ministry of Health, as well as the limited treatment expense compensation, constituted a violation of the child applicant's right to life under Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms. The applicants also claimed that the length of the administrative proceedings was excessively prolonged, and therefore violated their right to a hearing "within a reasonable time" under Article 6(1) of the Convention, as well as their rights to an effective remedy under 13 of the Convention.

101. The Court found that the actions of Turkey contravened the right to life under Article 2 of the Convention. It also held that the applicants had access to civil and administrative courts but that the redress was inappropriate and insufficient. In particular, the Court found it unacceptable that the applicants were left on their own to cover the high costs of the child applicant's continued treatment. The Court concluded that the Ministry of Health should have been required to pay the treatment and medication costs for the child applicant for the entirety of his lifetime. The Court also found that the length of the proceedings had violated the applicants' rights to a hearing "within a reasonable time" under Article 6(1), as well as their rights to an effective remedy under Article 13 of the Convention.

102. The Court made an order of Eur 300,000 in respect of pecuniary damage; Eur 78,000 in respect of non-pecuniary damage; and that the Government "must provide free and full medical cover for the first applicant during his lifetime".

103. It appears that this welcome and instructive Court order includes elements of rehabilitation as part of reparations. However, the order also raises some queries. In addition to pecuniary and non-pecuniary damages, Turkey was ordered to "provide free and full medical cover for the first applicant during his lifetime." The *International Guidelines on HIV/AIDS and Human Rights* emphasise the importance of a comprehensive continuum of prevention, treatment, care and support for those living with HIV: see Guideline 6 and paragraph 26 of the commentary. In short, "free and full medical cover" is necessary, but not sufficient. In *Oyal*, I am not clear whether or not the Court made sufficient allowance for the primary applicant's

life-long need for a comprehensive continuum of prevention, treatment, care and support, as anticipated under the international right to the highest attainable standard of health.

Signed by Professor Paul Hunt: Paul Hunt

On: 6 March 2015

At: Fisher Jones Greenwood LLP, Charter Court Newcomen Way Colchester CO4 4YA

In the presence of:

Rachel Earnshaw LLB
Solicitor