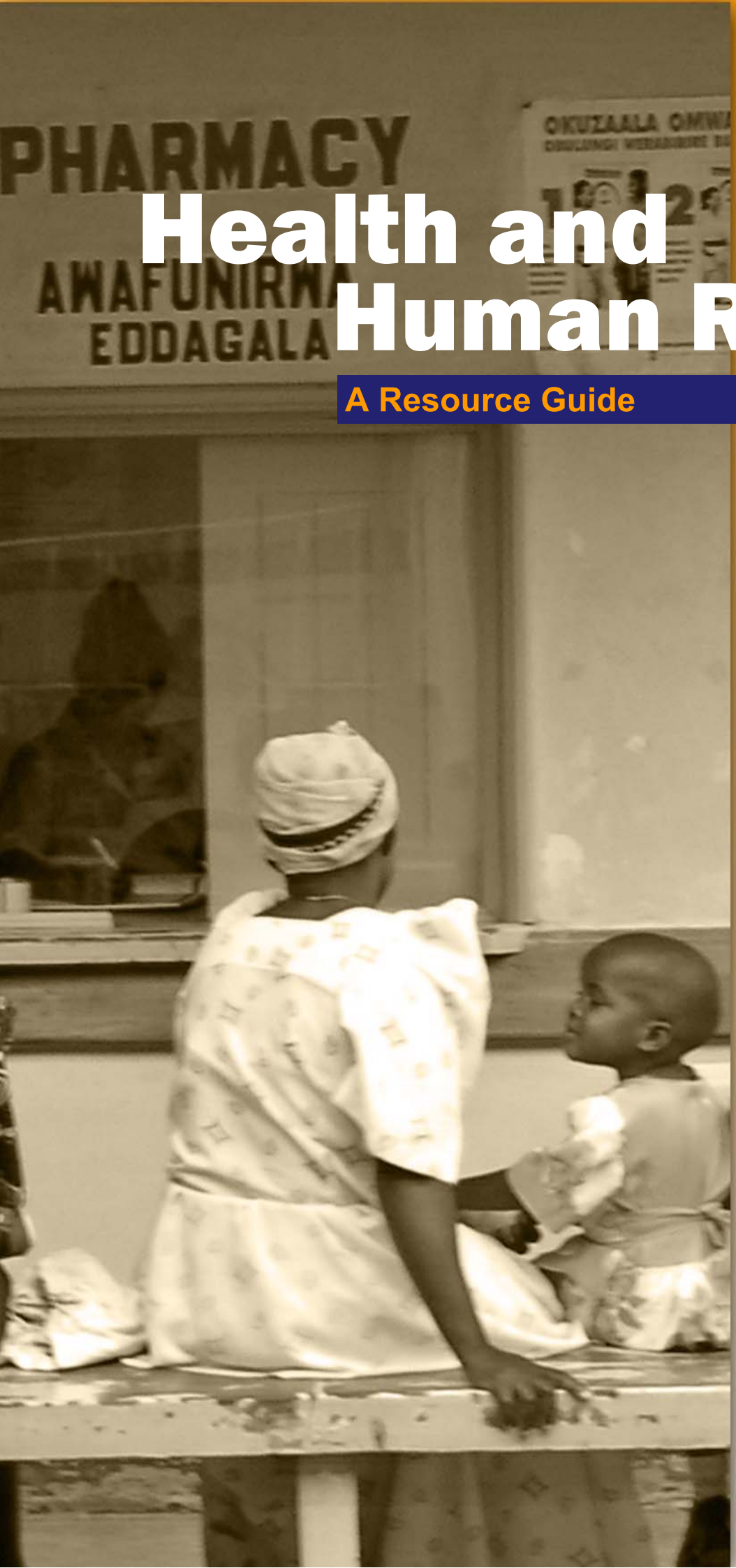


Health and Human Rights

A Resource Guide

Now we have the responsibility to move forward by recognizing that true interdependence and real interconnectedness requires that we -- from health and from human rights -- advance together: equal partners in the belief that the world can change.

Jonathan Mann (1947-1998)

OPEN SOCIETY INSTITUTE
Public Health Program

equitas
Centre international d'éducation aux droits humains
International Centre for Human Rights Education

OPEN SOCIETY INSTITUTE

equitas
Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Health and Human Rights

A Resource Guide

March 2009

Now we have the responsibility to move forward by recognizing that true interdependence and real interconnectedness requires that we—from health and from human rights—advance together: equal partners in the belief that the world can change.

Jonathan Mann (1947-1998)

Health and Human Rights – A Resource Guide

Fourth Edition, March 2009

Cover photograph courtesy Physicians for Human Rights.

Open Society Institute
400 West 59th Street, New York, NY 10019 USA
Website: www.soros.org

Equitas – International Centre for Human Rights Education
1425, René-Lévesque Blvd. West, Suite 407
Montréal, Québec, Canada H3G 1T7
Website: www.equitas.org

Table of Contents

Introduction

Chapter 1
Human Rights in Patient Care

Chapter 2
HIV/AIDS and Human Rights

Chapter 3
Harm Reduction and Human Rights

Chapter 4
Palliative Care and Human Rights

Chapter 5
Sexual Health and Human Rights

Chapter 6
Health and Human Rights in Minority Communities: The Roma and San

Chapter 7
Mental Health and Human Rights

Appendix
Links to Thirteen Health and Human Rights Documents

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Photo courtesy Paul McAdams

Introduction

Contents

Acknowledgements

This Resource Guide was edited and compiled by Jonathan Cohen, Project Director of the Open Society Institute Law and Health Initiative, Tamar Ezer, Program Officer in the Law and Health Initiative, Paul McAdams, Senior Education Specialist at Equitas – International Centre for Human Rights Education and Minda Miloff, consultant to Equitas.

The Guide was prepared for *Equal Partners: Health and Human Rights*, a global seminar for Open Society Institute and Soros Foundation staff held in Cape Town, South Africa from June 3-8, 2007.

The following people drafted, contributed, or commented on materials for the individual chapters of the Guide:

- **Introduction:**

  Magda Adamowicz, Iain Byrne, Dmytro Groysman, Karyn Kaplan, Jane Li, Judith W. Overall

- **Chapter 1: Human Rights in Patient Care**

  Magda Adamowicz, Dmytro Groysman, Sarah Kalloch, Emily Martinez, Judith W. Overall, Yervand Shirinyan, Anthony So

- **Chapter 2: HIV/AIDS and Human Rights**

  Emily Bell, Helena Choi, Delme Cupido, Ralf Jürgens, Rick Lines, Richard Pearshouse

- **Chapter 3: Harm Reduction and Human Rights**

  Balázs Dénes, Ralf Jürgens, Karyn Kaplan, Rick Lines, Kasia Malinowska-Sempruch, Nandini Pillai, Gang Song, Daniel Wolfe

- **Chapter 4: Palliative Care and Human Rights**

  Frank Brennan, Robert Burt, Mary Callaway, Kath Defilippi, Kathleen M. Foley, Liz Gwyther, Kiera Hepford, Sue Nieuwmeyer

- **Chapter 5: Sexual Health and Human Rights**

  Maxim Anmeghichean, Melissa Ditmore, Shannon Kowalski-Morton, Emily Martinez, Alice M. Miller, Yervand Shirinyan, Sue Simon, Rachel Thomas, Jessica Wahlstrom, Jill Wood

- **Chapter 6: Health and Human Rights in Minority Communities: The Roma and San**

  Claude Cahn, Heather Doyle, Eva Foldes, Emily Martinez, Willem Odendaal, Yervand Shirinyan

- **Chapter 7: Mental Health and Human Rights**
  Volha Baraulia, Jonathan Cohen, Tamar Ezer, Judith E. Klein, Emma Lozman, Camilla Parker

- **Appendix: Links to Thirteen Health and Human Rights Documents**
  Jane Li, Emma Lozman

The Guide's translation project was managed by Volha Baraulia. The Guide was formatted by Emma Lozman and other production assistance was provided by Paola Deles and Anna Vinnik. In addition, staff of the Open Society Institute Public Health Program and Human Rights and Governance Grants Program provided valuable comments on the Guide.

The Law and Health Initiative is a project of the Open Society Institute Public Health Program. *Equal Partners: Health and Human Rights* was co-sponsored by the Public Health Program together with the Open Society Institute Human Rights and Governance Grants Program (HRGGP) in collaboration with the Open Society Justice Initiative.

Preface

One of the most satisfying experiences of my human rights career was participating in litigation in the 1970s that closed the Willowbrook Developmental Center, a notoriously inhumane facility for persons with intellectual disabilities in New York City. Willowbrook was not only a health hazard to its more than 6,000 "mentally retarded" inmates, but a deep affront to the dignity and human rights of people with mental disabilities. The lawsuit was brought by the New York branch of the American Civil Liberties Union, of which I was executive director. It resulted in the resettlement of the inmates in state-supported community residences where they were able to lead near normal lives. It also spurred massive reform of New York State's system of care for the developmentally disabled, assisting many thousands of others to live outside institutions and contributed significantly to such reforms throughout the United States.

Willowbrook is an enduring symbol of the power of the law to improve the health of society's most marginalized persons. Whether people living with HIV or AIDS, drug users, sex workers, Roma, or people needing palliative care, those living on the furthest margins of society have one thing in common: violations of their human rights worsen their health. Extortion and arbitrary arrest of drug users impede access to harm reduction services and are a major cause of prison overcrowding. Violence and discrimination against men and women in prostitution makes it difficult to reach them with life-saving HIV-prevention services. Discrimination on the basis of HIV status, still widespread over 25 years into the epidemic, frustrates efforts to bring the epidemic under control.

This Resource Guide brings together two of the Open Society Institute's largest priorities: our public health portfolio on the one hand, and our numerous law and human rights initiatives on the other. By working together, each of these programs can accomplish their goals more effectively. Health advocates can better serve their clients by harnessing the power of the law to secure protection against human rights violations. Human rights advocates can increase their reach by attending to the negative health repercussions of extensive human rights abuses. At the foundation level, collaboration between legal and health staff can substantially enrich their professional experience.

I recommend this Guide to all staff dedicated to the important pursuit of health and human rights.

Aryeh Neier
June 2007

About this Guide

Purpose and organization

This Resource Guide is a user-friendly, multi-purpose tool that can be used on a regular basis on the job. To ensure easy and widespread access to the Guide, a web-friendly version is available at www.equalpartners.info. On this website, you will also find translations of the guide into several other languages.

The Guide covers the basic concepts and resources in health and human rights and contains **seven chapters**, each on a different health issue of priority concern to the Open Society Institute (OSI) and Soros Foundations Network (SFN), and **one appendix**.

The seven chapters are:

- **Chapter 1:** Human rights in patient care
- **Chapter 2:** HIV/AIDS and human rights
- **Chapter 3:** Harm reduction and human rights
- **Chapter 4:** Palliative care and human rights
- **Chapter 5:** Sexual health and human rights
- **Chapter 6:** Health and human rights in minority communities
- **Chapter 7:** Mental health and human rights
- **Appendix:** Thirteen health and human rights documents

Each chapter is organized into six sections that answer the following questions:

- **How** is this human rights issue?
- **What** is OSI's work on this issue?
- **Which** are the most relevant international and regional human rights standards related to this issue?
- **What** are some effective human rights programming on this issue?
- **Where** can I find additional resources on this issue?
- **What** are key terms related to this issue?

How to use and modify the Guide

The Guide is a practical **reference tool** for you to use in your day-to-day work. You can also **add** new materials as you see fit, **take notes** in the margins, and **print** specific sections for use in training.

Review the following table for examples on how you can use and modify each section of the Guide.

Chapter heading	How to use and modify the Guide
How is this human rights issue?	Use these **introductory sections** for a quick definition of each health issue, or re-print them in a report or advocacy document.
What is OSI's work on this issue?	Share these **descriptions of OSI's work** with potential grantees or advocacy partners.
Which are the most relevant international and regional human rights standards related to this issue?	Consult the **tables** to construct human rights arguments, identify opportunities for using human rights mechanisms, or conduct legal research. If a regional or international human rights body issues a new ruling on one of the issues, add this to the relevant table.
What are some effective human rights programming on this issue?	Review the **project examples** to develop your annual strategy or encourage local partners to take on health and human rights work. If you encounter a good example of health and human rights programming, you can write it up as a project example and add it to the appropriate chapter.
Where can I find additional resources on this issue?	Refer to the **resources lists** to deepen your understanding on any of the topics. As you discover additional good readings and trainings for each topic, you can add them to the relevant resource list and share them with colleagues working on these issues.
What are key terms related to this issue?	Check the **glossaries** to look up a term related to any of the issues. If you discover a new term that is not included in one of the glossaries, you can look up the definition and add it to the appropriate chapter.

Putting the Guide into action

This Guide is a **starting point** for a wide range of health and human rights programming within OSI and the SFN. The Guide will provide you with ideas, information, and resources to develop programs in any of the six subject areas covered in each chapter.

You can use the Guide to:	How
Collaborate with colleagues on strategy development	There are many opportunities for Law Program and Public Health Coordinators to collaborate on health and human rights work. The Guide provides over thirty examples of projects that can be adapted at the country or regional level, as well as extensive information on developing claims before regional and international bodies. The annual strategy process is a good time to consult the Guide for ideas on how law and health staff can collaborate.
Develop regional or thematic courses and trainings	Each chapter of the Guide contains the information and resources needed to develop a course or training seminar on the topic of the chapter. For example, you can use the information in Chapter 2 to develop a course on HIV/AIDS and Human Rights for advocates in a particular region. While the chapters do not contain actual curricula or training materials, an experienced educator can use the information in the Guide to develop a course or seminar.
Identify human rights claims	The Guide contains hundreds of real-life examples of human rights abuses related to each of six health issues, as well as legal standards and precedents that can be used to seek redress for these abuses. The Introduction to the Guide briefly describes the main regional and international human rights mechanisms with which you can lodge complaints. There is great potential for using regional and international mechanisms to advance health-related claims, and this is an excellent area of collaboration for law program and public health staff.
Adapt the project examples in your country	Each chapter of the Guide contains three to five examples of effective health and human rights projects from around the world. Each project example summarizes the work accomplished and includes contact information for the implementing organization. You can adapt these project examples to any country or region. You can also share the project examples with your NGO partners to encourage them to take on more work on health and human rights.
Conduct further research	If you are conducting research on health and human rights—for example, writing an article or news item, preparing a conference presentation, or developing a Request for Proposals (RFP)—you can consult the Guide for a list of articles, books, websites, and other resources on each of the six issues the Guide covers. While not comprehensive, each resource list was prepared by experts in the field and contains their recommendations of the most useful resources.
Educate other funders	While this Guide is primarily directed at OSI and the SFN, it can also be used by other funders who are interested in health and human rights. The Guide (or sections of it) can be translated into local languages and adapted to local contexts. Parts of it can be expanded, abbreviated, or modified depending on the purpose and audience.

Using human rights mechanisms

Treaties and enforcement mechanisms

One of the main ways to advocate for health and human rights is to lodge complaints or file reports with regional or international human rights mechanisms. These mechanisms were established to enforce governments' compliance with the regional and international human rights treaties they have ratified. These treaties make up the so-called "hard law" of international human rights, while the interpretations of the treaty mechanisms make up "soft law" that is not directly binding on governments. There are two main types of enforcement mechanisms:

- **Courts**, which act in a judicial capacity and issue rulings that are binding on governments in the traditional sense;

- **Committees**, which examine reports submitted by governments on their compliance with human rights treaties, and in some cases examine individual complaints of human rights violations.

The main treaties and corresponding enforcement mechanisms discussed in this Guide are shown on the following page.

Using the mechanisms

One of the greatest advantages of regional and international human rights mechanisms is that they allow individuals and NGOs to lodge complaints or file reports of human rights abuses.

The best way to learn about how to use a particular mechanism is to visit its website or contact its Secretariat. The contact information for each enforcement mechanism discussed in the Guide, as well as some introductory information about its mandate and procedures is provided on the next pages.

Advocacy using these regional and international mechanisms go hand-in-hand with country advocacy as regional and international recommendations mean little without enforcement at the national level. Additionally, domestic remedies generally have to be exhausted (including the raising of regional and international claims) before complaints can be taken to regional or international bodies.

Treaties and corresponding enforcement mechanisms

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (**ICCPR**)	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
International Convention on the Elimination of all forms of Racial Discrimination (**ICERD**)	Committee on the Elimination of Racial Discrimination (**CERD**)
Convention concerning Indigenous and Tribal Peoples in Independent Countries (**ILO Convention**)	International Labour Organization (**ILO**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**) (with Committee of Ministers)
European Social Charter (**ESC**)	European Committee of Social Rights (**ECSR**) (with Governmental Committee and Committee of Ministers)
Framework Convention for the Protection of National Minorities (**FCNM**)	Committee of Ministers of the Council of Europe & Advisory Committee (**AC**)

Note: The above is only a fraction of the treaties and enforcement mechanisms that can be used to advocate for health and human rights. Some of the resources listed at the end of this Introduction contain more detailed information about the regional and international human rights systems.

Human Rights Committee

Mandate

The Human Rights Committee (HRC) oversees government compliance with the International Covenant on Civil and Political Rights (ICCPR). The HRC has two mandates: to monitor country progress on the ICCPR by examining periodic reports submitted by governments; and to examine individual complaints of human rights violations under the Optional Protocol to the ICCPR.

Civil society participation

NGOs can submit "shadow reports" to the HRC on any aspect of a government's compliance with the ICCPR. Shadow reports should be submitted through the HRC Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the Committee. The HRC meets three times a year. Individuals and NGOs can also submit complaints to the HRC under the Optional Protocol.

Contact
Patrice Gillibert
HRC Secretary, UNOG-OHCHR, CH 1211 Geneva 10, Switzerland
Tel: +41 22 917 9249
Fax: +41 22 917 9006
Email: pgillibert@ohchr.org
Web: www.unhchr.ch/html/menu2/6/hrc.htm

Committee on Economic, Social, and Cultural Rights

Mandate

The Committee on Economic, Social, and Cultural Rights (CESCR) oversees government compliance with the International Covenant on Economic, Social, and Cultural Rights (ICESCR). The CESCR monitors country progress on the ICESCR by examining periodic reports submitted by governments.

Civil society participation

NGOs can submit "shadow reports" to the CESCR on any aspect of a government's compliance with the ICESCR. Shadow reports should be submitted through the CESCR Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the Committee. The CESCR meets twice a year.

Contact
Wan-Hea Lee
CESCR Secretary, Office 1-025, Palais Wilson, Palais des Nations, 8-14 Avenue de la Paix, 1211 Geneva 10
Tel: +41 22 917 9321
Fax: +41 22 917 9046
Email: wlee@ohchr.org
Web: www.unhchr.ch/html/menu2/6/cescr.htm

Committee on the Elimination of Racial Discrimination

Mandate

The Committee on the Elimination of Racial Discrimination (CERD) is the body of independent experts that monitors implementation of the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) by states. It monitors country progress on ICERD by examining periodic reports submitted by governments. The Committee then addresses its concerns and recommendations to the country in the form of "concluding observations." Besides commenting on country reports, CERD monitors state compliance through an early-warning procedure and the examination of inter-state complaints and individual complaints.

Civil society participation

NGOs can submit "shadow reports" to the CERD on any aspect of a government's compliance with the ICERD. Shadow reports should be submitted through the CERD Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the committee. CERD meets twice a year.

Contact
Nathalie Prouvez
Secretary of the Committee on the Elimination of Racial Discrimination
Treaties and Commission Branch
Office of the High Commissioner for Human Rights
Palais Wilson - 52, rue des Pâquis, CH-1201 Geneva, Switzerland
Mailing address: UNOG-OHCHR, CH-1211 Geneva 10, Switzerland
Tel: +41.22.917.93.09,
Fax: +41.22.917.90.22
Email: nprouvez@ohchr.org
Web: www2.ohchr.org/english/bodies/cerd/index.htm

International Labour Organization

Mandate

The International Labour Organization (ILO), located within the United Nations, is primarily concerned with respect for human rights in the field of labour. In 1989, they adopted the Convention concerning Indigenous and Tribal Peoples in Independent Countries. States must provide periodic reports on their compliance with the Convention to the ILO and to national employers and workers associations. National employers and workers associations may submit comments on these reports to the ILO. The ILO Committee of Experts (CE) evaluates the reports and may send "Direct Requests" to governments for additional information. The CE then publishes its "Observations" in a report, presented at the International Labour Conference. On the basis of this report, the Conference Committee on the Application of Standards may decide to more carefully analyze certain individual cases and publishes its conclusions. Additionally, an association of workers or employers may submit a representation to the ILO alleging that a member state has failed to comply with the Convention and a member state may file a complaint against another.

Civil society participation

The Convention encourages governments to consult indigenous peoples in preparing their reports. Indigenous peoples may also affiliate with a worker association or form their own worker association in order to more directly communicate with ILO. The CE meets in November and December of each year, and the International Labour Conference is in June.

Contact
Office Relations Branch
4, rue des Morilons
CH-1211, Geneva 22, Switzerland
Tel. +41.22.799.7732
Fax: +41.22.799.8944
Email: RELOFF@ilo.org
Web: www.ilo.org/public/english/index.htm

Committee on the Elimination of All Forms of Discrimination Against Women

Mandate

The Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW Committee) oversees government compliance with the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). The CEDAW Committee has three mandates: to monitor country progress on CEDAW by examining periodic reports submitted by governments; to examine individual complaints of violations of women's rights under the Optional Protocol to CEDAW; and to conduct missions to state parties in the context of concerns about systematic or grave violations of treaty rights.

Civil society participation

NGOs can submit "shadow reports" to the CEDAW Committee on any aspect of a government's compliance with CEDAW. Shadow reports should be submitted through the Division for the Advancement of Women in New York, which also keeps a calendar of when governments come before the Committee. The CEDAW Committee meets twice a year. Individuals and NGOs can also submit complaints to the Committee under the Optional Protocol, or encourage the Committee to undertake country missions as part of its inquiry procedure.

Contact
Tsu-Wei Chang, Coordination and Outreach Unit, Division for the Advancement of Women, Department of Economic and Social Affairs,
Two UN Plaza,
Room DC2 12th Floor,
New York, NY, 10017
Tel: +1 (212) 963-8070, Fax: +1 (212) 963-3463
Email: changt@un.org
Web: http://www.un.org/womenwatch/daw/cedaw/cedaw38/NGOnote.pdf

Committee on the Rights of the Child

Mandate

The Committee on the Rights of the Child (CRC Committee) oversees government compliance with the Convention on the Rights of the Child (CRC). It monitors country progress on the CRC by examining periodic reports submitted by governments.

Civil society participation

NGOs can submit "shadow reports" to the CRC Committee on any aspect of a government's compliance with the Convention. Shadow reports should be submitted through the CRC Secretariat based at the Office of the High Commissioner for Human Rights (OHCHR) in Geneva, which also keeps a calendar of when governments come before the CRC Committee. It meets three times a year.

Contact
Maja Andrijasevic-Boko
CRC Secretary
8-14 Avenue de la Paix, CH 1211 Geneva 10, Switzerland,
Tel: +41 22 917 9000
Fax: +41 22 917 9022
Email: mandrijasevic@ohchr.org
Web: www2.ohchr.org/english/bodies/crc/index.htm

African Commission on Human and People's Rights

Mandate

The African Commission on Human and People's Rights, a body of the Organization of African Unity (OAU), has a broad mandate to protect and promote human rights in Africa, as well as to interpret the provisions of the African [Banjul] Charter on Human and People's Rights. The Commission monitors country progress on the Convention by: examining periodic reports submitted by governments; examining complaints of violations of the Convention's provisions brought by individuals, NGOs, and governments; and undertaking a range of promotional activities related to human rights in Africa.

Civil society participation

Individuals or organizations may submit complaints to the Commission, provided all local remedies have been exhausted and other admissibility criteria have been met. (The requirement of exhausting domestic remedies may be waived if it is obvious to the Commission that this procedure has been unduly prolonged.) Individual or organizational complaints are only considered by the Commission at the request of a majority of its members. Detailed information about the submission procedure can be found on the Commissions website: www.achpr.org/english/information_sheets/ACHPR%20inf.%20sheet%20no.3.doc .

NGOs with observer status with the Commission may attend the Commission's public sittings.

Additional treaties: Additional important treaties overseen by the African Commission on Human and People's Rights include the African Charter on the Rights and Welfare of the Child, OAU Doc. CAB/LEG/24.9/49 (1990) and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, Adopted by the 2nd Ordinary Session of the Assembly of the Union, Maputo, CAB/LEG/66.6 (Sept. 13, 2000), reprinted in 1 Afr. Hum. Rts. L.J. 40.

Note on the African Human Rights Court: To complement the mandate of the African Commission, the African Charter on Human and People's Rights contains a Protocol calling for the establishment of an African Court on Human and People's Rights. As of April 2007, judges for the African Court had been sworn in, however the Court was not yet operational. Once operational, the Court will have jurisdiction over the African Charter and its Protocols and any other "relevant human rights instrument" ratified by the concerned parties. The Court will accept complaints from the Commission, States Parties, and African Intergovernmental Organizations.

Contact
African Commission on Human and People's Rights,
48 Kairaba Avenue, P.O. Box 673 Banjul, The Gambia
Tel: +220 4392 962, 4372 070, 4377 721-23
Fax: +220 4390 764
Email: achpr@achpr.org
Web: www.achpr.org

European Court of Human Rights

- **Mandate**

  The European Court of Human Rights (ECtHR), a body of the Council of Europe (COE), enforces the provisions of the [European] Convention for the Protection of Human Rights and Fundamental Freedoms. The ECtHR adjudicates both disputes between states and complaints of individual human rights violations. The Committee of Ministers of the Council of Europe is responsible for monitoring the implementation of judgments made by the ECtHR. (See note on Committee of Ministers below.)

- **Civil society participation**

  Any individual or government can lodge a complaint directly with the ECtHR alleging a violation of one of the rights guaranteed under the Convention, provided they have exercised all other options available to them domestically. An application form may be obtained from the ECtHR website (www.echr.coe.int/echr/).

  The Council of Europe has established a legal aid scheme for complainants who cannot afford legal representation. NGOs can file briefs on particular cases either at the invitation of the President of the Court, or as "Amici Curia" (Friends of the Court) if they can show that they have an interest in the case or special knowledge of the subject matter, and that their intervention would serve the administration of justice. Hearings of the ECtHR are generally public.

Contact
European Court of Human Rights,
Council of Europe, 67075 Strasbourg-Cedex, France,
Tel: +33 3 88 41 20 18
Fax: + 33 3 88 41 27 30
Web: www.echr.coe.int

European Committee of Social Rights

Mandate

The European Committee of Social Rights (ECSR), also a body of the Council of Europe (COE), conducts regular legal assessments of government compliance with provisions of the European Social Charter. These assessments are based on reports submitted by governments at regular two-to-four-year intervals known as "supervision cycles." The Governmental Committee and the Committee of Ministers of the Council of Europe also evaluate government reports under the ECSR. (See note on Committee of Ministers below.)

Civil society participation

Reports submitted by governments under the European Social Charter are public and may be commented upon by individuals or NGOs. International NGOs with consultative status with the COE, as well as national NGOs authorized by their government, may also submit "collective complaints" to the COE alleging violations of the Charter.

Contact
Web: www.humanrights.coe.int/cseweb/GB/index.htm

Advisory Committee

Mandate

The Advisory Committee (AC) assists the Committee of Ministers in monitoring compliance with the Framework Convention for the Protection of National Minorities (FCNM). It monitors country progress on the FCNM by examining periodic reports submitted by governments. Besides examining these reports, the AC may hold meetings with governments and request additional information from other sources. The AC then prepares an opinion, which is submitted to the Committee of Ministers. Based on this opinion, the Committee of Ministers issues conclusions concerning the adequacy of measures taken by each state party. The AC may be involved by the Committee of Ministers in the monitoring of the follow-up to the conclusions and recommendations.

Civil society participation

NGOs can submit "shadow reports" to the AC on any aspect of a government's compliance with the FCNM. Shadow reports should be submitted through the FCNM Secretariat.

Contact
Directorate General of Human Rights (DGII)
Secretariat of the Framework Convention for the Protection of National Minorities
F – 67075 STRASBOURG CEDEX
France
Tel: +33/(0)3.90.21.44.33
Fax: +33/(0)3.90.21.49.18
Email: minorities.fcnm@coe.int
Web: www.coe.int/minorities

UN Charter bodies

In addition to the treaty bodies listed above, there are a number of bodies created under the Charter of the United Nations for the protection and promotion of human rights.

The principal charter body is the Human Rights Council (HRC), which replaced the Commission on Human Rights (CHR) in 2006. The HRC is a subsidiary organ of the UN General Assembly with a mandate "to address situations of violations of human rights, including gross and systematic violations."

The responsibilities of the Human Rights Council include: the Universal Periodic Review (UPR); the Special Procedures; the Human Rights Council Advisory Committee (formerly the Sub-Commission on the Promotion and Protection of Human Rights); and the Complaints Procedure. These responsibilities are summarized at:
http://www.ohchr.org/english/bodies/hrcouncil/docs/FACTSHEET_OUTCOMES_FINAL.pdf

Universal Periodic Review (UPR)

Beginning in 2008, the HRC will periodically review the human rights obligations and commitments of all countries. All UN Member States will be reviewed for the first time within four years. A working group will meet three times per year for two weeks to carry out the review. The review will take into account a report from the State concerned, as well as recommendations from the Special Procedures (see below) and Treaty Bodies (see above) and information from non-governmental organizations and national human rights institutions.

Special Procedures

"Special Procedures" is the general term given to individuals (known as "Special Rapporteurs," "Special Representatives," or "Independent Experts") or groups (known as "Working Groups") mandated by the HRC to address specific country situations or thematic issues throughout the world. The HRC currently includes twenty-eight thematic and ten country Special Procedures.

Activities undertaken by the Special Procedures include responding to individual complaints, conducting studies, providing advice on technical cooperation at the country level, and engaging in general promotional activities. The Special Procedures are considered "the most effective, flexible, and responsive mechanisms within the UN system."[1]

Special Procedures cited in this Resource Guide include:

- Working Group on Arbitrary Detention
- Special Rapporteur on Extrajudicial, Summary or Arbitrary Executions

[1] FACTSHEET: Work and Structure of the Human Rights Council, July 2007.

- Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health
- Special Rapporteur on Violence against Women, its Causes and Consequences

For more information about the Special Procedures, see: http://www.ohchr.org/english/bodies/chr/special/index.htm

- **Human Rights Council Advisory Committee**

The HRC Advisory Committee functions like a "think tank," providing expertise and advice and conducting substantive research and studies on issues of thematic interest to the HRC at its request. The Committee is made up of eighteen experts serving in their personal capacity for a period of three years.

- **Complaints Procedure**

This confidential complaints procedure allows individuals or organizations to bring complaints about "gross and reliably attested violations of human rights" to the attention of the HRC. The procedure is intended to be "victims-oriented" and to conduct investigations in a timely manner. Complaints are reviewed by two working groups that meet at least twice a year for five days during each period.

Other committees and groups

- **Committee of Ministers**

The Committee of Ministers (www.coe.int/cm) is the decision-making body of the Council of Europe, and is comprised of the foreign ministers (or their permanent representatives) of all COE member states.

In addition to supervising judgments of the ECtHR and evaluating reports under the ECSR (see above), the Committee of Ministers also makes separate Recommendations to member states on matters for which the Committee has agreed to a "common policy"—including matters related to health and human rights.

Some of these Recommendations are provided by the **Parliamentary Assembly** of the Council of Europe (assembly.coe.int), which is a consultative body composed of representatives of the Parliaments of member states

- **European Union**

The European Union (www.europa.eu/europa.ed.int/eur-lex/) has twenty-seven member states and is a separate system from the Council of Europe (www.coe.int), which has forty-seven member states. Mechanisms for

advocating for health and human rights within the European Union (such as EU Directives and the European Court of Justice) are not discussed in this Guide. It should be noted, however, that all member states of the European Union are bound by the institutions and instruments under the Council of Europe.

Economic and Social Council (ECOSOC)

The UN Economic and Social Council (ECOSOC) coordinates the work of fourteen UN specialized agencies, functional commissions, and regional commissions working on various international economic, social, cultural, educational, and health matters. ECOSOC holds several short sessions per year as well as an annual substantive session for four weeks every July.

ECOSOC consults regularly with civil society, with close to 3,000 non-governmental organizations enjoying consultative status. ECOSOC-accredited NGOs are permitted to participate, present written contributions, and make statements to the Council and its subsidiary bodies. Information about NGOs with consultative status can be found at: http://www.un.org/esa/coordination/ngo/.

ECOSOC agencies and commissions that may be cited in or relevant to this Resource Guide include:

- Commission on the Status of Women
- Commission on Narcotic Drugs
- Commission on Crime Prevention and Criminal Justice
- Committee on Economic, Social and Cultural Rights
- International Narcotics Control Board

The Right to the Highest Attainable Standard of Health

What is the legal basis for the "right to health"?

- The best and most complete statement of the "right to health" can be found in the International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 12. It sets out "the right of everyone to the enjoyment of the **highest attainable standard of physical and mental health**."

- *See also* International Convention on the Elimination of All Forms of Racial Discrimination, article 5(e) (iv); Convention on the Elimination of All Forms of Discrimination, Articles 11(f) and 12; Convention on the Rights of the Child, Article 24.

- The Committee on Economic, Social and Cultural Rights, the UN body monitoring compliance with the ICESCR, has provided detailed guidance on implementing the right to health (General Comment 14).

What does the right to health mean?

- A right to **health care** that is **available, accessible, acceptable, and quality** and

- A right to the **underlying determinants of health**, including civil and political rights

What are the components of the right to health care?

- **Availability** of health facilities, goods, and services

- **Accessibility** of health facilities, goods and services; this includes:

  - Non-discrimination
  - Physical accessibility
  - Economic accessibility/affordability
  - Information accessibility

- **Acceptability** of health facilities, goods, and services; they must be:

  - Respectful of medical ethics
  - Culturally appropriate
  - Sensitive to gender and life-cycle requirements

- **Quality** health facilities, goods, and services that are scientifically and medically appropriate

How can this right be meaningfully protected if it is dependent on resources?

- This right contains a **minimum core**, priority obligations, and aspects for **progressive realization to the maximum of available resources**.

- The minimum core includes:

  - Non-discriminatory access to health care.
  - Equitable distribution of health facilities, goods, and services
  - Essential medicines, as defined by the WHO; this encompasses access to palliative care and harm reduction medications.
  - Minimum essential food, potable water, basic shelter, and sanitation.
  - National public health strategies and plans of actions adopted and implemented through a participatory process. National strategies and plans must give particular attention to vulnerable and marginalized groups in both their process and content.

- Priority obligations include:

  - Ensuring reproductive, maternal, and child health care.
  - Providing immunization against major infectious diseases.
  - Taking measures to prevent, treat, and control epidemics.
  - Providing education and information on major health problems.
  - Appropriately training health personnel, including education on health and human rights.

- National public health strategies and plans need to include **benchmarks** to measure progressive realization. There is thus an important **monitoring** role for civil society.

- Courts, tribunals, and health ombudspersons can also play a critical role in ensuring government accountability for the right to health.

Essential reading

General resources in health and human rights

Each chapter of this Guide contains topic-specific resources on the health issue covered by that chapter. The following are general resources on health and human rights, divided into the following categories:

- Conventions: UN
- Conventions: Regional
- Guidelines and interpretations
- Books
- Key articles, reports, and other documents
- Periodicals
- Websites
- Search engines
- Training materials

Conventions: UN

- International Covenant on Civil and Political Rights.
  Source: www.unhchr.ch/html/menu3/b/a_ccpr.htm
- International Covenant on Economic, Social and Cultural Rights.
  Source: www.unhchr.ch/html/menu3/b/a_cescr.htm
- International Convention on the Elimination of all forms of Racial Discrimination.
  Source: www.ohchr.org/english/law/cerd.htm
- Convention concerning Indigenous and Tribal Peoples in Independent Countries.
  Source: www.unhchr.ch/html/menu3/b/62.htm
- Convention on the Elimination of all Forms of Discrimination Against Women.
  Source: www.ohchr.org/english/law/cedaw.htm

- Convention on the Rights of the Child.
  Source: www.ohchr.org/english/law/crc.htm

- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.
  Source: www.ohchr.org/english/law/cat.htm

Conventions: Regional

- African Charter on Human and People's Rights.
  Source: www.achpr.org/english/_info/charter_en.html

- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.
  Source: www.achpr.org/english/_info/women_en.html

- African Charter on the Rights and Welfare of the Child.
  Source: www.achpr.org/english/_info/child_en.html

- [European] Convention on the Protection of Human Rights and Fundamental Freedoms.
  Source: conventions.coe.int/Treaty/en/Treaties/Html/005.htm

- European Social Charter.
  Source: conventions.coe.int/Treaty/EN/Treaties/Html/035.htm

- Framework Convention for the Protection of National Minorities.
  Source: conventions.coe.int/treaty/en/Treaties/Html/157.htm

Guidelines and interpretations

- The Siracusa Principles on the Limitation and Derogation Principles in the ICCPR, especially Article 25.
  Source: www1.umn.edu/humanrts/instree/siracusaprinciples.html

- The Maastricht Guidelines on Violations of Economic, Social, and Cultural Rights.
  Source: www1.umn.edu/humanrts/instree/Maastrichtguidelines_.html

- Committee on Economic, Social and Cultural Rights, General Comment 14, The Right to the Highest Attainable Standard of Health.
  Source: www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En

- Committee on the Elimination of Discrimination against Women, General Recommendation 24, Women and Health.

Source:
www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom24

Books

General Human Rights

- Buergenthal, Thomas and Dinah Shelton and David Stewart. *International Human Rights in a Nut Shell*. West Publishing Company, 1995.
- Cranston M. *What are Human Rights?* New York: Basic Books, 1973.
- Nussbaum M. Capabilities, Human Rights and the Universal Declaration. In: *Weston and Marks. The Future of International Human Rights*, Transnational Publishers, 1999.
- Orend B. *Human rights—Concept and Context*. Broadview Press, 2000.
- Steiner HJ and Alston P. *International Human Rights in Context – Law, Politics, Morals*. 2nd ed. Oxford University Press, 2000. Chapters 1, 4 and 11.
- Sen, Amartya, *Development as Freedom*. Pp.87-100. New York: Anchor Books, 1998.

Health and Human Rights

- Alfredsson, G. and K. Tomasevski. *A Thematic Guide to Documents on Health and Human Rights: Global and Regional Standards adopted by Intergovernmental Organizations, International Non-Governmental Organizations and Professional Associations*. Martinus Nijoff, 1998.
- Asher, Judith. *Right to Health: A Resource Manual*. Commonwealth Medical Trust, 2004
- Beyrer, Christopher and Hank Pizer, eds. *Public Health and Human Rights: Evidence-Based Approaches*. (forthcoming).
- Chapman, Audrey and Sage Russell, eds. *Core Obligations: Building a Framework for Economic, Social and Cultural Rights*. Intersentia, 2002.
- Cook, Rebecca J, Bernard Dickens, and Mahmoud Fathalla. *Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law*. Oxford: Oxford University Press, 2003.
- Farmer, Paul. *Infections and Inequalities: The Modern Plagues*. California: University of California Press, 2001.

- Farmer, Paul. *Pathologies of Power: Health, Human Rights and the New War on the Poor*. California: University of California Press, 2003.
- Gostin, Lawrence O. *Public Health Law: Power, Duty, Restraint*. California: University of California Press, 2003.
- Gruskin, Sofia and Michael A. Grodin, George J. Annas, and Stephen P. Marks, eds. *Perspectives on Health and Human Rights*. Routledge, 2005.
- Mann, Jonathan M. and Sofia Gruskin, Michael A. Grodin, and George J. Annas, eds. *Health and Human Rights: A Reader*. Routledge, 1999.
- Marks, Stephen. *Health and Human Rights: Basic International Documents*. Boston: Harvard University Press, 2006.

Key articles, reports, and other documents

- Annas, George J. Human Rights and Health—The Universal Declaration of Human Rights, 339 *New Eng. J. Med.* 1778 (1998).
- Asher, Judith. *Right to Health: A Resource Manual for NGOs.*, 2004 www.shr.aaas.org/Right_to_Health_Manual/index.shtml
- Beyrer, Chris. Public Health, Human Rights, and the Beneficence of States, *Human Rights Review* 2004, 5(1) 28-33.
- Burris Scott. "Law as a Structural Factor in the Spread of Communicable Disease." Houston Law Review 36 (1999): 1756-1786.
- Burris, Scott and Zita Lazzarini and Lawrence O Gostin. "Taking Rights Seriously." Journal of Law, Medicine & Ethics, 30(2002):490-491.
- Farmer P, Gastineau N. Rethinking Health and Human Rights: Time for a Paradigm Shift. J Law, Med and Ethics (2002) 30:4:655-666.
- Farmer, Paul. *Never Again? Reflections on Human Values and Human Rights*. Tanner lectures on Human Values. University of Utah: 2005.
- Goodman T. Is There A Right To Health? J. of Medicine and Philosophy, 30:643-662, 2005.
- Gruskin, Sofia and Trantola, Daniel. "Health and Human Rights, paper, to appear as chapter in The Oxford Textbook of Public Health, 4th edition, Detels, McEwan, Beaglehole and Tanaka, eds, (Oxford University Press).

- *Human Rights and Health in Prisons: a review of strategy and practice,* Penal Reform International and Royal Netherlands Tuberculosis Foundation (2006).
- *Human Right to Health Information Sheet 1: Human Right to Health,* National Economic and Social Rights Initiative.
- *Human Right to Health Information Sheet 2: Human Right to Health Care,* National Economic and Social Rights Initiative.
- Leary, V. "The Right to Health in International Human Rights Law," *Health and Human Rights: An International Journal*, 1994, 1(1):24-56.
- London, Leslie. "Human Rights and Public Health: Dichotomies or Synergies in Developing Countries? Examining the Case of HIV in South Africa." *Journal of Law, Medicine and Ethics* 30 (2002): 677-691
- London, Leslie. "Issues of equity are also issues of rights: Lessons from Experiences in Southern Africa," *BMC Public Health* 2007, 7:14.
- Mann, Jonathan. Medicine and Public Health, Ethics and Human Rights, Hastings Center Rep., May-June 1997.
- Ngwena, Charles. "The Recognition of Access to Health Care as a Human Right in South Africa: Is It Enough?" *Health and Human Rights: An International Journal* 5 (1): 26-44 (2000).
- Odinkalu, Chidi Anselm. "Analysis of Paralysis or Paralysis by Analysis? Implementing Economic, Social and Cultural Rights under the African Charter on Human and Peoples' Rights." *Human Rights Quarterly* 23.2 (2001) 327-369.
- Office of the High Commissioner for Human Rights, Fact Sheet on the Right to Health.
- Potts, Helen. Human Rights Centre. University of Essex. *Accountability and the Right to the Highest Attainable Standard of Health*. 2008. www2.essex.ac.uk/human_rights_centre/rth/docs/HRC_Accountability_Mar08.pdf
- Right to Health Unit, Human Rights Centre, University of Essex, Right to the Highest Attainable Standard of Health, Inter-Regional Conference on Human Rights and Judiciary Systems.
- Human Rights Centre, University of Essex, International Federation of Health and Human Rights Organizations. *Our Right to the Highest Attainable*

Standard of Health.
http://www2.essex.ac.uk/human_rights_centre/rth/docs/REVISED_MAY07_RtH_8pager_v2.pdf

- United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, Initial Report on Sources and Content of the Right to Health, E/CN.4/2003/58.

- United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, Report on Mission to Uganda, E/CN.4/2006/48/Add.2.

- United Nations Special Rapporteur on the Right to the Highest Attainable Standard of Health, Report on Progress and Obstacles to the Health and Human Rights Movement, in addition to Cases on the Right to Health and other Health- Related Rights, A/HRC/4/28.

- World Health Organization. 25 Questions and Answers on Health and Human Rights, Health and Human Rights Publications Series 1 (2002).

- World Health Organization. Fact Sheet on the Right to Health.

- Zuckerman, Barry and Ellen Lawton and Samatra Morton. *From Principles to Practice: Moving from Human Rights to Legal Rights to Ensure Child Health.*

Periodicals

- Health and Human Rights: An International Journal.

- The Lancet (contains a regular health and human rights section).

- BMC International Health and Human Rights.

Websites

- Amnesty International Health Professional Network
web.amnesty.org/pages/health-index-eng

- BMC International Health and Human Rights
www.biomedcentral.com/bmcinthealthhumrights/

- François Xavier Bagnoud Centre for Health and Human Rights, Harvard School of Public Health
www.hsph.harvard.edu/fxbcenter/

- Global Lawyers and Physicians
www.glphr.org

- The International Center for the Legal Protection of Human Rights (monthly report of significant human rights decisions from common law jurisdictions)
  www.interights.org

- International Federation of Health and Human Rights Organizations
  www.ifhhro.org

- International Society for Health and Human Rights
  www.ishhr.org

- International Helsinki Federation for Human Rights (IHF)
  The IHF is a community of 46 human rights NGOs in the OSCE area that co-operate on promoting implementation of human rights and compliance with international human rights standards.
  www.ihf-hr.org/index.php

- Johns Hopkins School of Public Health Center for Public Health and Human Rights
  www.jhsph.edu/humanrights/index.html

- National Economic and Social Rights Initiative
  www.nesri.org

- Physicians for Human Rights
  physiciansforhumanrights.org/

- Science and Human Rights Program of the American Association for the Advancement of Science
  shr.aaas.org

- Special Rapporteur on the Right to the Highest Attainable Standard of Health
  www2.essex.ac.uk/human_rights_centre/rth/rapporteur.shtm **or**
  www.ohchr.org/english/issues/health/right/

- University of Minnesota Human Rights Library contains a lengthy list of health and human rights websites, though many of these are out of date
  www1.umn.edu/humanrts/links/health.html

- World Health Organization's Health and Human Rights page
  WHO's 25 Questions and Answers on Health and Human Rights is a useful introductory document
  www.who.int/hhr/en/

Search engines

- The UN Treaty Body Database includes all general comments, concluding observations, reports, and other documents of the UN human rights system, organized by treaty monitoring body and special procedure.
  www.unhchr.ch/tbs/doc.nsf

- The International Human Rights Index also includes the above documents but is searchable by key word, country, and right.
  www.universalhumanrightsindex.org

- The University of Minnesota has an excellent database of international human rights documents and information. It is organized simply and clearly and is generally the easiest way to find documents.
  www1.umn.edu/humanrts/

- Professor Anne Bayefsky's website (York University, Toronto, Canada) includes international human rights documents and jurisprudence that are searchable by country, category of document, and theme or subject matter.
  www.bayefsky.com

- The Global Justice Center maintains a database of domestic and international court decisions that cite to CEDAW or the CEDAW Optional Protocol.
  www.globaljusticecenter.net/casebank

- The European Court of Human Rights maintains a database of decisions.
  cmiskp.echr.coe.int/tkp197/search.asp?skin=hudoc-en

- Health and Human Rights Info, a project of the International Society for Health and Human Rights, is a searchable database of organizations, manuals, training materials, projects and reports, and articles related to several areas of health and human rights.
  www.hhri.org

- The Harvard School of Public Health has produced a searchable database of syllabi from health and human rights courses around the world.
  www.hsph.harvard.edu/pihhr/syllabidatabase.html

Training materials

- The Human Rights Resource Center, part of the University of Minnesota human rights library, contains a range of interactive training packages on human rights.
  www1.umn.edu/humanrts/edumat/

- The website of Equitas contains a collection of education manuals and resources as well as extensive information and links to Equitas projects and partners.
  www.equitas.org

What are key terms related to health and human rights?

Glossary

The following terms relate both to health and human rights and to human rights in general.

A

Acceptability
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Acceptability: means that all health facilities, goods and services must be respectful of medical ethics, culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned (General Comment 14). *See also* "Adequacy," "Availability," and "Quality."

Accessibility
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health health. Accessibility: means that health facilities, goods and services have to be accessible to everyone without discrimination. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility (General Comment 14). *See also* "Acceptability," "Adequacy," and "Quality."

Accession
Acceptance by a state of the opportunity to become a party to a treaty and be legally bound by it. Unlike ***ratification***, this is a one-step process.

Actio popularis (public action)
A legal action brought by any member of a community in vindication of a public interest.

Adoption
Process by which the parties drafting a treaty agree to its text and open the treaty for ***accession*** or ***ratification*** by potential state parties.

Adoption theory
Theory maintaining that international law becomes an automatic part of domestic law following treaty ***accession*** or ***ratification***, without further ***domestication***.

Amicus curiae (friend of the court)
A legal document filed with the court by a party not involved in a lawsuit, generally advocating a particular legal position or interpretation.

Availability
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Availability: means that functioning public health and health care facilities, goods, and services, as well as programmes, have to be available in sufficient quantity. This should include the underlying determinants of health, such as safe drinking water, adequate sanitation facilities, clinics and health-related buildings, trained medical personnel, and essential drugs (General Comment 14). *See also* "Acceptability," "Accessibility," and "Quality."

B

Basic needs
Used largely in the development community to refer to basic health services, education, housing, and other goods necessary for a person to live.

C

Concluding observations
Recommendations by a treaty's enforcement mechanism on the actions a state should take in ensuring compliance with the treaty's obligations. This generally follows both submission of a state's ***country report*** and a constructive dialogue with state representatives.

Country report
A state's report to the enforcement mechanism of a particular treaty on the progress it has made in implementing it.

Customary international law
A source of international law consisting of rules derived form the consistent conduct of states acting out of the belief of a legal obligation. A particular category of customary international law, ***jus cogens***, refers to a principle of international law so fundamental that no state may opt out by treaty or otherwise.

D

De facto (in fact, in reality)
Existing in fact.

De jure (by right, lawful)
A situation or conclusion based on law.

Dignity
The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

Discrimination

Distinction between persons in similar cases on the basis of race, sex, relation, political opinions, national or social origins, association with a national minority, or personal antipathy (WHO).

Domestication
Process by which an international treaty is incorporated into domestic legislation.

E

Entry into force
Point at which a treaty becomes a legally binding document on all state parties.

Essential medicines
Medicines that satisfy the priority health-care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

Exhaustion of domestic remedies
Requirement to seek all available avenues for national redress before submitting a complaint on behalf of a victim to any regional or international tribunal. There are limited exceptions to this requirement if national remedies are unavailable, ineffective (sham proceedings), or unreasonably delayed.

G

General comments/recommendations
Interpretive texts issues by a treaty's enforcement mechanism on the content of particular rights. Although these are not legally binding, they are widely regarded as authoritative and have significant legal weight.

H

Health
A state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity (WHO).

Human rights
Universal legal guarantees for all human beings, set out in international standards, protecting human dignity and fundamental freedoms and privileges. Human rights cannot be waived or taken away.

Human rights covenants/conventions
Treaties which are legally binding on states which ratify them.

Human rights declarations
Statements of non-binding human rights norms and principles (though they may reflect binding customary international law).

Human rights indicators
Criteria used to measure compliance with international human rights standards.

I

Interdependent/ indivisible
Term used to describe the relationship between civil and political rights and economic and social rights. Interdependence and indivisibility mean that one set of rights does not take precedence over the other, and that guaranteeing each set of rights is contingent upon guaranteeing the other.

International law
The set of rules and legal instruments regarded and accepted as binding agreements between nations. Sources are: treaties, custom, general principles of law, and judicial decisions and juristic writings (Statute of the International Court of Justice, art. 38(1)(d)).

Interpretive declaration
Declaration by a state as to its understanding of some matter covered by a treaty. Unlike ***reservations*** (see below), declarations merely clarify a state's position and do not purport to exclude or modify the legal effect of a treaty.

M

Maximum available resources
Key provision of ICESCR, Article 2 obliging governments to devote the maximum of available government resources to realizing economic, social and cultural rights.

Monitoring/ fact finding/ investigation
Terms often used interchangeably, generally intended to mean the tracking and/or gathering of information about government practices and actions related to human rights.

N

Negative rights
State obligations to refrain from interfering with a person's attempt to do something.

Neglected diseases
Diseases affecting almost exclusively poor and powerless people in rural parts of low-income countries that receive less attention and resources.

P

Positive rights
State obligations to do something for someone.

Progressive realization
Requirement that governments move as expeditiously and effectively as possible toward the goal of realizing economic, social and cultural rights, and to ensure there are no regressive developments.

Protocol
Addition to a treaty that clarifies terms, amends text, or establishes new obligations.

Public health
What we as a society do collectively to ensure the conditions in which people can be healthy (Institute of Medicine).

Q

Quality
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Quality: means that health facilities, goods, and services must be scientifically and medically appropriate and of good quality. This requires skilled medical personnel, scientifically approved and unexpired drugs, and hospital equipment (General Comment 14). *See also* "Acceptability," Accessibility," and "Availability."

R

Ratification
Follows ***signature*** and indicates a state's acceptance of a treaty and agreement to be bound by it.

Reservation
A unilateral statement by a state when signing, ratifying, or acceding to a treaty which purports to exclude or modify the effect of certain treaty provisions. Under the Vienna Convention on the Law of Treaties, a state cannot enter a reservation that is "incompatible with the object and purpose of the treaty."

Respect, protect, and fulfill
Governments' obligations with respect to rights. ***Respect:*** government must not act directly counter to the human rights standard. ***Protect:*** government must act to stop others from violating the human rights standard. ***Fulfill:*** government has an affirmative duty to take appropriate measures to ensure that the human rights standard is attained.

Right to health
Right to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realization of the highest attainable standard of health.

S

Self executing treaty
A treaty that does not require implementing legislation for its provisions to have effect in domestic law.

Shadow report
Independent NGO submission to a treaty enforcement mechanism to help it assess a state's compliance with that treaty.

Signature
Expression of a state's willingness to continue the treaty-making process and proceed to ratification. Although the provisions of the treaty are not yet legally binding on the states, signature creates an obligation to refrain in good faith from acts that would defeat the object and purpose of the treaty.

Special procedures

Mechanisms with the Human Rights Council, including special rapporteurs, clarifying communications with countries, and country missions, to address country-specific human rights violations or thematic issues.

Special rapporteurs
Individuals appointed by the Human Rights Council to investigate human rights violations and present an annual report with recommendations for action. There are both country-specific and thematic special rapporteurs, including one on the right to the highest attainable standard of health.

T

Transformation theory
Theory maintaining that international law only becomes part of domestic law after ***domestication*** and the incorporation of treaty provisions into domestic legislation.

Treaty
A formal agreement entered by two or more nations which is binding upon them.

U

Underlying determinants of health
Conditions necessary for good health, including safe and potable water, adequate food, housing, halthy occupational and environmental conditions, health-related education, non-discrimination, etc. This includes both social and economic and civil and political rights.

W

Working groups
Small committees appointed by the Human Rights Council on a particular human rights issue. Working groups write governments about urgent cases and help prevent future violations by developing clarifying criteria on what constitutes a violation.

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Photo courtesy of Physicians for Human Rights

Chapter 1 Human Rights in Patient Care

"There is no difference between men, in intelligence or race, so profound as the difference between the sick and the well."

F. Scott Fitzgerald

Contents

Introduction

This chapter will introduce you to key issues and resources related to human rights in **patient care,** with a particular focus on issues such as **consent, confidentiality, access to information** and **care**.

While other chapters in this Resource Guide focus on specific populations—such as people living with and affected by HIV and AIDS, people who use drugs, sex workers, LGBT communities, and ethnic minorities—this chapter addresses human rights issues affecting patients as a whole.

The chapter is organized into six sections that answer the following questions:

- **How** is patient care a human rights issue?
- **What** is OSI's work in the area of human rights in patient care?
- **Which** are the most relevant international and regional human rights standards related to patient care?
- **What** are some examples of effective human rights programming in the area of patient care?
- **Where** can I find additional resources on human rights in patient care?
- **What** are key terms related to human rights in patient care?

As you read through this chapter, consult the **glossary of terms** found in the last section, *What are key terms related to patient care and human rights?*

How is patient care a human rights issue?

What is patient care?

Patient care refers to the prevention, treatment and management of illness and the preservation of physical and mental well-being through services offered by medical and allied health professions; this, and similar definitions, often are provided for the term *"health care"* as well. Patient care consists of services rendered by members of the health professions or non-professionals under their supervision for the benefit of the patient.[1] A **Patient** is a user of health care services, whether healthy or sick.[2]

What are human rights in patient care?

The concept of "**human rights in patient care**" brings together the rights of both patients and health care providers. It refers to the application of general human rights principles to all stakeholders in the delivery of health care. It encompasses all rights recognized under international law that are relevant to the provision of health services. This includes basic empowerment rights (such as information, consent, free choice, privacy and confidentiality), rights to a remedy for abuses, and rights of access to services.

Human rights in patient care is complementary to bioethics but provides a set of universally accepted norms and procedures for making conclusions about abuses within health care settings and providing remedies. It uses standards contained in the international human rights framework, which are often mirrored in regional treaties and national constitutions. It differs from patients' rights, which codify particular rights that are relevant only to patients rather than applying general human rights standards to all stakeholders in health care service delivery, including providers. It draws on concepts such as dual loyalty, which attributes much human rights abuse in health settings to health care providers' simultaneous and often conflicting obligations to their patients and to the State.

What are patient rights?

"**Patient rights**" refers to a "set of rights, responsibilities and duties under which individuals seek and receive health care services."[3]

The call for patients' rights is a movement that is growing globally to make governments and health care providers more accountable for providing access to quality health services. In 1997, the Council of Europe adopted the **Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine** (European Convention on Human Rights and Biomedicine). This convention sets out certain basic patient rights principles, such as equitable access to health care and protection of consent, private life, and right to information, binding on ratifying states.

[1] Dorland's Illustrated Medical Dictionary, 28th ed., p. 269
[2] Declaration on the Promotion of Patients' Rights in Europe, European Consultation on the Rights of Patients, WHO, Amsterdam 1994.
[3] European Observatory on Health Systems and Policies Glossary (citing USAID, 1999).

The **European Charter of Patients' Rights**, compiled in 2002 by Active Citizenship Network, a European network of civic, consumer, and patient organizations, provides a clear, comprehensive statement of patient rights. This statement was part of a grassroots movement across Europe for patients to play a more active role in shaping the delivery of health services and an attempt to translate regional documents on the right to health care into specific provisions.[4] Although this Charter is not legally binding, a strong network of patient rights groups across Europe have successfully lobbied their national government for recognition and adoption of rights in the Charter.[5] The Charter has also been used as a reference point to monitor and evaluate health care systems across Europe. In September 2007, the European Economic and Social Committee (EESE) approved its own initiative opinion on patients' rights, declaring that it "welcomes and acknowledges" the European Charter of Patients' Rights.

European Charter of Patients' Rights

Source: Active Citizenship Network, 2002

The 14 'immutable' rights	Description
1. Right to preventive measures	Every individual has the right to a proper service, in order to prevent illness.
2. Right of access	Every individual has the right of access to the health services that his or her health needs require. The health services must guarantee equal access to everyone, without discriminating on the basis of financial resources, place of residence, kind of illness, or time of access to services.
3. Right to information	Every individual has the right of access to all kinds of information regarding their state of health, the health services (and how to use them), and all that scientific research and technological innovation makes available.
4. Right to consent	Every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health. This information is prerequisite for any procedure and treatment, including participation in scientific research.
5. Right to free choice	Each individual has the right to freely choose from among different treatment procedures and providers, on the basis of adequate information.

[4] It is important to note that the pharmaceutical company Merck & Co. also provided funding for this movement.

[5] One of the activities of new EU member-states during the process of preparation for accession in the EU was adjustment of health care legislation towards European standards. Many countries, such as Bulgaria, adopted a new health law, whose structure and contents are strictly in line with the European Charter of Patients' Rights.

The 14 'immutable' rights	Description
6. Right to privacy and confidentiality	Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general.
7. Right to respect for patients' time	Each individual has the right to receive necessary treatment within a swift and predetermined period of time. This right applies at each phase of the treatment.
8. Right to observance of quality standards	Each individual has the right of access to high-quality health services, on the basis of the specification and observance of precise standards.
9. Right to safety	Each individual has the right to be free from harm caused by the poor functioning of health services, medical malpractice and errors, and the right of access to health services and treatments that meet high safety standards.
10. Right to innovation	Each individual has the right of access to innovative procedures (including diagnostic procedures), according to international standards and independently of economic or financial considerations.
11. Right to avoid unnecessary suffering and pain	Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness.
12. Right to personalised treatment	Each individual has the right to diagnostic or therapeutic programmes tailored as much as possible to his or her personal needs.
13. Right to complain	Each individual has the right to complain whenever he or she has suffered harm, and the right to receive a response or other feedback.
14. Right to compensation	Each individual has the right to receive sufficient compensation within a reasonably short time whenever he or she has suffered physical (or moral and psychological) harm caused by a health service treatment

Did you know?

- Worldwide, information about patient rights is severely lacking.
  - In **Macedonia**, while 82% of respondents stated that there are patient rights, 56% do not know what their rights are.[6]
  - In **Lithuania**,
    - 85% of medical staff (out of 255) and 56% of patients (out of 451) had heard of or read about patients' rights laws;
    - 50% of professionals and 69% of patients thought information about diagnosis, treatment results, and alternatives necessary for patients.[7]

- There are widespread misconceptions about the meaning of forms providing for patient consent to invasive surgery.
  - In a recent survey among 732 European surgical patients,
    - 46% believed that the primary function of the written consent form was to protect the hospital,
    - 68% thought that the form allowed doctors to take control, and
    - 41% believed consent forms made their wishes known.[8]

- Access to essential medicines is lacking in developing countries.
  - The total number of people without access to essential medicines is estimated at between 1.3 and 2.1 billion people.
  - According to a 1999 study, about 30% of the world population lacked access to essential medicines.
  - Only 10% of R&D spending is directed to health problems that account for 90% of the global disease burden.
  - A small number of companies dominate global production, trade, and sale of medicines. Ten companies account for almost half of all sales.[9]

- Worldwide, medicines are often inappropriately taken.
  - Half of all medicines are inappropriately prescribed, dispensed, or sold.
  - Half of all patients fail to take their medicines properly.
  - An estimated 2/3 of global antibiotic sales occur without any prescription.
  - In **Pakistan** and **India**, 70% of patients were prescribed antibiotics, and up to 90% of injections are estimated to be unnecessary.
  - In the **United States**, adverse drug events rank among the top 10 causes of death and cost between $30-130 billion each year.[10]

[6] Rights of Patients in Macedonia According to European Standards 2005.
[7] BMC International Health and Human Rights 2006, 6:10.
[8] BMJ September 2006.
[9] World Health Organization, The World Medicines Situation (2004).

What is OSI's work in the area of human rights in patient care?

Although OSI does not have a program on human rights in patient care, patient care issues arise in the work of the International Harm Reduction Development Program, International Palliative Care Initiative, Sexual Health and Rights Project, and Roma Health Project. Moreover, the OSI **Mental Health Initiative (MHI)** focuses on ensuring the human rights of people with mental disabilities to participate in society and live as equal citizens, working to end their unjustified and inappropriate institutionalization (www.soros.org/initiatives/mhi).

The **Human Rights and Governance Grants Program (HRGGP)** supports the leading mental disability rights NGOs working in Central and Eastern Europe and the former Soviet Union as well as other projects on patients' rights through human rights monitoring, documentation, and litigation.

The **Law and Health Initiative (LAHI)** has a specific objective to promote human rights in patient care (www.soros.org/initiatives/health/focus/law). It supports the establishment of human rights guidelines for the delivery of medical services and the training of health workers, as well as legal action to remedy abuses in the health care system. In February 2007, LAHI sponsored a one-week seminar, which brought together experts from legal, public health, and medical perspectives and patient advocates to think creatively about human rights in patient care and how to structure a course dealing with this concern. Topics explored included:

- International Framework for Health and Human Rights
- Regional and Constitutional Protection of Health
- Institutionalization and the Health Care System
- Criminalized Populations and Disease Vulnerability
- Patient Privacy, Consent, and Confidentiality
- Providers' Rights and Their Relationship to Patients' Rights
- Legal Remedies for Health Care Abuses
- Human Rights in Health Care Reform

Delegations came from six former Soviet Union countries: Armenia, Georgia, Kazakhstan, Kyrgyzstan, Russia, and Ukraine.

[10] World Health Organization, The World Medicines Situation (2004).

Which are the most relevant international and regional human rights standards related to patient care?

Overview

A wide variety of human rights standards at the international, regional, and national levels applies to patient care. These standards can be used for many purposes:

- **To document** violations of patient rights
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, **examples** of human rights violations related to patient care are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** and **provisions** from patient right charters and declarations, **interpreting** each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the violations, standards, and precedents and interpretations that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on patient care and human rights.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights **(ICCPR)**	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**) (with Committee of Ministers)
European Social Charter (**ESC)**	European Committee of Social Rights (**ECSR**)

Table 1: Patient care and the right to liberty and security of the person

Examples of Human Rights Violations	
• A hospital employs excessive restraints on patients, such as tying them to a bed or wheelchair for hours each day. • Mentally ill patients are confined without a set procedure or standard. • There are unjustified delays in reviewing whether mentally ill patients must continue to be institutionalized. • Patients are detained in hospitals for their inability to pay bills.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 9(1) Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law. **ACHPR 6** Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained. **ECHR 5(1)** Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.	**HRC:** considering a period of 14 days of detention for mental health reasons without review by a court in **Estonia** incompatible with ICCPR 9. [CCPR/CO/77/EST (HRC, 2003), para. 10]. **ECtHR:** establishing that civil commitment must follow a procedure prescribed by law and cannot be arbitrary; the person must have a recognized mental illness and require confinement for the purposes of treatment. [Winterwerp v. **The Netherlands**, 33 Eur. Ct. H.R. (ser. A) (1979)]. **ECtHR:** mandating speedy periodic legal review of civil commitment with the essential elements of due process. [X v. **United Kingdom**, 46 Eur. Ct. H.R. (ser. A) (1981)]. **ECtHR:** awarding damages for violation of liberty interests to a patient detained in a Hungarian psychiatric hospital for 3 years where the commitment procedure was superficial and insufficient to show dangerous conduct. [Gajcsi v. **Hungary** (Application No. 34503/03), Oct. 3, 2006].

Table 2: Patient care and the right to privacy

Examples of Human Rights Violations
• Patient medical information is open to all hospital staff, including those not involved in patient care. • Patients are forced to disclose their medical diagnosis to their employer in order to obtain sick leave from work. • Medical examinations take place under public conditions. • Terminally-ill patients are forced to remain in public wards. • Staff of medical/ psychiatric institutions routinely open patient mail and review their correspondence.

Human Rights Standards	Precedents and Interpretations
ICCPR 17(1) No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. **CRC 16(1)** No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation. **ECHR 8(1)** Everyone has the right to respect for his private and family life, his home and his correspondence. ***See also:*** • European Convention on Human Rights and Biomedicine, art 10(1): "Everyone has the right to respect for private life in relation to information about his or her health."	**CESCR:** referring to "the right to have personal health data treated with confidentiality." [CESCR GC 14, para 12]. **CRC Committee:** highlighting the need for confidentiality for adolescents with respect to sexual and reproductive health in **Djibouti** [CRC/C/97(2000)96, para. 555]. **ECtHR:** holding that "the protection of personal data, not least medical data, is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life. Respecting the confidentiality of health data is a vital principle . . . . It is crucial not only to respect the sense of privacy of the patient but also to preserve his or her confidence in the medical profession and in the health services in general." [M.S. v. **Sweden** (27/08/1997)]. **ECtHR:** noting that disclosure of health data "may dramatically affect a person's private and family life, as well as social and employment situation, by exposing him or her to opprobrium and the risk of ostracism." [Z. v. **Finland**, 25/02/1997]. ***See also:*** • The European Charter of Patients' Rights sets out: "Every individual has the right to the confidentiality of personal information, including information regarding his or her state of health and potential diagnostic or therapeutic procedures, as well as the protection of his or her privacy during the performance of diagnostic exams, specialist visits, and medical/surgical treatments in general." [art. 6].

Table 2: Patient care and the right to privacy, **continued**

Human Rights Standards	Precedents and Interpretations
	• Under the Declaration on the Promotion of Patients' Rights in Europe, "All information about a patient's health status . . . must be kept confidential, even after death." "Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy." [art. 4.1, 4.8].

Table 3: Patient care and the right to information

Examples of Human Rights Violations
• A state fails to provide information on various health care services. For instance, rape victims are entitled to obtain post-exposure prophylaxis to prevent HIV infection, but very few are aware of this option. • Hospitals fail to provide information on patient satisfaction, clinical performance, and waiting lists. • Physicians fail to comprehensibly explain to patients the facts related to their condition. • Physicians fail to provide patients with information about treatment options and the potential risks and benefits of each procedure. • Patients are denied access to their medical files. • Information services are unavailable for people who speak certain languages or who are deaf or blind.

Human Rights Standards	Precedents and Interpretations
ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice. **ACHPR 9 (1)** Every individual shall have the right to receive information. **(2)** Every individual shall have the right to express and disseminate his opinions within the law. **ECHR 10 (1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises. ***See also:*** • European Convention on Human Rights and Biomedicine, art 10(2): "Everyone has the right to know any information collected about his or her health."	**CESCR:** health care accessibility "includes the right to seek, receive and impart information and ideas concerning health issues." [CESCR GC 14, para 12]. ***See also:*** • Under the European Charter of Patients' Rights, "Every individual has the right of access to all kinds of information regarding their state of health and health services and how to use them, and all that scientific research and technological innovation makes available." [art. 3]. • The Declaration on the Promotion of Patients' Rights in Europe emphasizes, "Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment." Moreover, "[p]atients have the right to choose who, if any one, should be informed on their behalf." [art. 2.2, 2.6].

Table 4: Patient care and the right to bodily integrity

Examples of Human Rights Violations	
• Physicians either fail to obtain consent from patients before performing medical procedures, or do not provide patients with adequate information so that they can make an informed decision. • In the case of a very young patient or a patient lacking capacity, the hospital does not allow for a substitute decision-maker. • A hospital lacks standardized procedures for obtaining patients' consent to participate in scientific research. • Physicians ignore patient wishes regarding treatment. • Patients are not allowed to switch physicians or healthcare providers.	
Human Rights Standards	**Precedents and Interpretations**
ACHPR 4 Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. *Note:* The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, or European conventions, but has been interpreted to be part of the right to security of the person (ICCPR 9, ECHR 5), the right to freedom from torture and cruel, inhuman, and degrading treatment (ICCPR 7, ECHR 3), the right to privacy (ICCPR 17, ECHR 8), and the right to the highest attainable standard of health (ICESCR 12, ESC 11). ***See also:*** • CRC 19(1) (protecting the child from all forms of physical or mental violence) • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1): "Every woman shall be entitled to respect for her life and the integrity and security of her person." • European Convention on Human Rights and Biomedicine, art 5: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it."	**CESCR:** explaining that the right to health includes "the right to be free from non-consensual medical treatment and experimentation." [CESCR GC 14, para. 8]. **ECtHR:** "[The imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention" [Pretty v. **United Kingdom,** 2002]. **ECtHR:** finding a breach of physical and moral integrity when dimorphine was administered to a son against his mother's wishes and a DNR (Do Not Resuscitate) order was placed in his records without his mother's knowledge [Glass v. **United Kingdom** (Application no. 61827/00, 2004)]. ***See also:*** • The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, ("CPT 2001") : "[E]very competent patient…should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances." • The European Charter of Patients' Rights sets out the right to "informed consent." "A patient has the right to refuse a treatment or a medical intervention and to change his or her mind during the treatment, refusing its continuation." [art. 4]. Moreover, a patient has "the right to freely choose from different treatment procedures and providers on the basis of adequate information." [art. 5]. • Under the Declaration on the Promotion of Patients' Rights in Europe, "[t]he informed consent of the patient is a prerequisite for any medical intervention," and "[a] patient has the right to refuse or halt a medical intervention." [art. 3.1, 3.2].

Table 5: Patient care and the right to life

Examples of Human Rights Violations	
• Due to inadequate reproductive health and prenatal care, complications from pregnancy and childbirth are a leading cause of death for young women. • Ambulances fail to arrive at certain communities in a timely manner. • Patients are unable to obtain low cost medications due to bureaucratic hurdles and an overly restrictive patent regime. As a result, their life is in danger. • Health services do not include preventive screening for many types of cancer. As a result, patients learn they have cancer when it is already too late for effective treatment.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	**HRC:** explaining that the right to life "should not be interpreted narrowly" or "in a restrictive manner," and its protection "requires that States adopt positive measures . . . to increase life expectancy." [HRC GC 6, paras 1, 5]. **ECtHR:** holding that a violation of the right to life occurs "whre it is shown that the authorities . . . put an individual's life at risk through the denial of health care which they have undertaken to make available to the population generally." [Cyprus v. **Turkey**, 35 EHRR 721, para. 219 (2002)]

Table 6: Patient care and the right to the highest attainable standard of health

Examples of Human Rights Violations	
• Hospitals do not take adequate measures to prevent hospital-borne infections, oversee health risks following transfusions, and ensure their tests and treatment remain of high quality. • Hospitals fail to meet the needs of patients who require religious or psychological support or provide treatment appropriate for the terminally ill. • Hospitals fail to provide care suited to the needs of small children. • Long, unjustified delays in the provision of health services regularly lead to a worsening in patients' health. • A state lacks adequate compensation procedures for patients harmed by health care providers.	
Human Rights Standards	**Precedents and Interpretations**
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. **12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right 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. **CRC 24(1)** States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. **ACHPR 16(1)** Every individual shall have the right to enjoy the best attainable state of physical and mental health. **16(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick. **ESC 11** – The right to protection of health With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed . . . **(2)** to provide advisory and educational facilities for the promotion of health . . . ***See also:*** • African Charter on the Rights and Welfare of the Child, art. 14 (child's right to the highest attainable standard of health)	**CESCR:** "As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality." They must also be "sensitive to gender and life-cycle requirements." [CESCR GC 14, para 12]. **CESCR:** pointing to a need for federal legislation on the patient rights in **Russia**, including redress for medical errors. [E/C.12/1/ADD.94 (CESCR, 2003), para. 32]. **ECtHR**: holding that states have a duty to protect the health of detainees and lack of treatment may amount to a violation of the right to freedom from torture or to inhuman or degrading treatment [Hutardo v. **Switzerland** (Series A No. 280-A, 28/01/94); Ilhan v. **Turkey**, 34 EHRR 36 (2002)]. ***See also:*** • CPT 2001: The provision of basic necessities of life must always be guaranteed in institutions where the State has persons under its care and/or custody. These include adequate food, heating and clothing as well as, in health establishments – appropriate medication. [Para 33]. • The European Charter of Patients' Rights refers to the right to "the observance of quality standards," "safety," "innovation." [arts 8-10]. • The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, "Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider." [art. 5.3].

Table 7: Patient care and freedom from torture and cruel, inhuman, and degrading treatment

Examples of Human Rights Violations
• Victims of state torture are denied needed medical care. • Prisoners lack basic health services and are forced to subsist on very little food and with inadequate clothes and no heat during the winter. • Mentally ill prisoners are punished for symptoms of their illness, including self-mutilation and attempted suicide. • National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain.

Human Rights Standards	Precedents and Interpretations
ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. **ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment. ***See also:*** • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment • Code of Conduct for Law Enforcement Officials • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1) "All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited." • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment	**HRC:** calling for the improvement of hygienic conditions, regular exercise, and adequate treatment of the mentally ill in detention facilities in **Bosnia** and **Herzegovina** (both in prisons and mental health institutions). [CCPR/C/BIH/CO/1 (HRC, 2006), para. 19]. **ECtHR:** upholding prisoners' right to confinement under conditions compatible with human dignity. Prisoners' health and wellbeing must be adequately secured by the provision of requisite medical assistance. [Kudla v. **Pologna**, Oct. 26, 2000]. ***See also:*** • Committee Against Torture**:** pointing to overcrowding, inadequate living conditions, and lengthy confinement in Russian psychiatric hospitals as "tantamount to inhuman or degrading treatment." [CAT/C/RUS/CO/4 (CAT, 2007), para. 18]. • The European Charter of Patients' Rights sets out: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative care treatment and simplifying patients' access to them." [art. 11]. • Under the Declaration on the Promotion of Patients' Rights in Europe, "Patients have the right to relief of their suffering according to the current state of knowledge. . . . Patients have the right to humane terminal care and to die in dignity." [art. 5.10, 5.11].

Table 8: Patient care and the right to participate in public policy

Examples of Human Rights Violations	
• A country fails to adopt a national health plan or to make it publicly available to its citizens. • Citizens lack an opportunity to comment on and participate in the setting of public health priorities. • The government will not accept or respond to information and proposals on health care delivery submitted by citizens.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 25 Every citizen shall have the right and the opportunity, without . . . distinctions . . . **(a)** To take part in the conduct of public affairs, directly or through freely chosen representatives. **CEDAW 7** State Parties shall take all appropriate measures to eliminate discrimination against women in the political and public life of the country and, in particular, shall ensure to women, on equal terms with men, the right: . . . **(b)** [t]o participate in the formulation of government policy and the implementation thereof. ***See also:*** • CEDAW 14(2)(a) (right of rural women to participate in development planning) • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 9(1): "States Parties shall take specific positive action to promote participative governance and the equal participation of women in the political life of their countries." • The Ljubljana Charter on Reforming Health Care	**CESCR:** calling for countries to adopt "a national public health strategy and plan of action" to be "periodically reviewed, on the basis of a participatory and transparent process." [CESCR GC 14, para. 43]. **CESCR:** "Promoting health must involve effective community action in setting priorities, making decisions, planning, implementing and evaluating strategies to achieve better health. Effective provision of health services can only be assured if people's participation is secured by States." [CESCR GC 14, para. 54]. ***See also:*** • The European Charter of Patients' Rights has a whole section on the "Rights of Active Citizenship"--- citizens' "right to participate in the definition, implementation and evaluation of public policies relating to the protection of health care rights." [Part III].

Table 9: Patient care and the right to non-discrimination and equality

Examples of Human Rights Violations	
• Members of certain communities are treated in separate wards with a lower standard of care. • Health workers refuse to treat sex workers, drug workers, or LGBT persons. • Maternal and reproductive health services for women are lacking. • A country fails to provide health services to the poor or non-citizens.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 26 All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICESCR 2(2)** The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status. **ACHPR 2** Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. ***See also:*** • International Convention on the Elimination of All Forms of Racial Discrimination, art. 5(e)(iv) • Convention relating to the Status of Refugees • European Convention on Human Rights and Biomedicine, art 3 (equitable access to health care) • European Convention on Citizenship and the Convention Relating to the Status of Stateless Persons	**CESCR:** explaining that health facilities, goods, and services have to be accessible to everyone without discrimination "and especially to the most vulnerable and marginalized sections of the population." The Committee further urged particular attention to the needs of "ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS." [CESCR GC 14, para 12]. **CESCR:** explaining that health facilities, goods, and services "must be affordable for all," and "poorer households should not be disproportionately burdened with health expenses as compared to richer households." [CESCR GC 14, para 12]. **CESCR:** criticizing **China** for inadequate medical care provided to low-income patients. Many expensive drugs required by chronically ill and mentally ill patients are not subsidized and thus in practice denied them. [E/C.12/1/ADD.107 (CESCR, 2005), para. 87]. **CESCR:** admonishing **Russia** where hospitals and clinics in poor regions often do not stock all essential drugs. [E/C.12/1/ADD.94 (CESCR, 2003), para. 31]. **ESCR:** declaring that the health care system must be accessible to everyone, including the disadvantaged. [Conclusions XVII-2 and 2005, Statement of Interpretation on Article 11].

What are some examples of effective human rights programming in the area of patient care?

Introduction

In this section, you are presented with four **examples** of effective activities in the area of patient care and human rights. These are:

1. Litigation to protect the confidentiality of medical information in the Ukraine
2. Litigation to ensure patient treatment with dignity in the United Kingdom
3. Monitoring of patient rights in Europe
4. Engaging health workers in health rights education and action in Uganda

Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such a project **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this project?
- What **barriers** need to be overcome to ensure its successful replication?

Example 1: Litigation to protect the confidentiality of medical information in Ukraine

In 2006, on a patient's behalf, Vinnystya Human Rights Group challenged a Ukrainian regulation requiring the inclusion of a person's medical diagnosis in forms submitted to employers to permit absence from work due to sickness and the collection of benefits.

Project type
Litigation

Health and human rights issue
A government decree in Ukraine stipulated that a medical certificate, which included a person's diagnosis and ICD (International Classification of Diseases and Causes of Death) disease code, had to be submitted to employers to excuse absence from work due to sickness and allow for the collection of benefits.

Actions taken
- Vinnystya Human Rights Group filed a challenge to this regulation on behalf of Svitlana Yuriyivna Poberezhets at the Pecherskyi District Court in Kyiv.
- Ms. Poberezhets claimed that this regulation violated her rights to privacy and confidentiality under the Ukrainian Constitution and Basic Law on Health Care. She was forced to submit a medical certificate with information about her acute respiratory infection to her place of work, which was then disclosed to her co-workers.
- Vinnystya Human Rights Group and Ms. Poberezhets were opposed by the Ministry of Health, Ministry of Labour and Social Policy, the Social Insurance Fund for Temporary Disability, the Social Insurance Fund for Industrial Accidents and Occupational Diseases, and the Ministry of Justice.

Results
- On July 2006, the court agreed with Vinnystya Human Rights Group and Ms. Poberezhets that requiring the submission of diagnosis information to a person's place of work infringed on basic constitutional rights. The court specifically held that it violated (1) privacy protections under the Ukrainian Constitution and [European] Convention for the Protection of Human Rights and Fundamental Freedoms and (2) confidentiality protections under the Ukraine Basic Law on Health Care, Civil Code, and "On Information" Law.
- The court pointed out that regulatory bodies must act within the scope of their authority under the Constitution and legislation.
- It thus ordered the regulation's registration as unlawful and contradictory and its cancellation.
- The government later amended the decree, excluding confidential information from medical certificates.

Contact
Vinnystya Human Rights Group, Ukraine
Email: vpg@ukr.net

Example 2: Litigation to ensure patient treatment with dignity in the United Kingdom

A psychiatric patient in the UK sued a hospital which overmedicated her and treated her lice infection by shaving off her hair.

Project type
Litigation

Health and human rights issue
A psychiatric patient based at an NHS (National Health Service) hospital was making good progress. She was moved without notice to a private hospital with an NHS contract. She developed an infection of head lice. Initially, she was treated with anti-lice shampoo, but this was quickly discontinued. After a 20-minute talk with a doctor and nurse, she was persuaded to sign a consent form to have her hair completely shaved off. The patient was a woman in her 20's who was very careful about her appearance and had sported shoulder length blond hair for many years. At this time, she was receiving 7000 mg of anti-psychotics daily, compared with a maximum dose of 1000 mg recommended by the Royal College of Psychiatrists.

Actions taken
- The patient sued the hospital for assault and breach of human rights and lodged a claim against the doctor for overmedication.

Results
- The hospital made various offers for compensation and issued an apology. The patient and her family accepted an offer of just over £10,000. The court approved the compensation award.
- The doctor denied wrongdoing, but the court awarded £1000 in damages for the period of overmedication.
- Positive media coverage during this case drew public attention to the importance of patient rights protection and ensuring the humane treatment of psychiatric patients.

Contact
Christian Khan Solicitors, 42 Museum Street, Bloomsbury
London WC1A 1LY
Tel: +44-207-831-1750
Web: www.christiankhan.co.uk

Example 3: Monitoring of patient rights in Europe

In 2003, the Active Citizenship Network partnered with local NGOS to monitor the compliance of 13 European Union countries with the European Charter of Patients' Rights.

Project type
Human rights monitoring and documentation

Health and human rights issue
Governments across Europe have been slow to establish health care systems in line with WHO standards. With growing medical expenses, governments have been rationing health services. Patients, in turn, are pressing for greater access to medical information in order to play a more active role in managing their treatment and shaping the delivery of health services. With increasing freedom of movement across European Union states, there is also a need for greater harmonization of health systems and the assurance of basic standards.

Actions taken
- In 2003, the Active Citizens Network (ACN), a European network of civic, consumer, and patient organizations, undertook a two-year study of 13 European Union countries to see how they measure up to the European Charter of Patients' Rights.
- Working with public health experts, ACN translated the Charter into 160 measurable indicators that could be assessed across various countries.
- ACN partnered with local NGOs to carry out the monitoring project. Partner organizations interviewed 70 key stakeholders—including medical professionals, journalists, insurance carriers, and government ministry representatives—and visited 39 main hospitals in each of the European capital cities. NGOs further answered a questionnaire on their country's patient rights legislation. This methodology was piloted in Italy and then rolled out to the rest of the countries.

Results
- The results of the study were available in 2005 and publicly disseminated.
- The study concluded that Europeans do not have sufficient access to high-quality health care, medical innovation, or information about health care choices and documented the degree to which access to care is lacking.
- The monitoring project helped initiate a dialogue between civil society and governments on health care delivery. The hope is that this will lead to greater governmental accountability.
- Citizens can also use the results of the study as a basis for advocacy for better care and for health policy changes.

Contact
Active Citizenship Network (ACN)
Via Flaminia, 53-00196 Rome, Italy;
Tel.: (+39)06367181
Fax: (+39)0636718333
E-mail: info@activecitizenship.net
Web: www.activecitizenship.net

Example 4: Engaging health workers in health rights education and action in Uganda

In 2003, Ugandan health workers united to urge their colleagues and government to recognize and protect the right to health through anti stigma, health rights leadership, and health budget campaigns.

Project Type
Movement-building and advocacy

Health and human rights issue
Uganda faces major health and human rights challenges including AIDS-related stigma and discrimination, a lack of human rights awareness amongst health workers, and severe under-funding of the health sector.

Action taken
To address these and other health rights, seven health worker leaders founded the Action Group for Health, Human Rights and HIV/AIDS (AGHA) in 2003. AGHA brings together over 600 Ugandan doctors, nurses, other health professionals, NGOs and other institutions interested in promoting the right to health. AGHA spearheads three major campaigns to improve Uganda's AIDS and health response:

- Anti-Stigma Campaign: a Stigma Task Force of over 50 health workers to combat stigma in health settings through education of health workers and community members.
- The Health Rights Leadership Campaign: outreach and training to health workers, the general public, and the media on health and human rights in order to integrate human rights into the medical paradigm.
- Health Funding Campaign: Government advocacy on budget gaps for health services through the media, public forums, and research.
- Health Workforce Campaign: Advocacy for improved and increased health workforce.

Results
- The medical paradigm is changing to embrace human rights:
  - The AGHA Stigma Task Force has trained over 250 health workers in four districts on preventing stigma and discrimination and promoting patient rights, and AGHA's curriculum is now included in their official continuing medical education program.
  - The Uganda Medical Association has started a human rights committee.
  - AGHA's health student leadership program has over 300 members and chapters at all public medical schools in Uganda.
- Health rights are becoming entrenched in key Ugandan institutions:
  - The Ministry of Health and the Uganda Human Rights Commission have both created right to health desks.
  - AGHA has helped WHO train Parliamentarians in health, human rights, and policy.
- The health budget in Uganda is increasing: In April 2007, the parliament announced an 8 billion Uganda shilling increase in the health budget.

Contact
Action Group for Health, Human Rights and HIV/AIDS (AGHA)
PO Box 24667 Kampala Uganda
Tel: +256 414 348 491
Email: info@aghauganda.org; Web: www.aghauganda.org

Physicians for Human Rights (PHR)
2 Arrow Street Suite 301
Cambridge MA 02138
Tel: 1-(617) 301 4235

Where can I find additional resources on human rights in patient care?

Resources

To further your understanding on the topic of human rights in patient care, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions UN
- Declarations and resolutions: non-UN
- Books
- Reports, key articles, and other documents
- Periodicals
- Websites
- Blogs

Declarations and resolutions: UN

- Principles of Medical Ethics Relevant to the Role of Health Personnel, Particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1982).
  Source: www.unhchr.ch/html/menu3/b/h_comp40.htm

Declarations and resolutions: non-UN

- A Declaration on the Promotion of Patients' Rights in Europe: European Consultation on the Rights of Patients, Amsterdam (WHO, Regional Office for Europe 1994).
  Source: www.who.int/genomics/public/eu_declaration1994.pdf
- Charter on the Right to Health (International Union of Lawyers 2005).
  Source: www.uianet.org/documents/qquia/resolutions/Sante4GB.pdf
- Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Council of Europe 1997).
  Source: conventions.coe.int/Treaty/EN/Treaties/Html/164.htm

- Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data.
  Source: conventions.coe.int/Treaty/en/Treaties/Html/108.htm

- Declaration on Medical Care for Refugees (World Medical Association)
  Source: www.wma.net/e/policy/m10.htm

- Declaration on the Rights of the Patients (World Medical Association).
  Source: www.wma.net/e/policy/l4.htm

- European Charter of Patients Rights (Active Citizens Network, 2002).
  Source: www.activecitizenship.net/health/european_charter.pdf

- International Alliance of Patients' Organizations: Declaration on Patient-Centered Health Care (March 30, 2007).
  Source: www.patientsorganizations.org/

- Jakarta Declaration on Leading Health Promotion into the 21st Century (1997).
  Source: www.who.int/hpr/NPH/docs/jakarta_declaration_en.pdf

- Ljubljana Charter on Reforming Health Care (WHO, Regional Office for Europe 1996).
  Source: www.euro.who.int/AboutWHO/Policy/20010927_5

- Position Statement: Nurses and Human Rights (International Council of Nurses).
  Source: www.icn.ch/abouticn.htm

- Principles on the Effective Documentation of Torture. Istanbul Protocol
  Source: physiciansforhumanrights.org/library/istanbul-protocol.html

- Recommendation Rec (2000)5 and Explanatory Memorandum of Committee of Ministers to Member States on the Development of Structures for Citizen and Patient Participation in the Decision-Making Process Affecting Health Care (Council of Europe).
  Source:
  wcd.coe.int/ViewDoc.jsp?id=1062769&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75

Books

- Angell, Marcia. *The Truth about Drug Companies: How They Deceive Us and What to Do about It.* New York: Random House, 2005.

- British Medical Association. *The Medical Profession and Human Rights.* Zed Books, 2001.

- Den Exeter, Andre. *Health Care Law-Making in Central and Eastern Europe: Review of a Legal-Theoretical Model*, Intersentia, 2002.
- Gevers, J.K.M., Hondius, E.H., and Hubben, J.H, eds. *Health Law, Human Rights and the Biomedical Convention: Essays in Honour of Henriette Roscam Abbing,* 2005.
- Lavik, JL. *Pain and Survival: Human Rights Violations and Mental Health.* Scandinavian University Press, 1994.
- Rosenmoller, McKee and Baeten, eds. *Patient Mobility in the European Union: Learning from Experience.* European Observatory on Health Systems and Policies, 2006.
- World Health Organization. *Enforcement of Public Health Legislation.* WHO Western Pacific Region, 2006.

Reports, key articles, and other documents

- Amnesty International Ethical Code and Declarations Relevant to Health Professionals.
  Source: web.amnesty.org/pages/health-ethicsindex-eng
- Aydin, E., *Rights of Patients in Developing Countries: the Case of Turkey,* Journal of Medical Ethics 2004; 30:555-557.
- Crofts, N., Louie, R., Loff, B. *The next plague: stigmatization and discrimination related to hepatitis C virus infection in Australia.* Health and Human Rights, 2(2), 86-97 (1997).
- "*Cross-border Health Care in Europe*", Policy Brief, European Observatory on Health Systems and Policies (2005).
- Council of the European Union, General Secretariat: Conclusions of the Council on patient mobility and health care developments in the European Union, Brussels, 19 April 2004.
- EPHA Briefing on Human Rights, European Health Alliance (2005).
- Fallberg, Lars, "*Patients' Rights in Europe: Where do we stand and where do we go*," European Journal of Health Law 7: 1-3 (2000).
- Fridli, Judit, "*New Challenges in the Domain of Health Care Decisions*," Policy Paper, International Policy Fellowship Program, Open Society Institute, Budapest (2006).

- Gilson, Lucy. "*Trust and the Development of Health Care as a Social Institution*," Social Science & Medicine 56 1453-1468 (2003).
- Glinos, Irene A. and Baeten, *A Literature Review of Cross-Border Patient Mobility in the European Union*, Europe for Patients Project (September 2006).
- *Human Rights in Action---A Framework for Local Action* (designed by Department of Health, British Institute of Human Rights, and 5 NHS Trusts), Equality and Human Rights Group (2007).
- Hungarian Civil Liberties Union, Policy Paper on the Rights of Patients.
- Leenen, Henk, Givers, Sjef and Pinet, Genevieve (eds), "*Promotion of the Rights of Patients in Europe, a Comparative Study*," Amsterdam: Academic Publishers (1993).
- Mackintosh, Maureen. "*Do Health Care Systems Contribute to Inequalities*?" Poverty, Inequality and Health 175-193.
- Milevska-Kosova, Neda, "*Patients Rights as a Policy Issue in South Eastern Europe*, Policy Paper, International Policy Fellowship Program, Open Society Institute, Budapest (2006)
- *National Activities on Patients' Rights and Quality of Health Care (Asia and Pacific, Africa, Latin America, Countries in Transition, Developed Economies),* Consumers International (2005).
- *Patients' Rights in Europe: A Citizens' Report*, Summary of Meeting Organized by Active Citizenship Network at the European Parliament, Brussels, February 28 to March1, 2005, Health and Social Campaigners' Network, Wales, Commissioned by Oxford Vision 2020 (March 2005).
- "*Patients' Rights in Europe Today*," Speech, European Ombudsman (2005).
- PHR and University of Cape Town. Dual Loyalty And Human Rights in Health professional Practice: Proposed Guidelines and Institutional Mechanisms. Online at physiciansforhumanrights.org/library/report-dualloyalty-2006.htmlPolicy Paper on the Rights of Patients, Hungarian Civil Liberties Union.
- Rich, Robert F. and Merrick, Kelly R., *Cross Border Health Care in the European Union: Challenges and Opportunities*, University of Illionis Working Paper, October 2006.
- Scott, Penelope, *Undocumented Migrants in Germany and Britain: the Human "Rights" and "Wrongs" Regarding Access to Health Care*, Electronic Journal of Sociology (2004).

- *Social Challenge to Health: Equity and Patients' Rights in the Context of Health Reforms*, Council of Europe 5th Conference of European Health Ministers (1996).
- Stefanoska, Cavdar, Isajlovska, and Stefanovska, *"Rights of the Patients in Macedonia According to the European Standards,"* Report, Skopje: MIA--- Association of Health Education and Promotion of Health (2005).
- *Survey of the UK Public: Patients' Rights* (Backgrounder to Main Report: Patients' Rights in Europe and the UK), The Patients' Association (2005).
- United States Department of Health and Human Services, Centers for Medicare and Medicaid Services: 42 CFR Part 482, Medicare and Medicaid Programs; Hospital Conditions of Participation; *Patients Rights; Final Rule,* Federal Register, Friday, December 8, 2006
- Written Contribution to Communication from the Commission-Consultation Regarding Community Action on Health Services, ILGA Europe (2007).

Periodicals

- British Medical Journal
- Conflict and Health
- European Journal of Health Law
- Journal of Law, Medicine and Ethics
- Journal of Medical Ethics
- The Lancet

Websites

- British Medical association Human Rights Publications. www.bma.org.uk/ap.nsf/Content/HRpublications
- Europe for Patients Project www.europe4patients.org
- European Court of Human Rights- Mental Disability Cases www.mdac.info/resources/echr_cases.htm

- European Public Health Alliance
  www.epha.org

- Health and Social Campaigners' Network International
  www.patient-view.com/hscnetwork.htm

- Oxford Vision 2020
  www.oxfordvision2020.org

- The Patients Association
  www.patients-association.org.uk

- Penal Reform International
  www.penalreform.org/health-in-prisons.html

- Physicians for Human Rights
  physiciansforhumanrights.org/

- Sharing for Action, Patients Rights
  www.sharingforaction.med.bg.ac.yu

Blogs

- The Health Consumer Blog @ Health Consumer Powerhouse

- Global Directory of Patients' Organizations @ International Alliance of Patients' Organizations
  www.patientsorganizations.org

What are key terms related to human rights in patient care?

Glossary

A variety of terms is used in human rights and patient care work.

A

Ambulatory care
Medical care including diagnosis, observation, treatment, and rehabilitation provided on an outpatient basis.

D

Dual loyalty
Role conflict between professional duties to a patient and obligations—express or implied, real or perceived—to the interests of a third party such as an employer, insurer, or the state.

H

Health care or patient care (see also Patient care)
1. The prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by the medical, nursing, and allied health professions. This definition and similar ones sometimes are given for "*patient care*" as well. The World Health Organization states that this embraces all the goods and services designed to promote health, including preventive, curative, and palliative interventions, whether directed to individuals or populations.
2. "Any type of services provided by professionals or paraprofessionals with an impact on health status" (European Observatory on Health Systems and Policy online glossary).
3. "Medical, nursing or allied services dispensed by health care providers and health care establishments" (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Health care establishment
Any health care facility such as a hospital, nursing home, or establishment for disabled persons (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam, 1994).

Health care providers
Physicians, nurses, dentists, or other health professionals (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Health care system
The organized provision of health care services.

Human rights in patient care
Concept that brings together the rights of both patients and health care providers and refers to the application of general human rights principles to all stakeholders in the delivery of health care. It encompasses all rights recognized under international law that are relevant to the provision of health services.

I

Informed consent
A legal condition in which a person can be said to agree to a course of action based upon an appreciation and understanding of the facts and implications. The individual needs to be in possession of relevant facts and the ability to reason.

Informed consent in the health care context
A process by which a patient participates in health care choices. A patient must be provided with adequate and understandable information on matters such as the treatment's purpose, alternative treatments, risks, and side-effects.

In-patient
A patient whose care requires a stay in hospital or hospice facility for at least one night.

M

Medical intervention
Any examination, treatment, or other act having preventive, diagnostic therapeutic or rehabilitative aims and which is carried out by a physician or other health care provider (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

O

Out-patient
Patient receiving treatment without spending any nights at a health care institution.

P

Patient
A user of health care services, whether healthy or sick (Declaration on the Promotion of Patients' Rights in Europe, WHO, Amsterdam 1994).

Patient autonomy
The right of patients to make decisions about their medical care. Providers can educate and inform patients, but cannot make decisions for them.

Patient care (see also Health care)
The services rendered by members of the health professions or non-professionals under their supervision for the benefit of the patient. Similar definitions often are provided for the term "health care."

Patient-centered care
Doctrine recognizing the provision of health services as a partnership among health care providers and patients and their families. Decisions about medical treatments must respect patients' wants, needs, preferences, and values.

Patient confidentiality
Doctrine that holds that the physician has the duty to maintain patient confidences. This is to allow patients to make full and frank disclosure to their physician, enabling appropriate treatment and diagnosis.

Patient mobility
Concept describing patient movement beyond their catchment area or area of residence to access health care; mobility can take place within the same country or between countries.

Patient responsibility
A doctrine recognizing the doctor/patient relationship as a partnership with each side assuming certain obligations. Patient responsibilities include communicating openly with the physician or provider, participating in decisions about diagnostic and treatment recommendations, and complying with the agreed-upon treatment program.

Patients' rights
1. Set of rights calling for government and health care provider accountability in the provision of quality health services. Associated with a movement empowering patients, particularly in countries where patients are assuming a greater share of health care costs and thus expect to have their rights as "consumers" respected.
2. A set of rights, responsibilities and duties under which individuals seek and receive health care services (European Observatory on Health Systems and Policy online glossary).

Patient safety
Freedom from accidental injury due to medical care or medical errors (Institute of Medicine).

Primary health care
General health services available in the community near places where people live and work; the first level of contact individuals and families have with the health system.

S

Secondary health care
General health services available in hospitals.

T

Terminal care
Care given to a patient when it is no longer possible to improve the fatal

prognosis of his or her illness/condition with available treatment methods, as well as care at the approach of death (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Tertiary health care

Specialized health services available in hospitals.

OPEN SOCIETY INSTITUTE

equitas
Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Photo: International AIDS Conference Toronto, 2006, courtesy of Ellen Liu

Chapter 2
HIV/AIDS and Human Rights

"Realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS."

United Nations General Assembly, Declaration of Commitment on HIV/AIDS, para. 58

Contents

Introduction

This chapter will introduce you to key issues and resources in **HIV/AIDS** and **human rights** and help you understand why, now more than ever, HIV and AIDS must be understood and approached as a human rights issue.

The chapter is organized into six sections that answer the following questions:[1]

- **How** is HIV/AIDS a human rights issue?
- **What** is OSI's work in the area of HIV/AIDS and human rights?
- **Which** are the most relevant international and regional human rights standards related to HIV/AIDS?
- **What** are some examples of effective human rights programming in the area of HIV/AIDS?
- **Where** can I find additional resources on HIV/AIDS and human rights?
- **What** are key terms related to HIV/AIDS and human rights?

In addition, this chapter will also address how a human rights approach can be used to address the link between **HIV/AIDS** and **tuberculosis**.

As you read through this chapter, consult the **glossary of terms** found in the last section, *What are key terms related to HIV/AIDS and human rights?*

[1] Some of these questions are also addressed in Chapter 3 (Harm Reduction and Human Rights), Chapter 4 (Palliative Care and Human Rights) and Chapter 5 (Sexual Health and Human Rights).

How is HIV/AIDS a human rights issue?

What is unique about HIV/AIDS?

Since the first cases of AIDS were identified in 1981, it has been recognized that:

- Stigma and discrimination against people living with, affected by, and vulnerable to HIV infection are major obstacles to delivering HIV prevention, care and treatment services
- HIV stigma and discrimination are often entangled with the discrimination attached to being a woman, being poor, having a different sexual orientation, engaging in sex work or drug use, or being in prison
- Protection of human rights, both of those vulnerable to infection and those already infected, is not only important for individuals, but also produces positive public health results
- Supportive frameworks of policy and law are essential to effective HIV responses.

As the epidemic has progressed, it has also become increasingly clear that:

- National and local responses to HIV will not work without the full engagement and participation of those affected by HIV, particularly people living with HIV.
- The human rights of women, young people and children must be protected if they are to avoid infection and withstand the impact of HIV.
- The human rights of marginalized groups, including people who use drugs, sex workers, prisoners, and gay and bisexual men, must also be respected for the response to HIV to be effective.

By and large, human rights abuses related to HIV have not been significantly addressed in many countries. As a result, stigma and discrimination remain pervasive, and vulnerability to infection continues to be rooted in social, economic and gender inequalities. These realities contribute to the rising number of infections each year, with women, young people and marginalized groups getting infected at the fastest rates and bearing the worst impact of AIDS.

What is the link between HIV/AIDS and tuberculosis?

Tuberculosis (TB), a disease caused by the Mycobacterium tuberculosis bacterium that attacks the lungs, is a major cause of death among people living with HIV and AIDS. HIV compromises the immune system and thus increases the likelihood of TB infection, progression, and relapse. It is estimated that one-third of the 40 million people living with HIV worldwide are co-infected with TB. TB kills up to half of all people with HIV worldwide.

Unlike HIV, however, TB can be cured. Treatment with anti-TB drugs has been shown to prolong the lives of people living with HIV by at least two years. Offering TB tests and treatment to people with HIV—and vice versa—greatly increases the chances that both diseases can be controlled.

Inadequate and inconsistent treatment practices, on the other hand, can cause drug-resistant strains of TB. Multi-drug resistant tuberculosis (MDR-TB) is difficult to treat and can be fatal. The emergence of MDR-TB thus poses a grave threat not only to be people with TB, but to overall progress in the global fight against HIV and AIDS.

Why a human rights response to HIV?

- When human rights inform the content of national responses to HIV, vulnerability to HIV infection is reduced and people living with HIV can live with dignity.

- When human rights principles guide the process by which local and national responses are implemented, the results are responses tailored to the needs and realities of those affected. Such principles include non-discrimination, participation, inclusion, transparency and accountability.

- Where States are providing comprehensive HIV prevention, care and impact mitigation programmes to all those in need, supporting vulnerable people to be able to act on the information and services they receive, and allowing the full participation of all those affected in the design and implementation of HIV programmes, they are fulfilling their HIV-related human rights obligations and mounting an effective response to HIV.

- In contrast, where human rights are not respected, protected, and promoted, the risk of HIV infection is increased, people living with and affected by HIV and AIDS suffer from discrimination, and an effective response to the epidemic is often impeded.

What are AIDS-related human rights?

In order to ensure an effective response to HIV and AIDS, all people living with, affected by, and vulnerable to HIV and AIDS must have a full range of internationally-recognized human rights respected, protected, and fulfilled:

These include the **right to**:

- Non-discrimination and equal protection on the basis of actual or perceived HIV status
- Access to effective and evidence-based HIV-prevention services
- Access to anti-retroviral treatment, including treatment to prevent mother-to-child transmission of HIV
- Due process in the criminal justice system, particularly for groups at risk of HIV such as sex workers, people who use drugs, and men who have sex with men
- Choice of one's place of residence and migration
- Seek and enjoy asylum
- Medical treatment without coercion and with guarantees of privacy
- Freedom of opinion and expression and the right to freely receive and impart HIV-related information
- Freedom to form and participate in HIV and AIDS organizations and associations
- A work environment that is respectful of HIV status
- Marry and to found a family
- Equal access to education, including for children affected by HIV
- A standard of living adequate to maintain good health, including social security, assistance and welfare
- Freedom from torture and cruel, inhuman or degrading treatment or punishment.

Human Rights and HIV/AIDS: Now More Than Ever

Ten Reasons why human rights should occupy the center of the global response to HIV/AIDS:

1. Universal access will never be achieved without human rights.
2. Gender inequality makes women more vulnerable to HIV, with women and girls now having the highest rates of infection in heavily affected countries.
3. The rights and needs of children and young people are largely ignored in the response to HIV, even though they are the hardest hit in many places.
4. The worst affected receive the least attention in national responses to HIV.
5. Effective HIV-prevention, treatment, and care programs are under attack.
6. AIDS activists risk their safety by demanding that governments provide greater access to HIV and AIDS services.
7. The protection of human rights is the way to protect the public's health.
8. AIDS poses unique challenges and requires an exceptional response.
9. "Rights-based" responses to HIV are practical, and they work.
10. Despite much rhetoric, real action on HIV/AIDS and human rights remains lacking.

Source: Open Society Institute Law and Health Initiative, 2007. Endorsed by 24 HIV/AIDS and human rights organizations worldwide.

2

Did you know?

- Around the world, people living with HIV and AIDS have been segregated in schools, hospitals, and prisons; refused employment; denied the right to marry; required to submit to HIV tests as a condition of entry into other countries; banished by their communities; and killed because of their HIV-positive status.

- As of 2003, almost half of governments in sub-Saharan Africa had yet to adopt legislation or court rulings specifically outlawing discrimination against people living with HIV and AIDS.

- As of 2003, only one-third of countries worldwide had adopted legal measures specifically outlawing discrimination against populations especially vulnerable to HIV and AIDS.

- Surveys conducted in Southern Africa between 2000-2001 found that:[2]
  - Fewer than half of respondents in **Botswana** would buy fresh vegetables from a shopkeeper living with HIV or AIDS
  - One-third of respondents from **Lesotho** felt that a female teacher who is HIV-positive but not sick should not be allowed to continue teaching in school

[2] Measure DHS, HIV and AIDS Survey Indicators Database. Online: www.measuredhs.com/hivdata/.

- Approximately one-third of respondents from **Namibia** were secretive about a family member's HIV status.

- Surveys conducted in Central Asia between 2000-2002 found that:[3]
  - Only 8% of respondents in **Tajikistan** would buy fresh vegetables from a shopkeeper living with HIV or AIDS
  - 15% of respondents from **Tajikistan** felt that a female teacher who is HIV-positive but not sick should not be allowed to continue teaching
  - In **Uzbekistan**, 30% of male respondents and 46% of female respondents were secretive about their family members' HIV status.

- In a study conducted in an eastern Chinese coastal city, half of participants believed that punishment was an appropriate response towards those living with HIV, over half (56%) were unwilling to be friends with HIV-positive people, and 73% thought that those living with HIV should be isolated.[4]

- An evaluation of the implementation of the Declaration of Commitment on HIV and AIDS undertaken in 2006 in 14 countries concluded that human rights abuses of vulnerable populations continue unabated, denying them access to services and effective tools for preventing HIV infection and to life-saving AIDS drugs that will keep them alive.[5]

- In its most recent report on the global AIDS epidemic (2006), the Joint United Nations Programme on HIV/AIDS (UNAIDS) noted that "half of countries submitting reports to UNAIDS noted the existence of policies that interfere with the accessibility and effectiveness of HIV-related measures for prevention and care." [6]

The good news

- Litigation on behalf of people living with and affected by HIV has resulted in tangible court victories in numerous countries:
  - In South Africa, the Constitutional Court held the government in violation of the constitution for failing to provide nevirapine to pregnant women to prevent mother-to-child transmission of HIV
  - In Serbia in 2007, a woman with HIV was awarded damages from the European Court of Human Rights after she was banned from seeing her child
  - In 2007, the Mexican Supreme Court ruled it was unconstitutional to ban members from the military on the grounds of their HIV status.

[3] Measure DHS, HIV and AIDS Survey Indicators Database. Online: www.measuredhs.com/hivdata/.
[4] UNAIDS, Report on the Global AIDS Epidemic: A UNAIDS 10th anniversary special edition (2006), pp. 86-87.
[5] ICASO, Community Monitoring and Evaluation. Implementation of the UNGASS Declaration of Commitment on HIV and AIDS, 2006.
[6] UNAIDS, Report on the Global AIDS Epidemic: A UNAIDS 10th anniversary special edition (2006), p. 57.

- Legislative reform to address the human rights aspects of HIV is underway in many countries: In 2006, the Canadian HIV/AIDS Legal Network released a multi-volume model law resource on HIV and AIDS and the rights of people who use drugs, which is being used for advocacy in countries as diverse as Georgia, Indonesia, Thailand, and Ukraine.

- A growing number of NGO coalitions are uniting to address the human rights aspects of HIV. These include the Observatoire de la réponse au VIH/sida au Sénégal (Watchdog of the response to HIV and AIDS in Senegal) and the AIDS and Rights Alliance of Southern Africa (ARASA). These coalitions have shown that human rights are an effective organizing principle for mobilizing civil society against AIDS.

What is OSI's work in the area of HIV/AIDS and human rights?

OSI's work on HIV/AIDS and human rights cuts across several network programs. Programs include:

- The **HIV/AIDS and Civil Society Project**
  Supports the development of independent civil society movements to respond to HIV and AIDS epidemics worldwide.

- The **International Harm Reduction Development Program**
  Supports access to HIV prevention, treatment, and care programs for people who use drugs (see Chapter 3).

- The **International Palliative Care Initiative**
  Supports access to comprehensive HIV care, including access to opioid pain medication, for people living with HIV and AIDS (see Chapter 4).

- The **Sexual Health and Rights Project**
  Supports access to HIV prevention, treatment, and care programs for sex workers and LGBT communities (see Chapter 5).

- **Public Health Watch**
  Supports civil society-led monitoring and advocacy on government responses to HIV and AIDS and tuberculosis worldwide.

- The **Law and Health Initiative**
  Works with each of the above programs to support responses to HIV and AIDS that focus on law and human rights.

OSI engages with the **Global Fund to Fight AIDS, Tuberculosis and Malaria** to ensure that the Fund is adequately supported, and that it meaningfully includes civil society in the projects it supports.

Some examples of projects include:

- In Southern Africa, the region of the world most affected by AIDS, provision of unrestricted institutional support and technical assistance to six organizations working to advance human rights responses to HIV.

- "Ensuring Justice for Vulnerable Communities in Kenya: A Review of HIV/AIDS-related Legal Services," a report on access to legal services for people living with, affected by, and at risk of HIV in Kenya. Produced by the Law and Health Initiative.

- "Human Rights and HIV/AIDS: Now More Than Ever," a ten-point declaration endorsed by 24 NGOs that outlines why, now more than ever,

human rights should occupy the center of the global response to HIV and AIDS. Produced by the Law and Health Initiative.

- Networking, a satellite session, and venues for human rights activists at the 2006 International AIDS Conference (IAC), including support for clinical legal educators from Mozambique, Thailand, and Ukraine to attend the conference.

For detailed information, see www.soros.org/initiatives/health/focus/law

Which are the most relevant international and regional human rights standards related to HIV/AIDS?

Overview

A variety of human rights standards at the international and regional levels applies to HIV and AIDS. These standards can be used for many purposes:

- **To document** violations related to HIV and AIDS
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies.

In the tables on the following pages, **examples** of human rights violations related to HIV and AIDS are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** interpreting each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on HIV/AIDS and human rights.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (**ICCPR**)	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**)
European Social Charter (**ESC**)	European Committee of Social Rights (**ECSR**)

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

Table 1: HIV/AIDS and the right to life

Examples of Human Rights Violations	
• Police fail to investigate the murder of a person living with HIV. • Government places unjustified legal restrictions on access to life-saving HIV-prevention or treatment measures. • Government imposes a death sentence for intentional transmission of HIV. • Woman is denied access to post-exposure prophylaxis to prevent HIV following rape.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life. **(2)** In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgment rendered by a competent court. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	**HRC:** states that art. 6 of the ICCPR creates positive obligations on States to protect life, and that "the Committee considers that it would be desirable for States parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics" {General Comment on the Right to Life, paragraph 5, General Comment 6} Interpreting the right to life, the HRC has recommended that **Namibia** "pursue efforts to protect population from HIV/AIDS" and "adopt comprehensive measures encouraging greater numbers of persons suffering from HIV and AIDS to obtain adequate antiretroviral treatment and facilitate such treatment" (2004). It has also called for "equal access to treatment" in **Kenya** (2005) and for **Uganda** to "allow greater number of persons suffering from HIV/AIDS to obtain adequate antiretroviral treatment" (2004).

Table 2: HIV/AIDS and freedom from torture and cruel, inhuman and degrading treatment, including in prison

Examples of Human Rights Violations	
• Outreach workers conducting HIV-prevention with MSM are detained and beaten by police. • An activist is detained and tortured for exposing State complicity in a HIV blood scandal. • Prisoners are denied HIV-related information, education, and means of prevention (e.g., condoms, sterile injection equipment, and bleach), or HIV testing and treatment. • Authorities fail to take steps to prosecute or prevent prison rape.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation. **ICCPR 10(1)** All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. **ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment. ***See also:*** • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment (1987) • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1989) • Code of Conduct for Law Enforcement Officials (1979) • Standard Minimum Rules for the Treatment of Prisoners (1955)	**HRC:** In 2006, expressed concern about the "high incidence of HIV/AIDS and tuberculosis among detainees in facilities of State, along with absence of specialized care for pre-trial detainees" in **Ukraine**. The Committee recommended that Ukraine relieve prison overcrowding, provide hygienic facilities, assure access to health care and adequate food, and reduce the prison population, including by using alternative sanctions. **EctHR:** finding failure to provide a prisoner with timely and appropriate AIDS and TB treatment to constitute a violation of the right to freedom from torture and inhuman or degrading treatment [Yakovenko v. **Ukraine** (Application 15825/06), Oct. 25, 2007].

Table 3: HIV/AIDS and the right to liberty and security of the person

Examples of Human Rights Violations	
• Government quarantines people living with HIV or detains them in special colonies. • Penal code imposes explicit prison term for intentional transmission of HIV. • Government requires HIV testing either for all individuals or as a condition of employment, immigration, or military service.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 9(1) Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law. **ACHPR 6** Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained. **ECHR 5(1)** Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law: ***See also:*** • Code of Conduct for Law Enforcement Officials (1979) • Basic Principles on the Use of Force and Firearms by Law Enforcement Officials (1990) • Reports of the UN Commission on Human Rights Working Group on Arbitrary Detention (2003-2005)	**WG Arbitrary Detention**: expressed concern at the arbitrary detention of "drug addicts" and "people suffering from AIDS;" recommended that, "with regard to persons deprived of their liberty on health grounds, the Working Group considers that in any event all persons affected by such measures must have judicial means of challenging their detention." (2003) **ECtHR**: "Held that the detention of an HIV-positive gay man violated article 5 as it was not necessary to prevent him from spreading HIV to others.." {Enhorn v. **Sweden**, 2005}

Table 4: HIV/AIDS and the right to liberty of movement

Examples of Human Rights Violations	
• A State conducts HIV screening at its borders or requires disclosure of HIV status as a condition of immigration. • A State singles out HIV status as a reason for denying longer-term residency, while not imposing a similar restriction on other diseases. • A State screens all migrant workers for HIV and categorically deports those who test positive.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 12(1) Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence. **(2)** Everyone shall be free to leave any country, including his own. **(3)** The above-mentioned rights shall not be subject to any restrictions except those which are provided by law, are necessary to protect national security, public order (*ordre public*), **public health** or morals or the rights and freedoms of others, and are consistent with the other rights recognized in the present Covenant {emphasis added}. **ACHPR 12 (1)** Every individual shall have the right to freedom of movement and residence within the borders of a State provided he abides by the law. **(2)** Every individual shall have the right to leave any country including his own, and to return to his country. This right may only be subject to restrictions, provided for by law for the protection of national security, law and order, **public health** or morality {emphasis added}.	*According to research conducted for this Table, no regional or international human rights body has applied the right to liberty of movement explicitly to the context of HIV and AIDS.*

Table 5: HIV/AIDS and the right to seek and enjoy asylum

Examples of Human Rights Violations	
• A State returns an asylum-seeker to a country where she or he faces persecution on the basis of HIV status or HIV activism. • A State excludes people living with HIV from being granted asylum, or discriminates on the basis of HIV status in the context of travel regulations, entry requirements, or immigration and asylum procedures. • Refugees and asylum seekers face discrimination in access to HIV prevention and treatment services.	
Human Rights Standards	**Precedents and Interpretations**
ACHPR 12 (3) Every individual shall have the right, when persecuted, to seek and obtain asylum in other countries in accordance with laws of those countries and international conventions. ***See also:*** • Convention relating to the Status of Refugees (1951)	**HRC:** has confirmed that the right to equal protection of the law prohibits discrimination in law or in practice in any fields regulated and protected by public authorities. This would include travel regulations, entry requirements, and immigration and asylum procedures. The **United Nations High Commissioner for Refugees**, while not a treaty body, issued policy guidelines in 1988 stating that refugees and asylum seekers should not be targeted for special measures regarding HIV infection and that there is no justification for screening being used to exclude HIV-positive individuals from being granted asylum.

Table 6: HIV/AIDS and the right to privacy

Examples of Human Rights Violations	
• A person is tested for HIV without his or her consent. • A hospital or health care worker fails to maintain confidentiality of a patient's HIV status or medical records. • Government requires registration of all people living with HIV by name. • Government requires disclosure of HIV status on certain forms such as sick-leave certificates, job applications, and medical prescriptions. • Penal code criminalizes certain sexual acts between consenting adults, such as fornication, oral sex, sodomy, or adultery.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 17(1) No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honor and reputation. **ECHR 8(1)** Everyone has the right to respect for his private and family life, his home and his correspondence.	**HRC:** In finding that the right to privacy is violated by laws that criminalize homosexual acts between consenting adults {see *Toonen v.* ***Australia***, 1991}, the Human Rights Committee noted that "…the criminalization of homosexual practices cannot be considered a reasonable means or proportionate measure to achieve the aim of preventing the spread of HIV and AIDS…[B]y driving underground many of the people at risk of infection…[it] would appear to run counter to the implementation of effective education programmes in respect of the HIV and AIDS prevention" (see also, Chapter 4, Sexual Health and Human Rights).

Table 7: HIV/AIDS and freedom of expression and information

Examples of Human Rights Violations	
• Government censors HIV-prevention information directed at LGBT persons, sex workers, or people who use drugs on the grounds it is obscene or promotes criminalized behavior. • Schools deny young people information about HIV and AIDS, safer sex, sexuality, and condoms. • Media reporting on HIV engages in stigma and stereotyping rather than providing factual information. • Government restricts a newspaper, website, or other communication by activists critical of government AIDS policies.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice. **ACHPR 9 (1)** Every individual shall have the right to receive information. **ECHR 10(1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises. **(2)** Every individual shall have the right to express and disseminate his opinions within the law.	**CRC Committee:** concluded that adolescent's right to information about HIV and AIDS is part of the right to information {General Comment 3, 2003, Paragraph 4}. **SR Education:** has noted the need for sexuality education in schools, as well as the need for schools to ensure the safety of gay and lesbian students. **SR Freedom of Expression and Information:** has commented on the abuse of the rights of sex workers and LGBT persons; noted restrictions on public speech and denial of HIV and AIDS information to these communities; noted the detention of persons in **Kuwait** because of a letter mentioning a lesbian relationship; and expressed concern in **Uganda** about the arrests and harassment of two gender-non-conforming women.

Table 8: HIV/AIDS and freedom of assembly and association

Examples of Human Rights Violations	
• State restricts formation of nongovernmental, community-based, or service organizations working on HIV and AIDS, or imposes prohibitive bureaucratic requirements. • Police disperse a peaceful and authorized demonstration by AIDS activists. • Organizations such as trade unions or professional associations deny membership on the basis of HIV status.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 21 The right of peaceful assembly shall be recognized. **22(1)** Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests. **(2)** No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (*ordre public*), the protection of public health or morals or the protection of the rights and freedoms of others. **ACHPR 10** Every individual shall have the right to free association provided that he abides by the law. **11** Every individual shall have the right to assemble freely with others. The exercise of this right shall be subject only to necessary restrictions provided for by law in particular those enacted in the interest of national security, the safety, health, ethics and rights and freedoms of others. **ECHR 11** Everyone has the right to freedom of peaceful assembly and to freedom of association with others, including the right to form and to join trade unions for the protection of his interests.	*According to research conducted for this Table, no regional or international human rights body has applied the protection of freedom of assembly and association explicitly to the context of HIV and AIDS.*

Table 9: HIV/AIDS and the right to marry and found a family

Examples of Human Rights Violations	
• State requires HIV testing or proof of HIV-negative status as a condition of marriage. • State forces woman living with HIV to undergo abortion or sterilization, rather than providing her with information and services to prevent mother-to-child transmission of HIV. • Women are denied equal rights in marriage, divorce, or within families, thus decreasing their ability to negotiate safer sex or leave relationships that pose a risk of HIV. • State denies migrants the right to be accompanied by family members, thus increases risk of HIV through casual sex. • State denies asylum to HIV-positive claimant while granting asylum to his or her family.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 23(2) The right of men and women of marriageable age to marry and to found a family shall be recognized. **ECHR 12** Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right.	**CEDAW Committee:** recommended that **Kenya** "take appropriate action to eliminate all discriminatory laws, practices and traditions and ensure women's equality with men particularly in marriage and divorce, burial and devolution of property upon death in accordance with provisions of CEDAW," including through passage of HIV and AIDS legislation (2003). **ECtHR:** ruled the rights of a Serbian woman living with HIV were violated when she was banned from seeing her child (2007).

Table 10: HIV/AIDS and the right to non-discrimination and equality under law

Examples of Human Rights Violations	
• A person is denied work, housing, medicine, or education due to actual or presumed HIV status. • A child affected by HIV faces discrimination because of his or her parents' HIV status. • Government-sponsored HIV-prevention materials exclude information targeted at certain minorities such as LGBT persons, persons with disabilities, or people who use drugs. • Discrimination in access to property and divorce render women more vulnerable to HIV.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 2(1) Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICCPR 26** All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ACHPR 2** Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. **3 (1)** Every individual shall be equal before the law. **(2)** Every individual shall be entitled to equal protection of the law. **ECHR 14** The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.	**CHR:** confirmed that the term "other status" in anti-discrimination provisions includes health status, including HIV status (1995 and 1996). **CRC Committee:** in the context of anti-discrimination, recommended: that **Kazakhstan** undertake awareness-raising and sensitization of legal and other professionals on the impact of HIV and AIDS on children (2006); and that **Ukraine** monitor the situation of "economically disadvantaged households, children living in rural areas, children in institutions, children with disabilities, children belonging to national minorities such as **Roma** children, and children affected with HIV/AIDS" and develop anti-discrimination strategies for these populations (2002). **CEDAW Committee:** has made several recommendations on the elimination of discrimination against women in the context of HIV and AIDS (see Table 12, below). **Committee on the Elimination of Racial Discrimination:** expressed concern at the high rate of HIV and AIDS among minorities and ethnic groups and recommended that governments take appropriate action in **Estonia** (2006) and **South Africa** (2006 and 2003).

Table 11: HIV/AIDS and the right to the highest attainable standard of health

Examples of Human Rights Violations
• State fails to take progressive steps to ensure access to HIV-prevention information and services (e.g. condoms, sterile syringe programs, VCT), or imposes restrictions on such services. • State fails to take progressive steps to ensure access to anti-retroviral drugs, treatment for opportunistic infections, opioid pain medications for palliative care, or comprehensive TB care. • State fails to ensure that sex workers, MSM, prisoners, people who use drugs, and other vulnerable groups enjoy proportionate access to HIV prevention, treatment, and care services.

Human Rights Standards	Precedents and Interpretations
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. **12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases. **ACHPR 16 (1)** Every individual shall have the right to enjoy the best attainable state of physical and mental health. **(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick. ***See also:*** • Convention on the Elimination of All Forms of Discrimination Against Women, 12(1) • Convention on the Rights of the Child, 24(1)	**CESCR**: Art. 12 includes "the right to prevention, treatment and control of epidemic…diseases," including HIV. Recommendations include: **Georgia** to undertake general HIV-prevention measures (2002); **Moldova** to "intensify efforts" on HIV (2003); **Russia** to take "urgent measures to stop the spread of HIV" and related discrimination (2003); **Ukraine** to provide HIV information to adolescents (2001). **CRC Committee:** has recommended that States improve HIV-prevention services for children, protect children from HIV-based discrimination, and include children's rights in HIV strategies (see, e.g., comments on **Benin** (2006), **Senegal** (2006), **Swaziland** (2006), **Nigeria** (2005), **Uganda** (2005), **Armenia** (2004), **Burkina Faso** (2002), **Mozambique** (2002), **Ukraine** (2002), **Kenya** (2001), **Georgia** (2000), **Tajikistan** (2000), and **South Africa** (2000). The Women's Committee has made similar comments on **Mali** (2006), **Burkina Faso** (2005), and **Angola** (2004). The CRC Committee has also recommended that **Russia** study its practice of "segregating children of HIV-positive mothers in hospital wards or separate orphanages and of HIV-positive children being refused access to regular orphanages, medical care and educational facilities" (2005).

Table 12: HIV/AIDS and the rights of women and children

Examples of Human Rights Violations	
• Women face discrimination in the family, in education, employment and health care, and in access to property, and are denied an effective remedy for violence, including marital rape. • Women are denied access to a full range of health services, including reproductive health care, to prevent and mitigate the impact of HIV for themselves and their children. • Children are denied access to comprehensive HIV-prevention services and information. • Children orphaned or affected by AIDS are withdrawn from school, denied their inheritance, and forced into hazardous situations such as forced labor, begging, and sexual exploitation.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 3 The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights set forth in the present Covenant. **23 (3)** No marriage shall be entered into without the free and full consent of the intending spouses. **(4)** States Parties to the present Covenant shall take appropriate steps to ensure equality of rights and responsibilities of spouses as to marriage, during marriage and at its dissolution. In the case of dissolution, provision shall be made for the necessary protection of any children. **24 (1)** Every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State. **ACHPR 18 (3)** The State shall ensure the elimination of every discrimination against women and also ensure the protection of the rights of the woman and the child as stipulated in international declarations and conventions. ***See also:*** • Convention on the Elimination of All Forms of Discrimination against Women • Convention on the Rights of the Child	**CRC Committee:** Recommendations include: **Kazakhstan** to sensitize legal and other professionals on the HIV among children (2006); **Moldova** to study situation of adolescent sexual and reproductive health, including HIV (2002); **Swaziland** (2006), **Uganda** (2005), and **Botswana** (2004) to prioritize budget allocations to HIV-affected children; **Botswana** to ensure free trade agreements do not impede access to low-cost HIV medicines for children (2004); **Mozambique** (2002), **Uganda** (2005), and **Swaziland** (2006) to improve alternate care for AIDS orphans; **Benin** (2006) and **Nigeria** (2005) to ensure educational opportunities for children affected by HIV {See also, CRC recommendations on children who use drugs, Chapter 3, Table 10}. **CEDAW Committee:** Recommendations include: **Moldova** to target "high-risk groups" with HIV strategies (2006); **Russia** to address gender aspects of HIV (2002); **Angola** to "widely promote" sex education and study adolescent health (2004); **Kenya** to address HIV-related sex discrimination (2003); **Uganda** to "pay full attention to provisions of health services for prostitutes" (2002); **Burkina Faso** to implement a range of measures on women and HIV and AIDS (2000 and 2005). CEDAW Committee has also requested countries, including **Moldova** (2000) and **Mali** (2006), to gather information on measures to reduce HIV among women.

What are some examples of effective human rights programming in the area of HIV/AIDS?

Introduction

In this section, you are presented with **four examples** of effective activities in the area of HIV/AIDS and human rights. These are:

1. Litigation to advance access to HIV treatment in South Africa
2. Providing a "toolkit" for a human rights approach to AIDS in Botswana
3. Legislating for health and human rights: developing, and advocating for, better laws on drug use and HIV/AIDS
4. Uniting to demand government (and NGO) action and accountability on HIV/AIDS in Senegal

Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such a project **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this project?
- What **barriers** need to be overcome to ensure its successful replication?

Example 1: Litigation to advance access to HIV treatment in South Africa

In 2001, the Treatment Action Campaign (TAC) and the AIDS Law Project (ALP) took legal action to secure access to medication to prevent mother-to-child transmission of HIV through litigation to have such treatment declared a constitutional right.

Project type
Litigation and community mobilization

Health and human rights issue
Treatment for HIV is unavailable to the vast majority of people who need it in South Africa. In 2001, it was estimated that approximately 70,000 children would be infected with HIV through mother-to-child transmission alone. Although treatment with azidothymidine (AZT) or nevirapine can significantly reduce the risk of HIV transmission from mother to child, as of 2001 the South African government was restricting this treatment to two pilot sites in each province.

Actions taken
Following a number of failed attempts to convince the Minister of Health to broaden the prevention of mother-to-child transmission (PMTCT) program, TAC and two other plaintiffs filed a notice of motion with the Pretoria High Court alleging that the National Minister of Health as well as the Ministers of Health for all the provinces were in breach of s. 27 of the South African Bill of Rights, which protects "the right to have access to health care services."

Results and lessons learned
- In December 2001, the High Court ruled in favour of TAC and ordered the Minister of Health to make nevirapine available in all public hospitals and clinics where testing and counselling facilities existed. The court also ordered the Minister of Health to come up with a programme to prevent or reduce MTCT and to submit reports to the court outlining that programme.

- The Minister of Health appealed the decision to the South African Constitutional Court, which denied the appeal and found that the Minister of Health had a constitutional duty to give pregnant women access to nevirapine. The victory proved that human rights litigation can be an effective tool to advance access to medicines, particularly in democracies whose constitutions recognize access to health care as a human right.

- However, litigation is only one of many strategies that are needed to make HIV medicines genuinely available to all those who need them. Other factors that contributed to the success of the litigation included: a broad social movement accompanying the litigation; charismatic and committed leadership on the part of people living with HIV; alliances with treatment activists around the world; the existence of a constitutional democracy with independent courts and a constitution protecting health rights; and a legacy of public interest litigation dating back to the apartheid era.

Contact
Treatment Action Campaign
34 Main Road
Muizenberg, 7945 South Africa
Email: info@tac.org.za
Web: www.tac.org.za

AIDS Law Project
Unit 6/002, 6th Floor
Braamfontein Centre 23 Jorrisen St.
Braamfontein, 2017 South Africa
Email: info@alp.org.za
Web: www.alp.org.za

Case citation
www.constitutionalcourt.org.za/uhtbin/cgisirsi/vqHa0JTfqU/323010030/9

Example 2: A "toolkit" for a human rights approach to AIDS in Botswana

To demystify the human rights approach to HIV for local activists and government officials, the Botswana Network on Law, Ethics, and HIV/AIDS (BONELA) produced a user-friendly manual for action on HIV/AIDS and human rights.

Project type
Training and advocacy

Health and human rights issue
In its work with communities, health workers, government officials, NGOs, and businesses, BONELA observed a lack of awareness about what human rights are, and how to respect and promote these rights in people's everyday lives. There was a lack of training materials on human rights that suited a local context, and human rights were often misunderstood as a foreign or "Western" concept that was not applicable to Botswana.

Actions taken
BONELA created a 14-part manual on AIDS and human rights:

- The Manual acts as both a *resource* and as a *tool for capacity building, training, and awareness raising.* It provides accurate, interesting, clear, and relevant information on key issues related to AIDS and human rights.

- The Manual uses a building-block approach in which the first 4 modules deal with foundational aspects needed for any discussion around human rights and HIV and AIDS. The user chooses from among other modules (5-14) appropriate to the intended target group. Each module suggests activities—including scenarios, discussion points, debates, and role plays—that can be used in community-led workshops or seminars.

- The introductory manual provides guidance on planning participatory learning methods and organizing a workshop or seminar.

Results and lessons learned
- The manual has catalyzed local and national workshops and seminars on HIV/AIDS and human rights, leading to much greater awareness of human rights issues and, in some cases, legal and policy change. A network of "resource focal persons" committed to rights-based approaches in health care facilities PWA groups has been established.

- As a small NGO, BONELA has had difficulty supporting its focal persons. To address this, it has allocated staff time, raised funds, and partnered with other NGOs with the mandate and interest to provide support.

- Raising awareness is important, but there is also a need for advocacy at policy level. There is a need to engage, sensitize, and persuade legislators of the importance of rights-based approaches to HIV. An informed and committed health care worker, for example, will have difficulty integrating human rights principles into her work without a policy mandate to do so.

Contact
Botswana Network on Law, Ethics, and HIV/AIDS
Plot 50662, Medical Mews, Fairgrounds
Gaborone, Botswana
P.O. Box 402958
Email: bonela@botsnet.bw
Manual at: www.bonela.org

Example 3: Developing and advocating for better laws on drug use and HIV

The Canadian HIV/AIDS Legal Network has developed a model-law resource for NGOs and governments seeking to adopt human rights-based law and policy related to HIV among people who use drugs. The Legal Network is now actively promoting this resource at the country level.

Project type
Law reform

Health and human rights issue
Many countries with injection-driven HIV epidemics emphasize criminal enforcement of drug laws over public health approaches, thereby hindering effective responses to HIV and AIDS. Despite evidence supporting harm reduction services, millions of people around the world who use drugs lack access to such services because of legal and social barriers.

Actions taken
The Legal Network developed a "model law" resource providing a detailed framework of legal provisions and commentary on public health approaches to injection-driven HIV. The resource is aimed at policy-makers and advocates in developing and transitional countries where legislative drafting resources may be scarce. At the country level, the resource has been used:

- In collaboration with the State Department in **Ukraine**, to research and draft regulations permitting sterile syringe programs in prisons;
- In a submission to the sub-committee reviewing anti-drug legislation in the parliament of **Indonesia**, to encourage legal recognition of harm reduction;
- In the preparation of training modules on harm reduction and human rights for front-line harm reduction service providers in **Russia**;
- To advocate for the development of a harm reduction policy in **Thailand**.

Results and lessons learned
- HIV prevention, care and treatment services operate best within a clear legal framework that specifically protects the human rights of people who use drugs and enables harm reduction measures.
- Law reform is not a complete solution to effectively addressing the HIV epidemic among people who use illegal drugs, but it is a necessary and often neglected step.
- Reforming law and policy around drug use and HIV and AIDS within a particular jurisdiction can be challenging because of: hostility or inertia on the part of key government stakeholders; stigma and discrimination in the general population against people who use drugs; criminalization and social marginalization of people who use drugs, which often makes it dangerous for them to publicly advocate for their rights; and competing demands on the time and energy of local advocates.

Contact
Richard Pearshouse
Canadian HIV/AIDS Legal Network
Tel: 1-(416) 595 1666 ext 230
Email: rpearshouse@aidslaw.ca

Model law resource available at:
www.aidslaw.ca/modellaw

Example 4: Uniting to demand action and accountability on HIV in Senegal

Despite international praise for its response to HIV, Senegal was excluding vulnerable groups and civil society perspectives as it took its HIV response to a national scale. Five groups united to form a "watchdog" on the government's AIDS response. Through a report, media advocacy, and meetings with government officials, they succeeded in changing key aspects of national AIDS policy.

Project type
Networking, documentation and advocacy

Health and human rights issue
Senegal has been praised as one of the countries in the developing world that has been most successful in fighting AIDS. Yet, as the government attempted to take its HIV strategy to scale, several problems emerged: the scale up proceeded without a clear strategy or vision; vulnerable populations (particularly orphans and vulnerable children) were not being targeted with interventions; respect for the rights and dignity of people living with HIV and AIDS was lacking; and access to HIV testing and treatment remained too limited. In general, civil society felt that it had been "pushed to the side" and had no real impact on government decision-making.

Actions taken
A group of five NGOs came together to denounce the problems that Senegal was facing in its response to HIV, to provide constructive solutions to overcoming these problems, and to participate in making necessary changes. They formed an informal network, the *Observatoire de la réponse au VIH/sida au Sénégal* (Watchdog of the response to HIV and AIDS in Senegal), which:

- Drafted a position paper highlighting the group's collective reflections and recommendations on how to improve Senegal's response to AIDS;
- Met with national HIV and AIDS authorities, as well as with international organizations, to present their analysis and seek feedback;
- Held a press conference to release the position paper and demand action;
- Succeeded in becoming actively involved in the processes and mechanisms established since to deal with the problems identified.

Results and lessons learned
- Today, civil society is more, and more meaningfully, involved in key aspects of Senegal's response to AIDS. The project has shown that strong civil society engagement with government can improve the response to AIDS, as many of the problems in Senegal's response to AIDS noted by the Observatoire are being addressed.
- Civil society organizations are most effective when they build coalitions and work together, propose concrete solutions based on sound analysis, and remain independent and critical of government while engaging with government officials.

Contact
Alliance Nationale Contre le Sida
Sacré cœur 3, Villa N°9405
Dakar, Sénégal
Website: www.ancs.sn
Report at:
www.aidsalliance.org/sw44583.asp

Where can I find additional resources on HIV/AIDS and human rights?

Resources

The most comprehensive collection of resources on HIV/AIDS and human rights is contained in a CD-ROM on "HIV/AIDS: Law, Ethics and Human Rights" produced by UNAIDS and the Canadian HIV/AIDS Legal Network in 2006. Copies of this CD-Rom may be obtained by emailing UNAIDS at unaids@unaids.org.

To further your understanding on the topic of HIV/AIDS and human rights, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions: UN
- Declarations and resolutions: non-UN
- Guidelines
- Books
- Reports, key articles, and other documents
- Periodicals
- Websites
- Blogs and list-serves
- Training manuals

Declarations and resolutions: UN

- UN Commission on Human Rights, Access to Medications in the Context of Pandemics such as HIV/AIDS, Tuberculosis and Malaria, Resolutions 2005/23, 2004/26, 2003/29, and 2002/32
- UN Commission on Human Rights, Protection of Human Rights in the Context of HIV/AIDS, Resolutions 2005/84, 2003/47, 2001/51, 1999/49, and 1996/43
- UN Commission on the Status of Women, Women, the Girl Child, and HIV/AIDS, Resolution 47/1 (2003)

- United Nations General Assembly Special Session on HIV/AIDS, Declaration of Commitment on HIV/AIDS, Resolution A/RES/S-26/2, June 27, 2001

- United Nations General Assembly Special Session on HIV/AIDS, Roundtable 2: HIV/AIDS and Human Rights, A/S-26/RT.2, June 25, 2001

Declarations and resolutions: non-UN

- Demand for Action on TB and HIV. Glen Cove: Open Society Institute Public Health Watch, 2007

  This demand for action, signed by 43 participants in a meeting hosted by Public Health Watch, calls on the international community to take immediate action against TB, including MDR and XDR-TB, and to integrate TB and HIV programs worldwide.

- Global Treatment Access Group. The Global AIDS Crisis: Four Steps for Canada. A Civil Society Platform for Action. GTAG, 2007.

  This call for action highlights what high-income countries like Canada should do to address the global AIDS crisis.
  Source: www.aidslaw.ca/gtag

- Human Rights and HIV/AIDS: Now More Than Ever (2nd edition). New York: Open Society Institute Law and Health Initiative, 2007.
  This ten-point declaration, endorsed by 24 NGOs, outlines why, now more than ever, human rights should occupy the center of the global response to HIV and AIDS.
  Source: www.soros.org/initiatives/health/focus/law

- The Patients' Charter for Tuberculosis Care: Patients' Rights and Responsibilities. World Care Council, 2006.

  Initiated and developed by patients around the world, this charter outlines the rights and responsibilities of people with TB and aims to make TB patients and their providers more accountable to each other. The charter was developed in tandem with the International Standards for Tuberculosis Care.

Guidelines

- Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, International *Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version*, Second International Consultation on HIV/AIDS and Human Rights (Geneva, September 23-25, 1996) and Third International Consultation on HIV/AIDS and Human Rights (Geneva, July 25-26, 2002). Geneva: UNAIDS, 2006.

The Guidelines provide comprehensive, detailed, and specific guidance on how human rights should be promoted and protected in the context of the HIV and AIDS epidemic. The text and commentary of the Guidelines are available via the web.
Source: www.unaids.org or
www.ohchr.org/english/issues/hiv/guidelines.htm

The following documents explain how advocates can best use the Guidelines, and provides concrete examples of how their implementation can be assessed:

- AIDS & Rights Alliance for Southern Africa. HIV and Human Rights in SADC. Windhoek: ARASA, 2006.

  2006 marked the tenth anniversary of the development of the Guidelines. To mark this occasion, ARASA released this report of an evaluation of the steps taken by SADC countries to implement the Guidelines. The report is the first attempt at measuring the successes and failures of SADC countries in responding to HIV within human rights based framework.
  Source: www.arasa.info/publications.php

- International Council of AIDS Service Organizations. Advocates Guide to the International Guidelines on HIV/AIDS and Human Rights. Toronto: ICASO, 1999.

  An easy-to-read summary of the Guidelines, explaining to advocates how they can best use the Guidelines in their day-to-day work.
  Source: www.icaso.org

- Watchirs, H. A Rights Analysis Instrument to Measure Compliance With the International Guidelines on HIV/AIDS and Human Rights. Australian National Council on AIDS and Related Diseases, 1999.

  This rights analysis instrument was developed to measure states' compliance with the Guidelines. It has been applied in Australia {see: Watchirs H. AIDS Audit - HIV and Human Rights: An Australian Pilot. Law & Policy 2003; 25 (3): 245–268} and served as the basis for a legislative audit undertaken in Nepal {see: National Centre for AIDS and STD Control, POLICY Project/Nepal, and Forum for Women, Law and Development. HIV/AIDS and Human Rights: A Legislative Audit. Kathmandu, Nepal: Forum for Women, Law and Development, 2004 (Publication No. 76}.
  Source: www.policyproject.com/pubs/countryreports/NEP_LegAudit.pdf

Books

- Beyrer C. *War in the Blood: Sex, Politics, and AIDS in Southeast Asia.* Zed Books, 1998.

- Farmer P. *Pathologies of Power. Health, Human Rights, and the War on the Poor.* Berkeley: University of California Press, 2005.

- Frankowski S. *Legal Responses to AIDS in Comparative Perspective*. Kluwer Law International, 1998. (This book is a collection of ten essays on legal responses to HIV and AIDS, written by scholars from five continents: Africa, Asia, Australia, Europe and America).

- Gostin L. *The AIDS Pandemic: Complacency, Injustice, and Unfulfilled Expectations*. University of North Carolina Press, 2003.

- Lewis S. *Race Against Time: Searching for Hope in AIDS-Ravaged Africa*. Toronto: House of Anansi Press Inc., 2005.

- Siplon P. *AIDS and the Policy Struggle in the United States*. Washington, DC: Georgetown University Press, 2002.

- Webber DA. *AIDS and the Law*. Aspen Publishers, 1997 (last updated, 2004). In addition to the most comprehensive analysis available about legal issues related to HIV and AIDS in the United States, this book also contains chapters on the law related to HIV and AIDS in Australia, Canada, Namibia, South Africa, and the United Kingdom.
  Source: www.aidsandthelaw.com for more information and ordering information.

Reports, key articles, and other documents

- AIDS and Rights Alliance for South Africa. *Proposed SADC Code on Gender and HIV/AIDS*. ARASA, 2005.

  This code contains "urgent measures needed to promote the equality of women and the reduction of women's risk of HIV infection". The Code is available in English and Portuguese. It is similar to the 'Code on HIV/AIDS and Employment' that was adopted by SADC 1997, but focuses specifically on the gendered dimensions of the AIDS epidemic.

- Altman, D., HIV, Homophobia, and Human Rights. *Health and Human Rights,* 2 (4), 15-22 (1998).

- Amnesty International. *Women, HIV/AIDS and human rights*. London: AI, 2004.

  This paper offers a human rights analysis of the gender-specific factors that put women at risk of contracting HIV and of the consequences of contracting HIV that women face. It underlines the need for government action in a rights-based approach to the gender-related aspects of HIV and AIDS prevention, treatment and support.
  Source: web.amnesty.org/library/Index/ENGACT770842004

- Amon J. Preventing the further spread of HIV/AIDS: The essential role of human rights. New York: Human Rights Watch, 2006.

  Argues that, even as treatment options are expanding, responses to HIV and AIDS in many places are getting further from the kind of science-based, human-rights informed response that has been proven to stop the spread of the disease. Left unaddressed, human rights abuses will undermine both HIV and AIDS prevention and treatment.
  Source: hrw.org/wr2k6/hivaids/index.htm

- Canadian HIV/AIDS Legal Network. A human rights approach to HIV/AIDS. Montreal: The Network (no date).

  Describes in detail what is meant by a human rights approach to HIV and AIDS. Available in English and French.
  Source: www.aidslaw.ca

- Center for Health and Gender Equity. Policy brief: Implications of U.S. policy restrictions for programs aimed at commercial sex workers and victims of trafficking worldwide. Tacoma Park: The Center, 2005.

  Explains the implications for effective HIV prevention, and the promotion of both human rights and public health, of US policy restrictions for programs aimed at sex workers.
  Source: www.genderhealth.org

- Csete J. HIV/AIDS and human rights: we've only just begun. *HIV/AIDS Policy & Law Review* 2005; 10(1): 1, 7-13.

  Describes the human rights framework that is the foundation for a more effective response to HIV and AIDS and stresses the urgency of paying more than lip service to the need to put human rights at the centre of the fight against HIV and AIDS in Canada and beyond. Available in English and French.
  Source: www.aidslaw.ca

- Csete J, Elliott R. Scaling up HIV testing: human rights and hidden costs. *HIV/AIDS Policy & Law Review* 2006; 11(1): 1, 5-10.

  Discusses the human rights and ethical issues raised by provider-initiated routine HIV testing. Available in English and French.
  Source: www.aidslaw.ca

- Criminal Law, Public Health and HIV Transmission, a Policy Options Paper, UNAIDS, Geneva (2002).

- Gruskin S. Human rights and public health: An overview. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 78-81.

  Explains how a human rights framework can be applied to dealing with public health issues and, specifically, HIV and AIDS. The example of women's reproductive health is used to highlight governmental responsibility for both health and human rights. Available in English and French.
  Source: www.aidslaw.ca

- Heywood M. Human rights and HIV/AIDS in the context of 3 by 5: time for new directions? *Canadian HIV/AIDS Policy & Law Review* 2004; 9(2): 1, 7-13.

  Argues that, over the last decade, the success of the human rights–based approach to HIV and AIDS has been spotty, and describes the challenges that remain in implementing a human rights approach. Argues that human rights advocacy needs to continue, but that new directions are required, and outlines new directions in the areas of confidentiality and openness, HIV testing, and health systems. Available in English and French.
  Source: www.aidslaw.ca

- International Council of AIDS Service Organizations. Community Monitoring and Evaluation. Implementation of the UNGASS Declaration of Commitment on HIV/AIDS. Toronto: ICASO, 2006.

  This study evaluated the extent to which governments have implemented the UNGASS Declaration of Commitment. It found that "human rights abuses of vulnerable populations continue unabated."
  Source: www.icaso.org

- Jürgens R. Increasing Access to HIV Testing and Counseling While Respecting Human Rights. Background paper (revised). New York: Public Health Program, OSI, 2007.

  Discusses the human rights and public health issues related to scaling up access to HIV testing.
  Source:
  www.soros.org/initiatives/health/articles_publications/publications/testing_20070907

- Malinowska-Sempruch K, Gallagher S (eds). *War on Drugs, HIV/AIDS and Human Rights*. New York, Amsterdam, Brussels: International Debate Education Association, 2004.

  A collection of essays by people working in the area of harm reduction, drug policy and human rights.

- Maman S, Groves A, King E, Pierce M, Wyckoff S. HIV Testing During Pregnancy: A Literature and Policy Review. Background paper. New York: Public Health Program, OSI, 2008.

  Source:
  www.soros.org/initiatives/health/focus/law/articles_publications/publications/hivtesting_20080916

- Mann J. Human rights. In: Smith RA (ed). Encyclopedia of AIDS: A Social, Political, Cultural, and Scientific Record of the HIV Epidemic. 1998.

  An introduction to HIV/AIDS and human rights by the late Jonathan Mann.
  Source: www.thebody.com/encyclo/human_rights.html

- Patterson D, London L. International law, human rights and HIV/AIDS. *Bulletin of the World Health Organisation* 2002; 80(12): 964-969.

This article explores the relevance of international human rights law in the response to the HIV and AIDS epidemic at national and international levels.
Source: www.who.int/entity/bulletin/archives/80(12)964.pdf

- OSI Public Health Fact Sheet. *Women and HIV Testing, Policies, Practices, and the Impacts on Health and Human Rights* at: Source: www.soros.org/initiatives/health/focus/law/articles_publications/publications/womenhiv_20080730

- Piot P. Why AIDS is exceptional. Geneva: UNAIDS.

  In this speech given at the London School of Economics on 8 February 2005, Dr Piot, the Executive Director of UNAIDS, argues that AIDS continues to be "exceptional in so many ways that only an equally exceptional response will succeed."
  Source: www.unaids.org

- Roseman MJ, Gruskin S. HIV/AIDS & Human Rights in a Nutshell. Toronto & Boston: ICASO & Program on International Health and Human Rights, 2005.

  Intended to provide "a quick and useful guide for action, as well as an inspirational framework to carry HIV/AIDS and human rights actions forward." Available in English, French, Russian and Spanish.
  Source: www.icaso.org

- UNAIDS. From Principles to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS. Geneva: UNAIDS, 1999.

  Contains the text of the Declaration of the Paris AIDS Summit, explains why involving people living with and affected by HIV and AIDS is critical to the response to HIV and AIDS, and suggests how this can best be done in practice
  Source: www.unaids.org

- UNAIDS & Inter-Parliamentary Union. *Handbook for legislators on HIV/AIDS, law and human rights*. Geneva: UNAIDS, 1999.

  Based on the International Guidelines on HIV/AIDS and Human Rights, presents concrete measures that legislators can take to protect human rights and promote public health in responding to HIV and AIDS.
  Source: www.unaids.org

- UNAIDS. *HIV-related stigma, discrimination and human rights violations. Case studies of successful programmes*. Geneva: UNAIDS, 2005.

  This report provides a number of case studies of efforts to promote the human rights of people living with HIV and providing redress for violations of their human rights, in Venezuela, Namibia, India, and South Africa.

- UNAIDS. Intensifying HIV Prevention: A UNAIDS Policy Position Paper. Geneva: UNAIDS/05.18E, 2005.

This paper aims to "energize and mobilize an intensification of HIV prevention with an ultimate aim of universal access to HIV prevention and treatment". It recognizes that ensuring that "human rights are promoted, protected and respected and that measures are taken to eliminate discrimination and combat stigma" is an "essential policy action" for HIV prevention (at 23).
Source: www.unaids.org

- UNAIDS & Canadian HIV/AIDS Legal Network. Courting rights: case studies in litigating the human rights of people living with HIV. Geneva: UNAIDS, 2006.

  Presents examples where a whole range of people – from people living with HIV, to activists, to prisoners – have demanded that human rights related to HIV be recognized and enforced in national courts of law.
  Source: www.unaids.org or www.aidslaw.ca

- UNESCO & UNAIDS. *HIV/AIDS and Human Rights - Young People in Action*. Geneva, 2001.

  This kit presents ideas for youth action on human rights and HIV and AIDS.
  Source: www.unaids.org/en/Issues/Impact_HIV/hivHRlaw.asp

- University of Toronto, Case Study: Treatment Action Campaign v. the Minister of Health.
  Source: www.law-lib.utoronto.ca/diana/casestudies.html

- World Health Organization. *25 questions & answers on health & human rights*. Geneva: WHO, 2002.

  Part of the WHO Health and Human Rights Publication Series which aims to clarify the relationship between human rights and specific health topics. Suggests answers to key questions which come to mind in exploring the linkages between health and human rights. Available in many languages.
  Source: www.who.int/hhr/activities/publications/en

- World Health Organization, UNAIDS, and Office of the United Nations High Commissioner for Human Rights. *HIV/AIDS – Stand up for human rights*. Geneva, 2003.

  This cartoon is designed to empower young people to promote human rights in relation to HIV and AIDS, to raise awareness of the key linkages between HIV/AIDS and human rights, to demystify the disease and to combat the myths and taboos associated with HIV and AIDS. Available in English, French, and Thai.
  Source: www.who.int/hhr/activities/publications/en/

Periodicals

- Health & Human Rights

A journal dedicated to studying the relationship between human rights and health. Three issues of the journal have focused on HIV/AIDS and human rights.
Source: www.hsph.harvard.edu/fxbcenter/journal.htm

- HIV/AIDS Policy & Law Review
  Provides analysis and summaries of current developments in HIV/AIDS-related policy, law, and human rights.
  Source: www.aidslaw.ca

Websites

The following websites contain useful information on HIV/AIDS and describe projects undertaken on HIV and AIDS and human rights:

- Accion Ciudadana Contra el SIDA (Venezuela)

  In Spanish only. Contains many relevant materials, including a manual on HIV/AIDS and human rights.
  www.accsi.org.ve

- AIDS Law Project (South Africa)

  Together with the website of the Canadian HIV/AIDS Legal Network, this site is the most comprehensive source for information on legal and human rights issues related to HIV and AIDS.
  www.alp.org.za

- AIDS Law Unit of the Legal Assistance Centre (Namibia)
  www.lac.org.na/alu/default.htm

- AIDS Legal Network (South Africa)

  Among other things, contains information on a Training Manual – HIV/AIDS & Human Rights: Towards a supportive and enabling environment for women, children and other vulnerable groups. The manual includes four modules pertaining to defining and understanding core concepts, to the meaning and implication of Guideline 8 of the International Guidelines on HIV/AIDS and Human Rights, to South Africa's response to the principles outlined in Guideline 8 and to practical advocacy steps aimed at enhancing the access to, and implementation of, legislative and policy measures. Also contains an HIV/AIDS and the Law Trainers' Manual.
  www.aln.org.za

- AIDS Rights Alliance for Southern Africa (ARASA)

  This website contains a number of useful documents, including an HIV/AIDS and Human Rights Advocacy Resource Manual, a Draft Code on HIV/AIDS and Gender, and a report on HIV and human rights in SADC countries.
  www.arasa.info

- Botswana Network on Ethics, Law, and HIV (BONELA)
  www.bonela.org

- Canadian HIV/AIDS Legal Network

  Together with the website of the AIDS Law Project (South Africa), this site is the most comprehensive source for information on legal and human rights issues related to HIV and AIDS. All materials are in English and French. Some materials are also available in Spanish and Russian and in some other languages.
  www.aidslaw.ca

- Center for HIV Law and Policy
  www.hivlawandpolicy.org

- Center for Reproductive Rights
  www.reproductiverights.org

- Health Action AIDS (USA)
  A project of Physicians for Human Rights (www.phrusa.org) in coordination with Partners in Health (www.pih.org). The site contains a section on HIV/AIDS and human rights.
  www.phrusa.org/campaigns/aids/index.html

- Human Rights Watch
  Contains a section on HIV/AIDS and human rights with many reports on human rights abuses in the context of the global HIV and AIDS epidemic and other materials.
  www.hrw.org

- Hungarian Civil Liberties Association
  Hungarian and English. Among other things, HCLU has produced a book on HIV/AIDS and human rights in Hungary and a policy paper on HIV and AIDS.
  www.tasz.hu

- International Council of AIDS Service Organizations (ICASO)
  Contains documents on issues related to HIV/AIDS and human rights, including an advocates' guide to the International Guidelines on HIV/AIDS and Human Rights and a paper on "HIV/AIDS and Human Rights in a Nutshell."
  www.icaso.org

- Lawyers Collective HIV/AIDS Unit (India)
  www.lawyerscollective.org

- Office of the United Nations High Commissioner for Human Rights
  At www.ohchr.org/english/issues/hiv/index.htm, contains a section dedicated to HIV/AIDS and human rights, including an "introduction to HIV/AIDS and human rights" and a list of documents, including resolutions, general comments and reports by various UN bodies on issues related to HIV and AIDS and human rights.
  www.ohchr.org

- Open Society Institute – Public Health Program
  Contains, among other things, the NGO declaration "Human Rights and HIV/AIDS: Now More than Ever", and a background paper on scaling up access to HIV testing in resource-poor countries.
  www.soros.org/initiatives/health/

- Program on International Health and Human Rights (United States)
  Contains a number of publications and other information about HIV/AIDS and human rights.
  www.hsph.harvard.edu/pihhr/index.html

- Southern African Litigation Center
  Supports litigation and advocacy to mitigate the negative impact of HIV/AIDS in Southern Africa; the program launched a case law database that provides free access to judicial decisions form around the world on HIV/AIDS-related issues.
  www.southernafricalawcenter.org/salc/casedocket/casedocketlisting.aspx?Category=hiv

- Uganda Network on Law, Ethics, and HIV
  www.uganet.org

- UK AIDS and Human Rights Project
  Among other things, contains a series of fact sheets on HIV/AIDS and human rights and on HIV and AIDS and prisoners' rights.
  www.aidsrightsproject.org.uk

- UNAIDS
  Contains a section on HIV, human rights and law, explaining why protection of human rights is critical to a successful response to HIV and AIDS, with links to many resources on issues related to HIV/AIDS and human rights produced by UNAIDS and to the work of the UNAIDS Global Reference Group on HIV/AIDS and Human Rights.
  www.unaids.org

- United Nations Development Programme (UNDP)
  One of the focus areas of the UNDP HIV and AIDS activities is human rights, gender, and HIV and AIDS. At www.undp.org/hiv/focus03.htm, the site contains materials related to human rights and HIV and AIDS, including a discussion paper on human rights, gender and HIV and AIDS prepared for the round table on human rights, gender and HIV and AIDS held during the 2005 UN General Assembly High Level Meeting on HIV and AIDS. The Paper argues that if the dual and synergistic challenges of gender equality and respect for human rights are not addressed, the achievement of the Millennium Development Goals and the targets of the Declaration of Commitment on HIV/AIDS will be jeopardized.
  www.undp.org

- World Health Organization (WHO)

The site contains information about WHO's work on health and human rights and a number of publications on the topic.
www.who.int/en/

- Zambia AIDS Law Research and Advocacy Network (ZARAN)
  www.zaran.org

Blogs and list-serves

- American Bar Association AIDS Coordinating Committee, HIV-LEGAL Listserv
  www.abanet.org/AIDS/listserv.html

- HealthGAP (Global Access Project)
  www.healthgap.org

- AIDS and Rights: A Collaborative Blog Focused on HIV and AIDS and Human Rights
  www.eliminateaids.blogspot.com

Training Manuals

- AIDS Law Project, Lawyers for Human Rights and Joint Oxfam HIV/AIDS Programme. *HIV/AIDS and the Law. A Trainer's Manual* (second edition), 2005.

  A practical manual aiming to assist people who train others on HIV and AIDS and the law.
  Source: www.aln.org.za

- AIDS Legal Network. Training Manual – HIV/AIDS & Human Rights: Towards a supportive and enabling environment for women, children and other vulnerable groups. ALN, 2005.

  This training manual focuses on Guideline 8 of the International Guidelines on HIV/AIDS and Human Rights. It is prepared for a facilitation approach based on interaction, participation, information sharing and skills development and targets trainers within civil society.
  Source: www.aln.org.za

- AIDS & Rights Alliance for Southern Africa. *HIV/AIDS and Human Rights Advocacy Resource Manual*. Windhoek: ARASA, 2006.

  The purpose of this manual is to set out information on HIV/AIDS and human rights, with a focus on Southern Africa, in an accessible and user-friendly format. The manual provides its readers with a better understanding of the links between HIV/AIDS and human rights; sets out ways in which law and policy can and should promote an effective human rights based

response to HIV and AIDS in Southern Africa; gives examples of how Southern African countries have used rights-based law and policy to respond to HIV and AIDS; and provides readers with ideas on how to strengthen a rights-based response to HIV and AIDS in their own countries and in the region.
Source: www.arasa.info/publications.php

- Asia Pacific Council of AIDS Service Organizations. HIV/AIDS and Human Rights: A Training Manual for NGOs, Community Groups and People Living with HIV/AIDS, 2002.

  This manual contains a series of training modules designed to introduce a human rights approach to HIV and AIDS.
  Source: www.apcaso.org

- Botswana Network on Law, Ethics, and HIV/AIDS. *Human Rights and HIV: A Manual for Action*. BONELA, 2005.

  The manual aims to "provide the right tools for local activists, government officers, health care workers and people living with HIV and AIDS to pursue a human rights approach to the many problems posed by the epidemic".
  Source: www.bonela.botsnet.co.bw

- HIV & AIDS Legal Clinic (Ontario). *HIV & the Law Advocate's Manual.* Toronto: HALCO, 2004.

  A lay advocates manual designed to help people living with HIV or AIDS and front line workers in agencies working with people living with HIV or AIDS understand more about the legal issues affecting them.
  Source: www.halco.org

- University of Toronto. Women, HIV/AIDS and Human Rights-syllabus and annotated bibliography.2006.

  Prepared for a series of four workshops held at the University of Toronto, August 4-17, 2006. Hard copies of the full text syllabus also available while supplies last.
  Contact: reprohealth.law@utoronto.ca
  Source: www.law-lib.utoronto.ca/diana/women-hiv-aids/contents.htm

What are key terms related to HIV/AIDS and human rights?

Glossary

A variety of terms is used in HIV and AIDS and human rights work. The following list is not comprehensive, but will introduce you to basic acronyms and other terms often used by AIDS activists.

A

ARV, ART

Acronyms for anti-retroviral and anti-retroviral treatment. Anti-retroviral drugs inhibit various phases of the life-cycle of the human immunodeficiency virus (HIV), thus reducing HIV-related symptoms and prolonging life-expectancy of people living with HIV. Treatment with ARVs is also used to prevent transmission of HIV from mother-to-child and to prevent HIV infection following exposure.

D

DOC

Acronym for the *Declaration of Commitment on HIV/AIDS*, adopted by the United Nations General Assembly in a special session in June 2001. The DOC recognizes that "realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS" (paragraph 58).

G

GIPA

Abbreviation for "greater involvement of people living or affected by HIV/AIDS". The importance and benefits of involving people living with HIV or AIDS in formulating policy and delivering services has been widely recognized, first at the 1994 Paris AIDS Summit and more recently in the *Declaration of Commitment on HIV/AIDS*.

Global Fund

Abbreviation for the Global Fund to Fight AIDS, Tuberculosis and Malaria, the central global mechanism for channelling funds between rich and poor countries to finance national responses to HIV and AIDS.

Guidelines

Abbreviation for the *International Guidelines on HIV/AIDS and Human Rights*, an authoritative set of non-binding legal and policy recommendations issued by UNAIDS and the Office of the High Commissioner for Human Rights (OHCHR) in 1998.

P

PEPFAR
Acronym for the President's Emergency Plan for AIDS Relief, a five-year, US$15-billion AIDS package authorized by U.S. President George W. Bush and enacted by the U.S. Congress in 2003 under the *U.S. Global Leadership on HIV/AIDS, Tuberculosis and Malaria Act*. PEPFAR is the largest program to combat HIV and AIDS financed by a single donor government.

PMTCT
Acronym for prevention of mother-to-child transmission of HIV, or transmission during pregnancy, labour and delivery, or breastfeeding. Without treatment, approximately 15-30% of babies born to mothers living with HIV will be infected during pregnancy and delivery, and a further 5-20% will become infected through breastfeeding.

PWA, PLWA, PLWHA
Acronyms for person living with HIV or AIDS.

S

Stigma and discrimination
The United Nations has called **stigma** and **discrimination** associated with HIV and AIDS "the greatest barriers to preventing further infections, providing adequate care, support and treatment and alleviating impact." **Stigmatization** leads to **discrimination**.

- **Stigma** is "a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons." People who are stigmatized are usually considered deviant or shameful for some reason or other, and as a result are shunned, avoided, discredited, rejected, restrained or penalized. As such, stigma is an expression of social and cultural norms, shaping relationships among people according to those norms. Stigma marks the boundaries a society creates between "normals" and "outsiders", between "us" and "them".

- **Discrimination** in the context of HIV and AIDS has been defined as "any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health."

  Discrimination can be **legitimate** and **illegitimate**.
  - ***Illegitimate*** discrimination is unjustified, disproportionate, and arbitrary.
    - A measure or an action is *unjustified* if it lacks rational and objective reasons.
    - It is *disproportionate* if the means employed and their consequences far exceed or do not achieve the aims pursued.
    - It is *arbitrary* if it seriously infringes the rights of the individual and is not necessary to protect the health of others.

U

UNAIDS
Acronym for the Joint United Nations Programme on HIV/AIDS, a consortium of eight United Nations agencies addressing various aspects of the global AIDS epidemic. UNAIDS has a small program dedicated to address the legal, ethical, and human rights aspects of HIV and AIDS.

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains International Centre for Human Rights Education

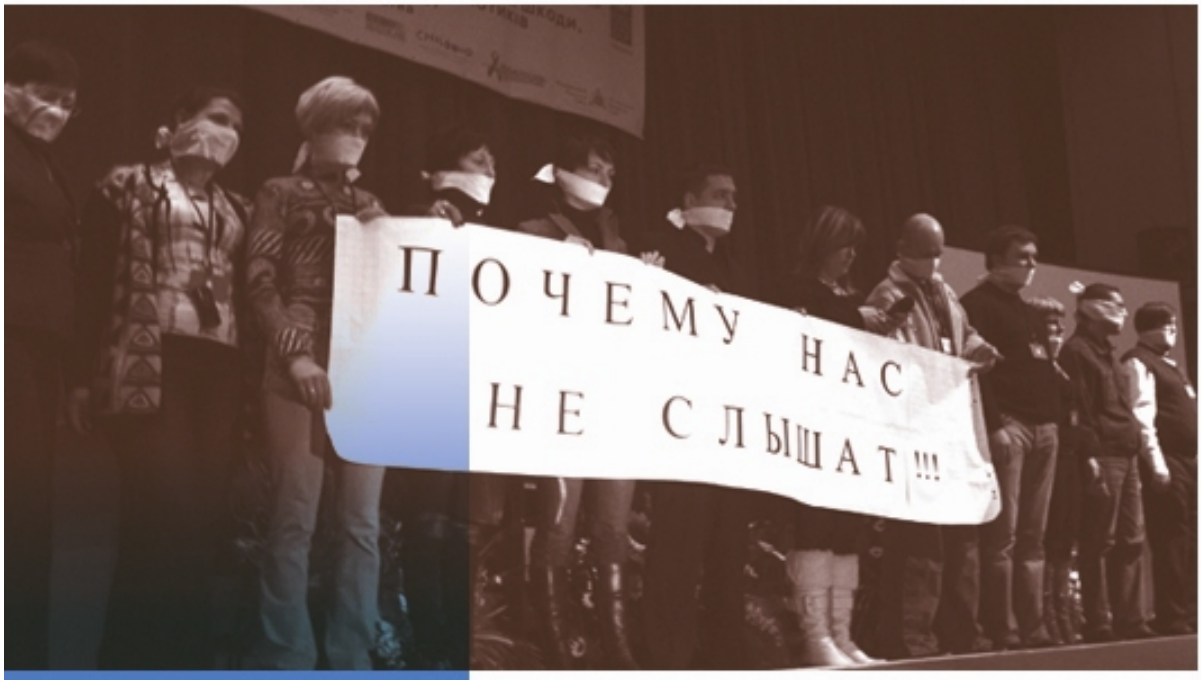


Photo: "Why don't you hear us?" Matt Curtis, 2007

Chapter 3 Harm Reduction and Human Rights

"They treat us like dirt. I just want to be treated like a normal human being."

Yevgeny, injecting drug user in Saint Petersburg, 2004

Contents

3

Introduction

This chapter will introduce you to key issues and resources in **harm reduction and human rights**, with a particular focus on the rights of people who inject illicit drugs.

The chapter is organized into six sections that answer the following questions:[1]

- **How** is harm reduction a human rights issue?
- **What** is OSI's work in the area of harm reduction and human rights?
- **Which** are the most relevant international and regional human rights standards related to harm reduction?
- **What** are some examples of effective human rights programming in the area of harm reduction?
- **How** can I find additional resources about harm reduction and human rights?
- **What** are key terms related to harm reduction and human rights?

As you read through this chapter, consult the **glossary of terms**, found in the last section, *What are key terms related to harm reduction and human rights?*

[1] Some of these questions are also addressed in Chapter 2, HIV/AIDS and Human Rights.

How is harm reduction a human rights issue?

What is harm reduction?

A common social response to people who use illegal drugs is to treat them like drugs: as something to be controlled and contained. Drug users are often subject to prolonged incarceration or institutionalization, or offered health care only if they demonstrate that they have stopped their drug use altogether. This is true despite evidence that dependence on certain drugs is chronic and relapsing, that active drug users can benefit from many forms of prevention and treatment, and that refusing services makes people who use drugs more vulnerable to a range of health and social problems.

Harm reduction takes a different and more pragmatic approach, recognizing that not everyone is able or willing to stop illicit drug use, and that those who are still using drugs can make choices to protect their health and the health of others. Also known as "harm minimization," harm reduction focuses on reducing the adverse consequences of drug use, including risk of HIV and other blood-borne infections, rather than on demanding that people stop drug use altogether. Central to much harm reduction is a belief that services should meet people who use drugs "where they are," rather than requiring people to fulfill many complicated requirements or behavioural changes before they get help.

Some common harm reduction measures include:

- **Access to HIV prevention**

  Provision of sterile injection equipment and prescription of orally-administered medications such as methadone or buprenorphine to reduce injection of heroin and other illicit opiates have been shown clearly to reduce HIV risk. Yet these services remain out of reach of people who inject drugs in many countries. Programs are either too small to reach all at risk, opposed by politicians who insist—without evidence—that they encourage drug use, or limited by police actions such as harassment of needle exchange workers and arrest of clients.

- **Access to HIV and drug treatment**

  Evidence shows that people who inject drugs can, with proper supports, enjoy the same benefits from antiretroviral treatment (ART) as other people with HIV. However ART remains limited or ineffective for drug users, if it is available at all. While effective treatment for drug addiction can enhance ART adherence, many drug treatment programs offer little more than forced labor and long-term detention, making these programs more like prison than like treatment. Even humane and effective drug treatment programs are of limited use if fear of harassment, arrest, or incarceration makes drug users reluctant to use them.

- **Access to sexual health services**

  Provision of sexual health services enables people who use drugs to protect themselves and their sexual partners from HIV, preventing further sexual transmission of an epidemic initially spread by drug use. UNAIDS urges that sexual health services be made available to all drug users and their partners. Source: UNAIDS, Intensifying HIV prevention: UNAIDS policy position paper. Geneva, 2005.

How is harm reduction related to human rights?

Drug users are vulnerable people. They suffer from inadequate medical assistance. They experience discrimination, invasion of privacy, police harassment, and social marginalization. They have to endure the arbitrary deprivation of rights, such as mandatory medical treatment. Their capacity to defend their interests is impaired by social stigmatization. One would assume that society's majority would oppose such violations. After all, arbitrary searches, disco raids, compulsory urine tests, and wrongful appropriation of confidential medical files are injustices suffered by nonusers as well. But the majority accepts the invasion of privacy in an attempt to have a drug-free environment. Support for the human rights of drug users is virtually nonexistent.
Judit Fridli, "Harm Reduction and Human Rights" *Harm Reduction News*, 2003

Harm reduction goes hand in hand with advocacy to ensure a range of human rights for people who use drugs. Such advocacy includes work to ensure:

- Access to information and measures to protect against disease and overdose
- Protection against cruel or inhumane treatment
- Protection against violations of privacy such as forced testing and registration
- Freedom of association and political participation.

Some harm reduction and human rights efforts include:

- **Protection against abuses by police and health care providers**

  Mistreatment of people who use drugs by police and healthcare providers is widespread. Police use the threat of incarceration or painful withdrawal symptoms to coerce testimony and extort money of people who use drugs. In many countries, police or health care providers release confidential information regarding HIV or drug using status, register drug users' names on government lists, and deny them employment or services. It is common for governments to impose lengthy prison sentences for minor drug offences. This not only constitutes cruel and unusual punishment, but also catalyzes HIV transmission, since hundreds of thousands incarcerated in environments where drug injection and unprotected sex continue, and where HIV treatment and prevention measures are often unavailable.

- **Support for political participation**

  More than two decades of experience with HIV have shown that "hard-to-reach" populations are their own best advocates. Despite the importance of involving those who are directly affected in the formation of AIDS policy, drug users have often been excluded, even from those mechanisms that are intended to increase participation of people living with HIV.

Did you know?

- Some 30% of new HIV infections outside of sub-Saharan Africa are due to contaminated injection equipment.[2]

- In Eastern Europe and Central Asia injecting drug use accounts for more than 80% of HIV cases, but less than 24% of people receiving HIV treatment. In South and South-East Asia, injecting drug users are from 4 to 75 percent of those infected, but only 1% of the people receiving HIV treatment.[3]

- **Thailand's** "War on Drugs" initiated in 2003 included:[4]
  - Arrest of tens of thousands of suspects on government "blacklists" or "watchlists "
  - Arrest quotas, arbitrary arrest, and other breaches of due process
  - Coerced or mandatory drug treatment
  - Intimidation of human rights defenders
  - More than 2,300 extrajudicial executions.

- Drug users or even those in neighborhoods where drug use is common are rounded up in advance of national or international events such as the Olympics or the UN's International Day against Drug Trafficking and Drug Abuse. Drug users are often forcibly tested and sent to prolonged mandatory treatment without evaluation by a medical professional or right of appeal.[5]

- Some countries, such as **Malaysia** and **Georgia**, criminalize the status of drug users. In Malaysia, law permits those suspected of drug use to be detained and forcibly tested. Those who test positive are subject to

[2] UNAIDS, 2006 Report on the Global AIDS Epidemic: www.unaids.org/en/HIV_data/2006GlobalReport/default.asp.
[3] Aceijas, C, et al. (2006). "Antiretroviral treatment for injecting drug users in developing and transitional countries 1 year before the end of the "Treating 3 million by 2005. Making it happen. The WHO strategy" ("3 by 5")." Addiction. 101(9).
[4] Thailand- Not Enough Graves: The War on Drugs, HIV AND AIDS, and Violations of Human Rights. (2004). Human Rights Watch. Vol. 16, No. 8 (C).
[5] Wolfe D., Malinowska-Sempruch K. (2004) Illicit Drug Policies and the Global HIV Epidemic, IHRD-Open Society Institute, New York.

mandatory detention in treatment centers, and those caught in possession of drugs are subjected to mandatory flogging and incarceration.[6]

- Other countries, including several in the Commonwealth of Independent States, do not criminalize drug use, but punish possession of "large" or "extra large" amounts of illicit drugs with prolonged imprisonment. "Large" amounts of drugs can be defined as the residue in a used syringe or half a cigarette of cannabis.[7]

- In parts of **Russia**, prisoners are tested for HIV and those who are positive are segregated—by a wire fence. Since injection is common but clean needles and syringes are not, injection equipment can be shared as many as forty times.[8]

- Across Asia, drug users are confined to treatment centers that are more like prisons than health care facilities, and that offer little or no psychosocial or medical support. In **China**, IDUs are arrested and forced into compulsory detoxification facilities, and those who return to drug use are sent to forced labor camps. In one study, as many as ten percent of drug users swallowed nails or glass to avoid such detention.[9]

The good news

- In **Brazil**, needle exchange services contributed to a remarkable 20 percent drop in HIV incidence among injecting drug users between 1998 and 2000.[10]

- Countries such **Spain** have successfully targeted injecting drug users in prison with HIV prevention interventions including needle exchange and opiate substitution treatment, achieving huge reductions in HIV prevalence among prisoners.[11]

- Human rights advocacy has led to tangible victories on behalf of people who use drugs:
  - In 2007, the European Court of Human Rights found in favor of a Russian drug user who had been entrapped by police and placed in prolonged detention without a trial or medical care

[6] Alternative Georgia (2005). Reforming Drug Policy for HIV/AIDS Prevention. Tbilisi: Union Alternative Georgia. Mazlan, M., Schottenfeld, R. S., & Chawarski, M. C. (2006). New challenges and opportunities in managing substance abuse in Malaysia. Drug and Alcohol Review, 25(5), 473-478.
[7] Alternative Georgia. Reforming Drug Policy for HIV/AIDS Prevention (2005). Tblisi: Union Alternative Georgia.
[8] Sarang, A., T. Rhodes, et al. (2006). "Drug injecting and syringe use in the HIV risk environment of Russian penitentiary institutions: Qualitative study." Addiction 101(12): 1787-96.
[9] Wolfe, D. (2007) Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union. International Journal of Drug Policy (in press).
[10] UN Economic and Social Council Commission on Human Rights, submitted by the Open Society Institute (OSI), a non-governmental organization in special consultative status, 3 March 2005.
[11] Status paper on prisons drugs and harm reduction, Regional Office of Europe-WHO, May 2005, www.euro.who.int/document/e85877.pdf.

- In Vancouver, **Canada**, documentation of police abuse against people who use drugs led to an independent investigation of the Police Department
- In **Hungary**, a public campaign against drug raids of discos led to a dramatic decline in raids and parliamentary proposals to reform anti-drug laws.

What is OSI's work in the area of harm reduction and human rights?

OSI's work on harm reduction and human rights is led by the **International Harm Reduction Development Program (IHRD).** Examples of harm reduction and human rights projects supported by IHRD include:

- Access to quality information and services
  - Support for access to substitution treatment in countries including **Albania**, **Kyrgyzstan**, **Lithuania**, and **Ukraine**.
  - The formation of harm reduction networks in Central and Eastern Europe, Russia, and Central Asia to help programs exchange information and advocate for change.

- Advocacy at national and international level
  - Highlighting the role that incarceration and forced institutionalization play in accelerating the HIV epidemic, and the policy changes that can reduce overcrowding, disease risk, and human rights violation.
  - Work with international human rights groups, such as Human Rights Watch, to ensure that abuses are carefully documented in countries such as **Russia**, **Ukraine**, and **Kazakhstan**.

- Technical assistance for harm reduction
  - Training of police and development of curricula to train law enforcement on how to work effectively without violating the rights of people who use drugs.
  - Pairing of local activists and international human rights groups for documentation projects, and analysis of relevant human rights covenants on questions relating to drug use and HIV prevention.

- Community organizing
  - Collaboration with leading advocates to ensure that concerns of drug users are represented at the UN Human Rights Council.
  - Working with groups such as the European AIDS Treatment Group, the Global Network of People Living with HIV and AIDS, the International Treatment Preparedness Coalition and local community groups to increase HIV treatment literacy and challenge the systematic exclusion of drug users from care.

For more information, visit IHRD's website: www.soros.org/harm-reduction

Which are the most relevant international and regional human rights standards related to harm reduction?

Overview

A variety of human rights standards at the international and regional levels applies to harm reduction. These standards can be used for many purposes:

- **To document** violations of the rights of people who use drugs
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies.

In the tables on the following pages, **examples** of human rights violations related to harm reduction are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** interpreting each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on harm reduction and human rights.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (**ICCPR**)	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**)
European Social Charter (**ESC**)	European Committee of Social Rights (**ECSR**)

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

Table 1: Harm reduction and the right to life

Examples of Human Rights Violations	
• A government authorizes or fails to investigate the murder of suspected drug traffickers as part of a crackdown on drugs. • An ambulance refuses to respond to a drug overdose because the underlying activity is "illegal". • A government imposes the death penalty for drug-related offenses. • Drug users die in locked hospital wards, such as the Moscow fire incident in December 2006.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life. **(2)** In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgment rendered by a competent court. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	**HRC:** Expressed concern over the extrajudicial killing of people who use drugs. Also stated definitively that capital punishment for drug offences is in violation of the ICCPR (Thailand, 2005). **SR Health:** expressed concern that the Anti-Narcotics Campaign [in Thailand], coupled with limited access to harm reduction services, had inadvertently created the conditions for a more extensive spread of [HIV] in Thailand" (2005).

Table 2: Harm reduction and freedom from torture and cruel, inhuman and degrading treatment, including in prisons

Examples of Human Rights Violations	
• Police or security officials officers beat and injure people suspected of using drugs. • Investigators force drug suspects into unmedicated withdrawal in order to extract confessions. • A government imposes lengthy mandatory prison sentences for minor drug-related offenses. • Persons convicted of drug offenses are detained, imprisoned, or committed to treatment in overcrowded and unsanitary facilities, without access to medical services. • Drug users are denied mental health treatment while in prison, jail, or drug treatment.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation. **ICCPR 10(1)** All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. **ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment. ***See also:*** • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment (1987) • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1989) • Code of Conduct for Law Enforcement Officials (1979) • Standard Minimum Rules for the Treatment of Prisoners (1955)	**HRC:** expressed concern about high rates of HIV and TB in **Ukraine**, and recommended that Ukraine provide hygienic facilities, assure access to health care and adequate food, and reduce the prison population, including by using alternative sanctions (2006). **SR Violence Against Women:** expressed concern that the **U.S**. was "criminalizing a large segment of its population" through drug charges, increasingly women, and that many of these offenses "may be more appropriately handled by a community-based system of welfare and social support, as is presently the case in certain European countries."(1999). **ECtHR:** Held that refusal of medical treatment to an HIV-positive detainee held on drug charges violated article 3 {Khudobin v. **Russia**, 2007}; that forcing a drug suspect to regurgitate to retrieve a balloon of heroin violated article 3 {Jalloh v. **Germany**, 2006}; and that the **UK** government breached article 3 by failing to provide necessary medical care to a heroin dependent woman who died in a UK prison while serving a four-month sentence for theft {McGlinchey and others v. UK, 2003}.

Table 3: Harm reduction and freedom from arbitrary arrest and detention

Examples of Human Rights Violations	
• Drug users are arrested or detained based on planted evidence or evidence obtained through an illegal search or seizure. • Drug users are imprisoned on criminal charges without a fair trial. • Drug users are committed to forced treatment or detoxification without their consent.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 9(1) Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law. **ACHPR 6** Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained. **ECHR 5(1)** Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law: ***See also:*** • Code of Conduct for Law Enforcement Officials (1979) • Basic Principles on the Use of Force and Firearms by Law Enforcement Officials (1990) • Reports of the UN Commission on Human Rights Working Group on Arbitrary Detention (2003-2005)	**HRC:** has held that protections under art. 9 apply to all forms of detention, including for "drug addiction" {General Comment 8, paragraph #1}); has expressed concern in **Mauritius** that bail is not allowed for persons arrested or held in custody for the sale of drugs, urging the government to "review the Dangerous Drugs Act in order to enable judges to make a case-by-case assessment on the basis of the offence committed" (2005); has expressed concern in **Ireland** about the 7-day period of detention without charge under the Drug Trafficking Act (2005). **CRC:** has expressed concern in **Brunei Darussalem** "that children abusing drugs may be placed in a closed institution for a period of up to three years" and recommended that the government "develop non-institutional forms of treatment of children who abuse drugs and make the placement of children in an institution a measure of last resort." (2003). **WG Arbitrary Detention**: from 2003-2005, has: expressed concern about arbitrary detention of "drug addicts" and "people suffering from AIDS;" recommended that persons deprived of their liberty on health grounds "have judicial means of challenging their detention;" concluded that bail conditions can be difficult to meet for people who use drugs; and recommended that states prevent over-incarceration of vulnerable groups. **ECtHR:** held that unjustified pre-trial detention of an HIV-positive detainee for one year and 23 days breached article 5(3) {Khudobin v. **Russia**, 2007}.

Table 4: Harm reduction and the right to a fair trial

Examples of Human Rights Violations	
• An individual is convicted of drug charges after having been lured into committing a drug offense by an undercover police officer. • A detainee is kept in pre-trial detention for drug charges for an unreasonable length of time. • An individual is convicted on a drug offense without trial. • An individual is convicted of a drug charge based on evidence obtained during an illegal police search of his or her home.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 9(3) Anyone arrested or detained on a criminal charge shall be brought promptly before a judge or other officer authorized by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release. . . **(4)** Anyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings before a court, in order that court may decide without delay on the lawfulness of his detention and order his release if the detention is not lawful. **ACHPR 7** 1. Every individual shall have the right to have his cause heard. This comprises: (a) the right to an appeal to competent national organs against acts of violating his fundamental rights as recognized and guaranteed by conventions, laws, regulations and customs in force; (b) the right to be presumed innocent until proved guilty by a competent court or tribunal; (c) the right to defence, including the right to be defended by counsel of his choice; (d) the right to be tried within a reasonable time by an impartial court or tribunal. **ECHR 6(1)** In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law. . . **(2)** Everyone charged with a criminal offence shall be presumed innocent until proved guilty according to law.	**ECtHR:** Held that where the activity of undercover agents instigates a drug offence and there is nothing to suggest the offense would have been committed without the police's intervention, this constitutes "incitement," and evidence obtained as a result cannot be used against a defendant. {Vanyan v. **Russia**, 2005, Teixeira de Castro v. **Portugal**, 1998}. Applying these cases in 2007, the **ECtHR** held that a Russian trial court should have considered evidence that a defendant facing drug charges had been entrapped by the police, especially considering that he did not have a criminal record and the only allegations of his involvement in drug dealing came from a police informant. {Khudobin v. **Russia**, 2007}.

Table 5: Harm reduction and the right to privacy

Examples of Human Rights Violations	
• Police are authorized to arrest or detain people based on suspected drug use, without having to prove possession or trafficking of drugs. • Police are authorized to test the urine of anyone suspected of using drugs. • Doctor discloses a patient's history of drug use or addiction without consent. • Clinic shares lists of registered drug users with law enforcement. • Police raid the home of a suspected drug user without evidence or judicial authorization.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 17(1) No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. **ECHR 8(1)** Everyone has the right to respect for his private and family life, his home and his correspondence.	**CRC:** expressed concern in **Armenia** at the criminalization of young drug users, and urged the government "to ensure that child drug abusers are not criminalized, but treated as victims in need of assistance towards recovery and reintegration." (2004). **ECtHR:** Held that strip searching and examination of a mother and her mentally disabled son who were attempting to visit another brother in prison constituted a violation of article 8 {Wainwright v. **United Kingdom**, 2006}.

Table 6: Harm reduction and freedom of expression and information

Examples of Human Rights Violations	
• Drug users are denied information about HIV prevention, harm reduction, and safer drug use. • Government bans publications about drug use or harm reduction, claiming they represent propaganda for illegal activity. • Government officials harass or detain individuals who speak publicly in favor of needle exchange, methadone, or other harm reduction measures. • NGOs are compelled to oppose harm reduction as a condition of government funding for work on HIV prevention.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice. **ACHPR 9 (1)** Every individual shall have the right to receive information. **ECHR 10(1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises. **(2)** Every individual shall have the right to express and disseminate his opinions within the law. ***See also:*** • CRC 13	**CRC:** has concluded that adolescent's right to information about HIV and AIDS is part of the right to information {General Comment 3, paragraph #4}; has called on **Panama** to "provide children with accurate and objective information about substance use, including hard drugs and tobacco, and protect children from harmful misinformation," as well as to "strengthen its efforts to address adolescent health issues…[including those] to prevent and combat HIV/AIDS and the harmful effects of drugs" (2003); has expressed concern in **Estonia** at "the increasing number of HIV-infections among injecting drug users" and encouraged the government to continue its efforts to provide children with accurate and objective information about substance use" (2003).

Table 7: Harm reduction and freedom of assembly and association

Examples of Human Rights Violations	
• Public authorities refuse to register a drug user association. • Police break up a peaceful demonstration against drug laws.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 21 The right of peaceful assembly shall be recognized. **22(1)** Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests. **(2)** No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (*ordre public*), the protection of public health or morals or the protection of the rights and freedoms of others. **ACHPR 10** Every individual shall have the right to free association provided that he abides by the law **11** Every individual shall have the right to assemble freely with others. The exercise of this right shall be subject only to necessary restrictions provided for by law in particular those enacted in the interest of national security, the safety, health, ethics and rights and freedoms of others. **ECHR 11** Everyone has the right to freedom of peaceful assembly and to freedom of association with others, including the right to form and to join trade unions for the protection of his interests.	*According to research conducted for this Table, no regional or international human rights body has applied the protection of freedom of assembly and association to the context of harm reduction.*

Table 8: Harm reduction and the right to bodily integrity

Examples of Human Rights Violations	
• A suspected drug user is abused by police. • Police fail to investigate a case of domestic violence against a drug-using woman. • Doctors compel a drug-using pregnant woman to undergo an abortion. • Police fail to investigate the assault or murder of a person suspected of using drugs, blaming it on "gang violence".	
Human Rights Standards	**Precedents and Interpretations**
ACHPR 4 Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **Note:** The right to bodily integrity is not specifically recognized under the **ICCPR** or **ICESCR**, but has been interpreted to be part of the right to security of the person, to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health. Similarly, the right to bodily integrity is not specifically recognized in **CEDAW**, although CEDAW has been widely interpreted to include the right to protection from violence against women.	**WG Enforced or Involuntary Disappearances:** has noted that, "An aspect of disappearances that has been underreported in the past and continues at the present time relates to the way in which acts of disappearance are perpetrated in conjunction with other gross violations, with targets drawn from among the most vulnerable groups in society. . . . Common examples brought to our notice were: disappearances, combined with "social cleansing," the urban poor, the unemployed, and the so-called "undesirables," including *prostitutes, petty thieves, vagabonds, gamblers and homosexuals as the victims*" [emphasis added].

Table 9: Harm reduction and the right to non-discrimination

Examples of Human Rights Violations	
• A person is denied work, housing, health care, education, or access to goods and services due to actual or suspected drug use. • Police disproportionately arrest migrants and racial minorities for drug offenses. • People who use drugs are underrepresented in HIV treatment programs despite accounting for a majority of people living with HIV.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 2(1) Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICCPR 26** All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ACHPR 2** Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. **ECHR 14** The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.	**Committee on the Elimination of Racial Discrimination:** has recommended that governments "should pay the greatest attention to the following possible indicators of racial discrimination: . . . The proportionately higher crime rates attributed to persons belonging to those groups, particularly as regards petty street crime and offences related to drugs and prostitution, as indicators of the exclusion or the non-integration of such persons into society" (2005). **SR Health:** expressed concern in **Romania** that "the stigma associated with commercial sex work and injecting drug use, for example, affects how people engaged in these activities are often treated by health-care workers, especially when requesting services such as tests for sexually transmitted infections" and encouraged the government to combat discrimination that creates barrier to services (2005).

Table 10: Harm reduction and the right to the highest attainable standard of health

Examples of Human Rights Violations	
• Drug users or suspected drug users are turned away from hospitals or treated with stigma and judgmental attitudes in the health system. • Government officials ban needle exchange programs or confiscate syringes from drug users, claiming they promote illegal activity. • Government bans substitution therapy with methadone.	
Human Rights Standards	**Precedents and Interpretations**
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. **12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases. **ACHPR 16 (1)** Every individual shall have the right to enjoy the best attainable state of physical and mental health. **(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick. ***See also:*** • CEDAW 12(1) • CRC 24(1)	**CESCR:** has noted that non-discrimination is an "underlying determinant of health," including non-discrimination on the basis of "health status," which should include drug addiction. **CESCR:** expressed concern in **Tajikistan** with "the rapid spread of HIV…in particular among drug users, prisoners, sex workers," and recommended that the government "establish time-bound targets for extending the provision of free testing services, free treatment for HIV and harm reduction services to all parts of the country" (2006). **CRC:** has commented that governments "are obligated to ensure the implementation of programs which aim to reduce the factors that expose children to the use of substances, as well as those that provide treatment and support to children who are abusing substances" (General Comment 3). **SR Health:** expressed concern in **Romania** that "the stigma associated with commercial sex work and injecting drug use, for example, affects how people engaged in these activities are often treated by health-care workers, especially when requesting services such as tests for sexually transmitted infections" and encouraged the government to combat discrimination that creates barriers to services (2005).

Table 11: Harm reduction and the rights of women and children

Examples of Human Rights Violations	
• Women are denied access to harm reduction services on an equal basis with men. • Pregnant women who use drugs are forced to undergo abortions or sterilization, or are penalized for attempting to injure their child. • Young people who use drugs are denied factual information and services about safer injection and harm reduction.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 3 The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights set forth in the present Covenant. **24 (1)** Every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his status as a minor, on the part of his family, society and the State. **ACHPR 18 (3)** The State shall ensure the elimination of every discrimination against women and also ensure the protection of the rights of the woman and the child as stipulated in international declarations and conventions. **(4)** The aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs. ***See also:*** • CEDAW 12(1) • CRC 24(1)	**CRC:** has identified that, "Children who use drugs are at high risk [of HIV]" and that "injecting practices using unsterilized instruments further increase the risk of HIV transmission;" has also stated that governments "are obligated to ensure the implementation of programmes which aim to reduce the factors that expose children to the use of substances, as well as those that provide treatment and support to children who are abusing substances" (General Comment 3, paragraph #39); has made country-specific recommendations on children who use drugs in **Armenia** (2004), **El Salvador** (2004), **Sao Tome and Principe** (2004), **Indonesia** (2004), **Brunei Darussalem** (2003), **Panama** (2003), **Estonia** (2003), **Ukraine** (2002), and **St. Vincent and the Grenadines** (2002). **SR Violence Against Women:** expressed concern that the **U.S.** was "criminalizing a large segment of its population" through drug charges, increasingly women, and that many of these offenses "may be more appropriately handled by a community-based system of welfare and social support, as is presently the case in certain European countries" (1999).

What are some examples of effective human rights programming in the area of harm reduction?

Introduction

In this section, you are presented with **five examples** of effective activities in the area of harm reduction and human rights. These are:

1. Mobilizing human rights allies in advocating for harm reduction
2. Responding to police brutality against people who use drugs in Vancouver
3. Peer-to-peer human rights documentation among IDUs in **Thailand**
4. Challenging illegal policing practices and detention conditions in **Russia** before the European Court of Human Rights
5. Challenging police raids and criminalization of drug use in **Hungary**.

Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such a project **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this project?
- What **barriers** need to be overcome to ensure its successful replication?

Example 1: Mobilizing human rights allies in advocating for harm reduction

Beginning in 2003 in collaboration with Human Rights Watch, OSI supported a series of meetings to bring together advocates for harm reduction with human rights organizations to discuss areas of common interest. The meetings led to a number of beneficial joint projects.

Project type
Networking; research and advocacy

Health and human rights issue
Protection of human rights is inherent to harm reduction, yet human rights and harm reduction advocates often do not have the opportunity to engage with one another. This project sought to build capacity of human rights organizations in Eastern Europe and the former Soviet Union to be allies in the struggle for harm reduction and against HIV and AIDS in the region.

Actions taken
A regional meeting in Budapest provided an initial networking opportunity for selected human rights organizations and harm reduction groups to identify key issues of common concern where human rights advocacy would be particularly fruitful. Through participatory discussions, the groups:

- Identified similarities and differences, issues of mutual interest, and potential for partnerships
- Agreed on a list of common interests and explored models of collaboration
- Identified opportunities for groups from individual countries to exchange ideas informally and reflect on areas of potential collaboration.

Results and lessons learned
- The Budapest meeting was replicated by participants in Russia, Tajikistan, and Ukraine during 2004-2005. A separate capacity-building meeting was held in Kiev in May 2003 with six participating NGOs from Ukraine, Russia and Tajikistan. The meeting also led to grants promoting research and advocacy for harm reduction-related human rights.
- The Moscow Helsinki Group, a leading human rights NGOs, received funds for a study on human rights abuses against people who use drugs in Russia. The Ukrainian Harm Reduction Network received a grant to support a human rights specialist to compile information and conduct international advocacy on human rights for people who use drugs.
- Throughout the meetings, harm reduction organizations examined how to motivate donors and governments to support human rights efforts. Benefits of creating a "common cause" between harm reduction and human rights groups can accrue to both sides, and include building new alliances, mobilizing new sources of funding, and forming productive collaborations. The meetings gave both harm reduction and human rights organizations resources and a common platform upon which to build.

Contact
International Harm Reduction Development – OSI
400 W. 59th Street, New York, NY 10017
Tel: 1-(212) 548 0111
Fax: 1-(212)548 4617
Email: IHRD@sorosny.org
Web: www.soros.org/harm-reduction

Example 2: Responding to police brutality against people who use drugs in Vancouver

In Vancouver, Canada, home to the worst HIV epidemic in North America, a small legal organization gathered sworn testimonies from people who use drugs about police brutality, and used these testimonies to advocate for changes in police policy and practice.

Project type
Documentation and advocacy; legal aid

Health and human rights issue
Police abuse has been shown to increase HIV, hepatitis C, and overdose risk among people who use drugs, as it increases the likelihood that they will share or reuse syringes, stay away from needle exchange programs, and inject quickly and in concealed locations. In Vancouver, the municipal government supports needle exchange, methadone, and safer injection facilities. However, abuse of people who use drugs by police threatened to undermine the public health benefits of these programs.

Actions taken
The Pivot Legal Society, a small legal aid organization, undertook a series of actions to document police misconduct against people who use drugs and press for internal and independent investigations.

- Pivot collected over 50 affidavits from people who use drugs about improper use of force or other violations of due process by police. Affidavits are carefully documented statements that are sworn by lawyers to ensure both the veracity and accuracy of the information.
- The affidavits were compiled in a report that was used to advocate for compensation and reform of police practice.
- Following an unsatisfactory internal investigation, Pivot took the case to court and to the Police Complaints Commissioner to call for an independent audit of both the internal investigation and the underlying allegations.

Results and lessons learned
- A combination of documentation, ongoing advocacy, and sometimes litigation is necessary to bring about accountability for police abuse. Detailed recommendations such as improved complaints procedures and monitoring of police conduct are also needed.
- Both internal and independent investigations of police misconduct need to be carefully monitored. This requires time, resources, and expertise.
- Lack of access to complaint procedures and legal assistance is a barrier to justice for those who experience abuse of police authority. By the same token, increased accountability and surveillance of police officers not only benefits people who use drugs and other marginalized groups, but all people who are owed a duty of service and protection by police.

Contact
Pivot Legal Society
42 Blood Alley
Vancouver, B.C. and
2985 W. 14th Avenue
Vancouver, B.C., V6K 2X5
Tel: 1-(604) 742-1843
Fax: 1-(604) 742-1844
Email: info@pivotlegal.org
Web: www.pivotlegal.org

Example 3: Peer-to-peer human rights documentation among IDUs in Thailand

In May 2002, a collaboration between an HIV-positive former injecting drug user in Thailand and a New York-based human rights advocate fused two areas of expertise to generate human rights documentation that would lead to the formation of Southeast Asia's only user advocacy group and unprecedented recognition of the health and human rights of people who use drugs in Asia.

Project type
Documentation and advocacy; community organizing.

Health and human rights issue
In Thailand, violence and discrimination against injecting drug users (IDUs) in the criminal justice and health systems have contributed to HIV prevalence of 50% since 1988. The Thai government flouts international standards for HIV prevention and treatment among IDUs, resorting to punitive drug treatment programs and rampant police abuse. IDUs are denied the benefits of Thailand's HIV response and represent nearly one-third of the country's new HIV infections.

Actions taken
Paisan Suwannawong, an HIV-positive former injecting drug user, partnered with Karyn Kaplan, HIV/AIDS officer at the International Gay and Lesbian Human Rights Commission (IGLHRC), to document human rights abuses against IDUs in Central, North and southern Thailand. Specifically, they:

- Interviewed 33 IDUs, officials from the Narcotics Control Board, Attorney General and Ministry of Public Health, as well as drug treatment providers
- On International Human Rights Day (December 10) 2002, reported findings back to IDU and community-based AIDS organizations and conducted a human rights and harm reduction training workshop
- For the first time ever, reported violations of IDUs' rights to the National Human Rights Commission and the Thai Parliament.

Results and lessons learned
- The project helped form Southeast Asia's first user advocacy group, the Thai Drug Users' Network (TDN). TDN and three partners received US$1.3 million from Global Fund to Fight AIDS, TB and Malaria to implement peer-driven HIV-prevention and harm reduction programs across Thailand.
- The project and Global Fund grant dramatically raised the profile of IDUs in Thailand and the region, leading to their unprecedented involvement in national and multilateral policymaking, funding, and program development.
- Additional user-driven human rights documentation projects, most notably during a violent "war on drugs" in 2003, were undertaken with Human Rights Watch and local experts, garnering further national and international awareness and solidarity for drug user issues in Thailand and the region.

Contact
Paisan Suwannawong and Karyn Kaplan
Thai AIDS Treatment Action Group (TTAG)
18/89 Vipawadee soi 40
Chatuchak, Bangkok
10900, THAILAND
Tel:+66-2-939-6434
Fax:+66-2-939-6437,
Email: karyn.kaplan@gmail.com,
paisan.suwannawong@gmail.com
Web: www.ttag.info

Example 4: Challenging illegal policing practices and detention conditions in Russia before the European Court of Human Rights

In 1999, an epileptic HIV-positive Russian citizen, Mr. Khudobin, was arrested in Moscow for buying one dose of heroin for an undercover agent. A lawyer successfully challenged several aspects of his detention and conditions of confinement before the European Court of Human Rights.

Project type
Litigation

Health and human rights issue
This case raises several health and human rights issues faced by people living with HIV who are detained on drug charges, including: conditions of pre-trial detention; respect of detainee's health status; and use of illegal policing practices.

Actions taken
Mr. Khudobin was arrested and detained on drug charges in 1999. After losing both his trial and appeal in Russia, he and his lawyer appealed to the European Court of Human Rights on the following grounds:

- That he had not received adequate medical treatment in the remand prison, and that the conditions of his detention were inhuman and degrading. (Despite his attorneys having informed the court of his medical status and requesting an independent medical review on behalf of his father, he remained in remand without a given reason)
- That, having spent more than one year in remand prison and having his detention repeatedly prolonged without reasons, his pre-trial detention exceeded the reasonable time
- That his applications for release were either delayed or not examined; and
- That his conviction was based on the police having illegally entrapped him.

Results and lessons learned
In January 2007, the European Court of Human Rights found that Russian authorities had violated Mr. Khudobin's rights under articles 3, 5(3), 5(4), and 6(1) of the ECHR. The Court's decision provides a legal basis for detainees in Russia to challenge the conditions of pre-trial detention based on their medical status. Specifically, the Court found:

- Under article 3, that Khudobin was refused proper medical assistance and denied the possibility of receiving it from other sources, and that his mental and physical suffering constituted degrading treatment.
- Under article 5(3), that Kudobin's detention of one year and 23 days was not justified by "relevant and sufficient" reasons; and under article 5(4), that the reviews of the applications for release were unduly delayed.
- Under article 6(1), that the trial court should have considered evidence that Mr. Kudobin had been entrapped by the police, especially considering that he did not have a criminal record and the only allegations of his involvement in drug dealing came from the police informant.

Contact
Kseniya Kostromina (lawyer for Mr. Khudobin)
Tel: +749-569-277-63 or +749-591-254-41

Example 5: Challenging police raids and criminalization of drug use in Hungary

The Hempseed Association, a Hungarian drug reform activist group, and the Hungarian Civil Liberties Union, Hungary's leading drug policy NGO, challenged the police practice of raiding discos and conducting forced urine tests in order to catch people using drugs.

Project type
Strategic litigation and advocacy

Health and human rights issue
In Hungary, police regularly raided discos and forced young club-goers to undergo urine tests. This violated privacy rights and rules of criminal procedure, and potentially forced discos underground, making it more difficult to conduct harm reduction outreach with club-goers.

Actions taken
Led by the Hempseed Association and with legal advice and representation from the HCLU, in the spring of 2005 individuals reported to the National Police Headquarters in Budapest to confess their non-violent drug use. The aim of this "Civil Obedience Movement" was to challenge the practice of forced urine tests and to raise the issue of decriminalization of drug use.

- Every Wednesday for five weeks, "self-reporters" including celebrities appeared at Police Headquarters. The HCLU provided each self-reporter with a legal manual. More than 60 people self-reported in total.
- The action attracted significant media attention and dominated public debate for weeks. Activists expressed their views to the media about the illegal practice of police raids and about decriminalization.
- HCLU made freedom-of-information requests to the Police about the cost of police raids, and used the data to show the raids were not cost-effective.

Results and lessons learned
- The action succeeded in its main goal, which was to obtain a statement from the Police that urine tests could only be conducted someone following initiation of a criminal procedure against them. This effectively made the urine test raids unlawful. The number of police raids seriously decreased, with very few raids occurring in 2006.
- The campaign also succeeded in making decriminalization of drug use a subject of mainstream debate. More than 70 professionals working on the drug field signed a petition supporting the aims of the campaign. Three months after the action, the first-ever draft Bill on decriminalization was introduced in Parliament.
- The campaign showed that good stories and human faces are an important and successful way of achieving media coverage of drug policy campaigns.

Contact
Hungarian Civil Liberties Union
Peter Sarosi, Drug Policy Program Director
Tel: +36-209-00-46
Email: sarosip@tasz.hu

The Hempseed Association
Peter Juhasz, Vice Chairman and Spokesperson
Tel: +36-30-47-42-403
Email: juhikap@gmail.com
Report at: www.drogriporter.hu (HCLU's drug policy site)

How can I find additional resources about harm reduction and human rights?

Resources

To further your understanding on the topic of Harm Reduction and human rights, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions: UN
- Declarations and resolutions: non-UN
- Books
- Reports, key articles, and other documents
- Periodicals
- Blogs and listserves
- Training opportunities

Declarations and resolutions: UN

- United Nations General Assembly Special Session on HIV/AIDS, Declaration of Commitment on HIV/AIDS, Resolution A/RES/S-26/2, June 27, 2001 (see references to human rights at pp. 58-61, 66, 96; see also, references to harm reduction at p. 24 in the follow-up declaration to the UNGASS in 2006)

  Source: data.unaids.org/pub/Report/2006/20060615_HLM_PoliticalDeclaration_ARES60262_en.pdf

Declarations and Resolutions: non-UN

- Dublin Declaration of Action (2004)

  The declaration on HIV and AIDS in prisons in Europe and Central Asia focuses on the magnitude of the HIV and AIDS problem in prisons and the rights of prisoners to an environment free of excess risk of infection. This includes policies and programs aimed at reducing spread and impact of disease as well as health care equal to that available outside of prisons.
  Source: www.eu2004.ie/templates/document_file.asp?id=7000 especially principle 6, articles 1, 10, 11

- Vancouver Declaration (2006)

  Following the International Conference on the Reduction of Drug Related Harm, an advocacy group wrote and released a declaration describing the prejudice they face as drug users around the world. They also documented their collective goals to overcome this prejudice.
  Source: hardcoreharmreducer.be/VancouverDeclaration.html

- The GIPA Principles (2004)

  The Principles of Greater Involvement of People with HIV/AIDS were derived from a principle embedded in the Paris AIDS Summit Declaration of 1994. This Declaration acknowledged the central role of people living with HIV in education and care, and in the design and implementation of national and international policies and programs in order to successfully tackle HIV/AIDS. It also acknowledged that, for positive people to take on a greater role in the response, they need increased support.
  Source: www.gnpplus.net/cms/filemgmt/visit.php?lid=114

- Resolution of William J. Bratton, Chief of Police, Los Angeles, California (2005)

  This declaration from the LA Chief of Police reaffirmed the dedication of the Los Angeles Police Department to reduce the spread of Hepatitis B, Hepatitis C and HIV through existing syringe exchange programs in the city.

- Manifesto of People Who Use Drugs

  This Manifesto is included in the booklet "Nothing About Us Without Us — Greater, Meaningful Involvement of People Who Use Illegal Drugs: A public health, ethical, and human rights imperative".
  Source: www.aidslaw.ca/publications/publicationsdocEN.php?ref=67

Books

- Baer, Singer and Susser. The Pursuit of Health as a Human Right: Health Praxis and the Struggle for a Healthy World. In Baer, Singer and Susser. *Medical Anthropology and the World System (second edition)*. Westport, Connecticut: Praeger (Chapter 7, pp. 169-226), 2003.

- Institute of Medicine of the National Academies. *Preventing HIV Infection among Injecting Drug Users in High-risk Countries*. Washington, DC: National Academy of Sciences, 2006.

- International Harm Reduction Development. *Delivering HIV Care and Treatment for People Who Use Drugs: Lessons from Research and Practice,* 2006.
  Source:
  www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/delivering_20060801

- International Harm Reduction Development. *Protecting the Human Rights of Injection Drug Users: the Impact of HIV/AIDS*. New York, NY: Open Society Institute, 2005.
  Source: www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/rights_20050228

- Malinowska-Sempruch, K. & Gallagher, S. *War on Drugs, HIV/AIDS and Human Rights*. New York, NY: International Debate Education Association, 2004.

- Marlatt, G. A. (Ed.) Harm reduction around the world. A brief history. *Harm reduction. Pragmatic strategies for managing high-risk behaviour.* New York: Guilford Press (Chapter 2, pp. 30-48), 1998.

- Riley, D. & O'Hare, R. Harm reduction: History, definition and practice. In J. A. Inciardi & L. D. Harrison (Ed.), *Harm Reduction. National and International Perspectives* (pp. 1-26). Thousand Oaks, CA: Sage Publications, 2000.

- WHO. *Evidence for Action: Effectiveness of community-based outreach in preventing HIV/AIDS among injecting drug users.* Geneva, 2004.
  Source: www.who.int/hiv/pub/idu/idu/en/

- Wolfe, D. Malinowska-Sempruch, K. *Illicit Drug Policies and the Global HIV Epidemic, Effects of UN and National Government Approaches*, Open Society Institute, 2004.

Reports, key articles, and other documents

- Betteridge, G. Prisoners' health and human rights in the HIV/AIDS epidemic — *HIV/AIDS Policy and Law Review 9(3)*, December 2004.
  Source: www.aidslaw.ca/publications/publicationsdocEN.php?ref=177)

- Burris, S., Blankenship, K.M, Donoghoe, M., Sherman, S., Vernick, J.S., Case, P., Lazzarini, Z., & Koester, S. (2004) Addressing the "Risk Environment" for Injection Drug Users: The Mysterious Case of the Missing Cop. *The Milbank Quarterly* 82 (1), 125–156.

- Canadian HIV/AIDS Legal Network (2006). Legislating for Health and Human Rights: Model Law on Drug Use and HIV/AIDS.
  Source: www.aidslaw.ca/publications/publicationsdocEN.php?ref=620 - 8 modules

- Elliott, R. Harm Reduction, HIV/AIDS, and the Human Rights Challenge to Global Drug Control Policy — *Health and Human Rights: An International Journal*, Vol. 8, No. 2, 2005.
  Source: www.aidslaw.ca/publications/publicationsdocEN.php?ref=78

- IHRA's 50 Best Collections Overview. These collections highlight around 50 papers in each area of harm reduction which best summarize the evidence-base, reasoning and justification for harm reduction interventions and approaches.
  Source: www.ihra.net/50BestCollectionsOverview

- Judit Fridli, (2003, Spring). Harm reduction is human rights. *Harm Reduction News*, 4(1), 3, 17. (Newsletter of International Harm Reduction Development Program, Open Society Institute).
  Source:
  www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/hrnfocus_20030301/hrn_spring2003.pdf

- Jürgens, Ralf. Betteridge, Glenn (2005) Prisoners Who Inject Drugs: A Public Health and Human Rights Imperative, 8(2) Health and Human Rights.
  Source: www.aidslaw.ca/publications/publicationsdocEN.php?ref=81

- Lines, Rick. (2006). From equivalence of standards to equivalence of objectives: The entitlement of prisoners to health care standards higher than those outside prisons. *International Journal of Prisoner Health*. 2(4): p. 269-280.

- Sarang, A. Stuikyte, R., Bykov, R. (2007) Implementation of harm reduction in Central and Eastern Europe and Central Asia. *International Journal of Drug Policy*. 18 (2): p.129-135.

Human Rights Watch reports

- Abusing the User: Police Misconduct, Harm Reduction, and HIV/AIDS in Vancouver.
  Source: www.hrw.org/reports/2003/canada/

- Fanning the Flames: How Human Rights Abuses are Fuelling the AIDS Epidemic in Kazakhstan.
  Source: hrw.org/reports/2003/kazak0603/

- Injecting Reason: Human Rights and HIV Prevention for Injection Drug Users - California: A Case Study.
  Source: www.hrw.org/reports/2003/usa0903/

- Locked Doors: The Human Rights of People Living with HIV/AIDS in China.
  Source: www.hrw.org/reports/2003/china0803/

- Not Enough Graves: The War on Drugs, HIV/AIDS, and Violations of Human Rights.
  Source: hrw.org/reports/2004/thailand0704/

- Rhetoric and Risk: Human Rights Abuses Impeding Ukraine's Fight Against HIV/AIDS.
  Source: hrw.org/reports/2006/ukraine0306/

International Journal of Drug Policy (search "human rights"; example):

- Cohen, J. and Csete, J. (2006) As strong as the weakest pillar: Harm reduction, law enforcement and human rights**.** *International Journal of Drug Policy. 17(2): Pages 101-103.*

Periodicals

- "AHR News", Quarterly newsletter of the Asian Harm Reduction Network
  Source:
  www.ahrn.net/index.php?option=content&task=view&id=2115&Itemid=2#newsletter

- Harm Reduction Journal
  Source: www.harmreductionjournal.com

- "Harm Reduction News" Quarterly newsletter of International Harm Reduction Development Program, Open Society Institute
  Source: www.soros.org/initiatives/health/focus/ihrd/news

- International Harm Reduction Association E-Newsletter
  Source: www.ihra.net/ENewsletters

- The International Journal of Drug Policy
  Source: www.journals.elsevierhealth.com/periodicals/drupol/home

Websites

- Asian Harm Reduction Network (AHRN)
  www.ahrn.net

- Australian Injecting and Illicit Drug Users League
  www.aivl.org.au

- Canadian HIV/AIDS Legal Network
  www.aidslaw.ca

- Canadian Medical Association Journal Collections
  www.cmaj.ca/cgi/collection/drug_misuse
- Central and Eastern Europe Harm Reduction Network (CEEHRN)
  www.ceehrn.org
- Chicago Recovery Alliance
  www.anypositivechange.org/hro.html
- Drug Action Network
  www.drugactionnetwork.com
- Drug Policy Alliance
  www.drugpolicy.org
- Harm Reduction Coalition (an informative source of drug related websites)
  www.harmreduction.org/resources/links.html#hr
- Humanitarian Action (Russia)
  www.humanitarianaction.org/index_eng.php3
- Human Rights Watch HIV/AIDS Program
  hrw.org/doc/?t=hivaids&document_limit=0,2
- International Drug Policy Consortium
  www.idpc.info
- International Harm Reduction Development program Open Society Institute
  www.soros.org/initiatives/health/focus/ihrd
- International Harm Reduction Association
  www.ihra.net
- MONAR Krakow Drugs Project (Poland)
  www.monar.krakow.pl
- North American Syringe Exchange Network
  www.nasen.org/index.htm
- PIVOT Legal Society
  www.pivotlegal.org
- Vancouver Area Network of Drug Users
  www.vandu.org

Blogs and list-serves

- AHRN
  info@ahrn.net

- CEEHRN
  ceehrn@yahoogroups.com

- "D'Alliance", Drug Policy Alliance Blog, *Drug Policy Alliance*
  blog.drugpolicy.org

- "Harm Reduction" *Wikipedia*
  en.wikipedia.org/wiki/Harm_reduction

- Harm Reduction Coalition Mailing List
  www.harmreduction.org/emailSignup.html

- Human Rights Watch
  hrw.org/blogs.htm

- "Network Blog", The Canadian Harm Reduction Network,
  www.canadianharmreduction.com/comments.php?thread=1

- "Sterling on Justice and Drugs"- blog at the *Criminal Justice Policy Foundation*
  justiceanddrugs.blogspot.com

- "The Speakeasy"- reader blogs at *StoptheDrugWar.org.*
  stopthedrugwar.org/speakeasy/reader

- "Time to Deliver", an independent, uncensored blog of activists at the Toronto International AIDS Conference
  www.timetodeliver.org/?cat=16

Training opportunities

- Harm Reduction Training Institute
  www.harmreduction.org/hrti/index.html

- OSI Public Health Seminars
  health.osf.lt/en/seminars/

- Salzburg Seminar
  www.salzburgseminar.org/2007/index.cfm

What are key terms related to harm reduction and human rights?

Glossary

A variety of terms is used in harm reduction and human rights work.

A

Addiction
A commonly-used term describing a pattern of drug use that indicates physical or mental dependence. It is not a diagnostic term and is no longer used by the World Health Organization (WHO).

Advocacy
Harm reduction efforts often include an advocacy component, which may involve lobbying for drug users' rights, or for funding for harm reduction programs, or trying to change public perception of drug users and of harm reduction.

AIDS
Acquired Immunodeficiency Syndrome (AIDS) is the severe manifestation of infection with the Human Immunodeficiency Virus (HIV).

Alcohol pad
A small piece of fabric soaked with alcohol, used to swab the skin before injecting. (Washing with soap and water is thought to be more effective at reducing infection than rubbing with an alcohol pad. Cleaning hands and potential sites of injection also reduces the potential for infection.)

B

Backloading and frontloading
"Backloading" and "frontloading" refer to a practice whereby one syringe is used to prepare the drug solution, which is then divided into one or more syringes for injection. The drug solution is shifted from one syringe into another with the needle (frontloading) or plunger (backloading) removed. HIV, hepatitis, and other infectious agents can be transmitted if the preparation syringe has been contaminated.

Biohazard containers
Puncture-resistant containers used for disposing of hazardous waste such as used syringes. The contents of biohazard containers are disposed of at a location specifically designed to negate the potential dangers of hazardous waste. The containers are ideally designed so that hazardous material cannot be removed once it is placed into the container.

Buprenorphine
A medication used in opioid substitution therapy programs. Buprenorphine is included in the World Health Organization (WHO) Model List of Essential Medicines.

C

Community-based outreach programs
These programs are an effective way to provide information and outreach services to drug users with the goal of prevention and health promotion.

Consumption rooms
A safe, clean place for drug users to inject sterilely and under medical supervision. Information, sterile injection equipment, and health services are often provided.

Cooker
Any item used to heat injectable drugs in order to turn them from powder or other non-liquid form into a liquid suitable for injection. (According to some experts, injection drug users often reused metal spoons for cooking drugs until harm reduction service providers began promoting the one-time use of disposable items, such as bottle caps or similarly shaped objects, in order to reduce the risk of disease transmission.)

Cotton
Any item used to filter out particles of solids from injectable liquid drugs, in order to prevent them from clogging syringes. From the point of view of sterile injection, the ideal filter is a sterilized cotton pellet, made of natural cotton fibers and especially cut for this purpose.

D

Decriminalization
Unlike legalization, decriminalization refers only to the removal of penal and criminal sanctions on an activity, which retains prohibited status and non-penal regulation.

Demand reduction
Programs and policies aimed at directly reducing demand for illicit drugs via education, treatment, and rehabilitation, without reliance on law enforcement or prevention of production and distribution of drugs.

Drop-in centre
Centers provide easy-to-access basic care and information to drug users.

Drug policy
Refers to the sum total of policies and laws affecting supply and/or demand of illicit drugs, and may include issues such as education, treatment, and law enforcement.

Drug use
Preferred term for use in harm reduction context, acknowledging that drug use is a nearly universal cultural behavior with a wide range of characteristics and impacts, depending on the individual user.

Drug-related harms
Include HIV and AIDS, other viral and bacterial infections, overdose, crime, and other negative consequences stemming from drug use and from policies and problems relating to drug use.

H

Harm reduction
Refers to a set of interventions designed to diminish the individual and societal harms associated with drug use, including the risk of HIV infection, without requiring the cessation of drug use. In practice, harm reduction programs include syringe exchange, drug substitution or replacement therapy using substances such as methadone, health and drug education, HIV and sexually transmitted disease screening, psychological counseling, and medical care.

Heroin
An illegal narcotic whose use is rare compared to the use of other drugs, but which has been viewed in many areas as a social scourge dangerous to health and related to criminality.

HIV
The Human Immunodeficiency Virus (HIV) attacks and weakens the immune system. HIV infection eventually leads to AIDS, but proper medical treatment can delay symptoms for years.

I

Injection equipment
Items such as syringes, cottons, cookers, and water used in the process of preparing and injecting drugs. Each of these can be contaminated and transmit HIV or hepatitis. The broader term "drug paraphernalia" comprises injection equipment as well as items associated with non-injection drug use, such as crack pipes.

L

Legalization
As opposed to decriminalization, legalization refers to the process of transferring an activity from prohibited status to legally controlled status.

M

Methadone
A medication used in opioid substitution therapy programs. It is included in the WHO Model List of Essential Medicines.

Methamphetamines
A group of substances, most of them synthetic, that have a stimulating effect on the central nervous system. Methamphetamines can be injected, snorted, smoked, or ingested orally. The popular term "crystal meth" usually refers to the smokeable form of methamphetamine. Other amphetamine-type stimulants include anoretics (appetite suppressants) and non-hallucinogenic drugs such as "ecstasy."

N

Needle or syringe exchange points
Programs that provide sterile syringes in exchange for used ones. In addition to exchanging syringes, needle exchange points often provide HIV prevention information and screening, primary health care, and referrals to drug treatment and other health and social services.

Needle sharing
The use by more than one person of the same needle, or, more generally, of the same injecting or drug-preparation equipment. It is a common route of transmission for blood-borne viruses and bacteria, and the prevention of needle sharing is a major focus for many harm reduction interventions.

O

Overdose prevention
Overdosing is an important cause of morbidity and mortality among drug users, and is a major focus of harm reduction initiatives, including outreach, health services, safe injection rooms, and access to information on how to reduce the likelihood of an overdose.

R

Risk behavior reduction
Behaviors which place drug users at risk of adverse consequences are a main focus of a set of harm reduction initiatives referred to as risk reduction for their focus on reducing the risk of drug-related harm.

S

Sex worker
A non-judgmental term which avoids negative connotations and recognizes that people sell their bodies as a means of survival, or to earn a living. (UNAIDS)

Shirka
The popular name for one of the most commonly injected opiate derivates used in Ukraine, a homemade preparation of acetylated or extracted opium. In the Odessa region, *shirka* refers to a homemade amphetamine derivate known elsewhere in the country as *vint* or *perventin*..

Substance abuse
A widely-used but poorly defined term that generally refers to a pattern of substance use that results in social or health problems, and may also refer to any use of illegal drugs.

Substitution or replacement therapy
The administration, under medical supervision, of a psychoactive substance pharmacologically related to the one creating dependence (often buprenorphine or methadone) to substitute for that substance. This aims at preventing withdrawal symptoms while reducing or eliminating the need or desire for illicit drugs. Substitution therapy seeks to assist drug users in switching from illicit drugs of unknown potency, quality, and purity to legal drugs obtained from health service providers or other legal channels, thus reducing the risk of overdose and HIV risk behaviors, as well as the need to commit crimes to obtain drugs.

Syringes or needles
The main components of a syringe are a needle, a tubular syringe barrel, and a plastic plunger. Graduated markings on the barrel of a syringe are used to measure the water or saline solution used to dissolve a solid substance into liquid form. Syringes and needles vary in size and do not always come as one piece; a syringe with the needle attached is often referred to as an "insulin syringe." While disinfection of syringes is possible, public health authorities recommend a new sterile syringe for every injection.

T

Ties or tourniquets
Items used to enlarge or "plump up" veins to facilitate injection. Ties should be clean because blood on a tie can be a source of infection. Common ties include a piece of rope, a leather belt, a terry cloth belt, a rubber hose, and a piece of bicycle inner tube.

V

Vint or Perventin
The popular names for an injected homemade amphetamine derivate.

W

Water

Water is used to dissolve solid substances (such as pills or powder) into a liquid form suitable for injection. Having a clean source of one's own water is important to prevent disease transmission. Harm reduction programs often distribute vials of distilled water, sterile water or sterile saline solution (all referred to as "waters") for this purpose.

Withdrawal

Clinical symptoms associated with ceasing or reducing use of a chemical agent that affects the mind or mental processes (i.e., a "psychoactive" substance). Withdrawal usually occurs when a psychoactive substance has been taken repeatedly and/or in high doses.

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Photo courtesy of Open Society Institute

Chapter 4 Palliative Care and Human Rights

"You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders,
founder of the modern Hospice movement

Contents

4

Introduction

This chapter will introduce you to key issues in **palliative care and human rights.**

The chapter is organized into six sections that answer the following questions:

- **How** is palliative care a human rights issue?
- **What** is OSI's work in the area of palliative care and human rights?
- **Which** are the most relevant international and regional human rights standards related to palliative care?
- **What** are some examples of effective human rights programming in the area of palliative care?
- **Where** can I find additional resources on palliative care and human rights?
- **What** are key terms related to palliative care and human rights?

As you read through this chapter, consult the **glossary of terms**, found in the last section, *What are key terms related to palliative care and human rights?*

How is palliative care a human rights issue?

What is palliative care?

Palliative care is an approach that **improves the quality of life of patients and their families** facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of **pain and other problems, physical, psychosocial and spiritual.**

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a multidisciplinary team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy, radiation therapy, HAART, and includes those investigations needed to better understand and manage distressing clinical complications.
  Source: WHO (World Health Organization) 2002 Definition of Palliative Care. Please see www.who.int/cancer/palliative/definition/en for a more complete reference.

What are palliative care rights?

Palliative care embraces human rights that are already recognized in national laws, international human rights documents, and other consensus statements.

Palliative care rights include the **right to**:

- Pain relief
- Symptom control for physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Family-centered care
- Care by trained palliative care professionals
- Receive home-based care when dying and to die at home if desired
- Treatment of disease and to have treatment withheld or withdrawn
- Information about diagnosis, prognosis, and palliative care services
- Name a health care proxy for decision making
- Not be discriminated against in the provision of care because of age, gender, socioeconomic status, geographic location, national status, prognosis, or means of infection.

Did you know?

- Death statistics
  - Of the 58 million people dying annually, at least 60% will have a prolonged advanced illness and would benefit from palliative care.
  - About 80% of the dying would benefit from palliative care to alleviate pain and suffering in their final days of life. Yet, in countries such as India, only around 1% of them are able to access such care.

- Elderly
  - There are 600 million people 60 years of age or older. By 2025 there will be 1.2 billion, and by 2050 the number will increase to 2 billion.

- Cancer
  - 7 million people die from cancer each year. There are 24.6 million people living with cancer. The incidence of cancer will more than double to an estimated 24 million new cancers per year by 2050.
  - The WHO has demonstrated that up to 90% of cancer patients can receive adequate therapy for their pain with opioid analgesics. Yet, in 2005, 80% of cancer patients did not have access to pain relieving drugs.
  - Despite the WHO stating that palliative care is essential to national cancer control programs, few countries have incorporated it.

- HIV and AIDS
  - In 2005, approximately 2.8 million people died of AIDS. An estimated 39.5 million people worldwide are living with HIV and AIDS. Up to 80% of patients in the advanced stages of AIDS suffer great pain, but very few have access to pain relieving drugs or palliative care services.
  - Pain management and palliative care have been shown to increase drug treatment adherence for both cancer and AIDS therapies.
  - Cancer patients in developing countries have access to opioid analgesics for pain management, but AIDS patients do not.
  - Despite UNAIDS stating that palliative care is essential to national HIV and AIDS plans, few countries have developed palliative care programs.

- Essential drugs
  - Eighteen pain and palliative care professional organizations from all over the world have created a list of essential drugs for palliative care. Fourteen drugs are currently on the WHO Essential Drug List, but few countries have incorporated them into their health care strategies.

- Barriers
  - The International Narcotics Control Board has strongly supported the appropriate use of analgesics for medical use; yet, patients, physicians and policy makers fear addiction and are reluctant to use or prescribe these drugs. Significant regulatory barriers also limit access.

- According to 2004 data published by the International Narcotics Board, 6 nations account for 79% of medical morphine consumption and 120 consumed little or no morphine.
- Despite the existence of a palliative care educational curriculum, little or no training on end of life care palliative care is given to health professionals.

- Caregivers
  - Most of the burden of care at home falls on women and girls. 68% of primary caregivers in South Africa were female; in Uganda 86% were female. Women and girls often give up their jobs or drop out of school to be caregivers.
  - In many countries, after a man's death, wives lose their homes because they have no legal rights to ownership. Children without a birth certificate lose access to the estate and may be unable to attend school because they lack school fees.

What is OSI's work in the area of palliative care and human rights?

OSI has worked to improve end-of-life care for patients and their families, with a special focus on vulnerable populations, including the elderly, children, and patients with cancer or HIV and AIDS. The main public health network program supporting work in this area is the **International Palliative Care Initiative (IPCI).** Work around the human rights implications of palliative care is still in its infancy with IPCI at the forefront. IPCI, along with OSI's Law and Health Initiative (LAHI), is supporting the development of a background paper and curriculum around palliative care as a human right, outlining the principal human rights norms relevant to palliative care and the legal procedures available to vindicate these rights. Other examples of projects supported by IPCI include:

- **Reports**
  - Brennan, F. Palliative Care as an International Human Right. Journal of Pain and Symptom Management special issue. Volume 33, Number 5, May 2007.

- **Convenings**
  - In October 2006, IPCI and LAHI convened a dialogue between palliative care providers and HIV and AIDS and legal advocates in South Africa to discuss the provision of better services to AIDS patients. A reference group formed to carry this project forward and is pursuing the pilot integration of legal services in a hospice, a joint palliative care/ legal advocates manual, and a potential test case around funeral benefits or disability grants.
  - In 2005, the Worldwide Alliance for Palliative Care convened the Second Global Summit on Hospice and Palliative Care in Seoul, Korea, which released the Korean Declaration on the Right of Palliative Care.
  - In 2006, OSI, with the International Association for Hospice and Palliative Care (IAHPC) and the World Health Organizations (WHO), convened 18 professional organizations to develop an essential medicines list for palliative care.
  - Regional Drug Availability Meetings in Hungary, Uganda, and Ghana have developed country plans to address regulatory barriers to essential pain medications.

- **Trainings**
  - Two -year International Pain Policy Fellowship, training fellows in evaluating regulatory barriers to opioid analgesics in their countries.
  - Two-year Palliative Care in AIDS and Cancer Fellowships, developing palliative care expertise in infectious diseases and in hospitals caring for oncology patients.
  - An annual Salzburg Palliative Care Course (AIDS, Cancer, Nursing).

For more information, visit IPCI's website: www.soros.org/initiatives/health/focus/ipci

Which are the most relevant international and regional human rights standards related to palliative care?

Overview

A wide variety of human rights standards at the international, regional, and national levels applies to palliative care. These standards can be used for many purposes:

- **To document** violations of palliative care rights
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, **examples** of human rights violations related to palliative care are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** and **provisions** from patient right charters and declarations, **interpreting** each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on palliative care and human rights.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (**ICCPR**)	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**)
European Social Charter (**ESC**)	European Committee of Social Rights (**ECSR**)

Table 1: Palliative care and freedom from cruel, inhuman, and degrading treatment

Examples of Human Rights Violations	
• National laws restricting opioid availability and access cause cancer and AIDS patients to suffer unnecessary pain. • Fearing prosecution by the state, a doctor refuses to prescribe morphine to relieve a patient's pain. • A country's laws prohibit the prescription of morphine to former drug users. A former drug user is in the advanced stages of AIDS and suffers a great deal.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. **ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment. ***See also:*** • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1) "All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited." • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment	**ECtHR:** finding continued detention of a cancer sufferer where it caused "particularly acute hardship" to constitute cruel, inhuman or degrading treatment [Mouisel v. **France**, 38 EHRR 34, para. 34 (2004)]. ***See also:*** • A right to avoid unnecessary pain and suffering is an important part of most patients' rights charters. For instance, the European Charter of Patients' Rights sets out: "Each individual has the right to avoid as much suffering and pain as possible, in each phase of his or her illness. The health services must commit themselves to taking all measures useful to this end, like providing palliative care treatment and simplifying patients' access to them." [art. 11]. • The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, similarly asserts: "Patients have the right to relief of their suffering according to the current state of knowledge. . . . Patients have the right to humane terminal care and to die in dignity." [art. 5.10, 5.11].

Table 2: Palliative care and the right to life

Examples of Human Rights Violations	
• Unable to obtain pain medication, an AIDS patient is unable to adhere to required treatment and continue taking antiretrovirals. As a result, the patient does not have much time to live.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	**HRC:** explaining that the right to life "should not be interpreted narrowly" or "in a restrictive manner," and its protection "requires that States adopt positive measures . . . to increase life expectancy." [HRC GC 6, paras 1, 5].

Table 3: Palliative care and the right to the highest attainable standard of health

<table>
<tr><th colspan="2">Examples of Human Rights Violations</th></tr>
<tr><td colspan="2">• A country does not provide for training in palliative care to its medical personnel. As a result, end of life patients do not receive adequate pain relief and physical, psychosocial, and spiritual, care.
• A state provides funding only for hospitals and not for hospices and home-based care facilities. As a result, patients must either forgo treatment or remain far from their homes and families.</td></tr>
<tr><th>Human Rights Standards</th><th>Precedents and Interpretations</th></tr>
<tr><td>ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

12(2) The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right 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.

CRC 24(1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.

ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health.

16(2) States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

ESC 11 – The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed . . . (2) to provide advisory and educational facilities for the promotion of health . . .

See also:
• African Charter on the Rights and Welfare of the Child, art. 14 (child's right to the highest attainable standard of health).</td><td>CESCR: affirming the importance of "attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity." [CESCR GC 14, para. 25].

CESCR: indicating that access to "essential drugs, as defined by the WHO Action Programme on Essential Drugs" is part of the minimum core content of the right to health. Fourteen palliative care medications are currently on the WHO Essential Drug List. [CESCR GC 14, para. 12].

CESCR: "States are under the obligation to respect the right to health by . . . refraining from denying or limiting equal access for all persons . . . to preventive, curative and palliative health services." [CESCR GC 14, para. 34].

See also:
• Under the Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation, "Patients have the right to enjoy support from family, relatives and friends during the course of care and treatment and to receive spiritual support and guidance at all times." [art. 5.9].</td></tr>
</table>

Table 4: Palliative care and the right to information

Examples of Human Rights Violations	
• People are denied information about hospice and palliative care services. • People are denied information about pain management. • People are denied information about their diagnosis and prognosis.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice. **ACHPR 9 (1)** Every individual shall have the right to receive information. **ECHR 10 (1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises. (2) Every individual shall have the right to express and disseminate his opinions within the law. ***See also:*** • European Convention on Human Rights and Biomedicine, art 10(2): "Everyone has the right to know any information collected about his or her health."	**CESCR:** health care accessibility "includes the right to seek, receive and impart information and ideas concerning health issues." [CESCR GC 14, para 12]. ***See also:*** • Under the European Charter of Patients' Rights, "Every individual has the right of access to all kinds of information regarding their state of health and health services and how to use them, and all that scientific research and technological innovation makes available." [art. 3]. • The Declaration on the Promotion of Patients' Rights in Europe emphasizes, "Patients have the right to be fully informed about their health status, including the medical facts about their conditions; about the proposed medical procedures, together with potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis, and progress of treatment." Moreover, "[p]atients have the right to choose who, if any one, should be informed on their behalf." [art. 2.2, 2.6].

Table 5: Palliative care and the right to non-discrimination and equality

Examples of Human Rights Violations	
• A country decides that it is not worth investing precious resources in providing care for the elderly. • Former drug users are denied access to opioid-based pain medication. • A state provides only limited health services to non-citizens and refugees, denying them access to palliative care.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 26 All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICESCR 2(2)** The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status. **ACHPR 2** Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. ***See also:*** • International Convention on the Elimination of All Forms of Racial Discrimination, art. 5(e)(iv) • Convention relating to the Status of Refugees • European Convention on Human Rights and Biomedicine, art 3 (equitable access to health care) • European Convention on Citizenship and the Convention Relating to the Status of Stateless Persons	**CESCR**: "[T]he range of matters" for which discrimination on the basis of age is acceptable "is very limited." In fact, States parties "are obliged to pay particular attention to promoting and protecting the economic, social and cultural rights of older persons." [CESCR GC 6, paras 12,13]. **CESCR:** emphasizing the need "to eliminate any discriminatory legislation and the need to ensure the relevant budget support" for the elderly. [CESCR GC 6, para. 18]. **CESCR:** upholding "the right of elderly persons to the enjoyment of a satisfactory standard of physical and mental health" and urging of "a comprehensive view, ranging from prevention and rehabilitation to the care of the terminally ill." [CESCR GC 6, para. 34]. **CESCR:** recommending that **Bulgaria** "take affirmative action for the well-being of older people," in light of their increasing number. [ICESCR, E/2000/22 (1999) 46, para. 238}. **CESCR:** noting "with satisfaction" **Finland's** inclusion of age as a prohibited ground of discrimination in its constitution. [CESCR, E/2001/22 (2000) 73, para. 433]. **CERD:** calling upon states to protect the adequate standard of health of non-citizens and refugees by ensuring their equal access to palliative health services. [CERD/C/NOR/CO/18 (CERD, 2006), para. 21; CERD/C/BWA/CO/16 (CERD, 2006), para. 19].

What are some examples of effective human rights programming in the area of palliative care?

Introduction

In this section, you are presented with four **examples** of effective activities in the area of palliative care and human rights. These are:

1. Petitioning the State Human Rights Commission for access to palliative care in **India**
2. Litigation to ensure access to morphine in **India**
3. Regulatory reform in **Romania**
4. Integration of patients' rights standards in hospice accreditation in **South Africa**

Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such a project **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this project?
- What **barriers** need to be overcome to ensure its successful replication?

Example 1: Petitioning the state human rights commission for access to palliative care in India

A cancer patient and the director of the Institute of Palliative Medicine petitioned the State Human Rights Commission to secure the training of palliative care professionals and the provision of palliative care in government hospitals.

Project type
Human Rights Commission Petition

Health and human rights issue
In India, training in palliative care was not included in the education of medical staff, and patients in certain districts could not obtain needed care and pain relief medication.

Actions taken
A cancer patient and the director of the Institute of Palliative Medicine, of the Kozhikode Government Medical College, petitioned the State Human Rights Commission for the provision of palliative care in government hospitals.

Results
In 2006, the Commission directed the government to:

- Take steps to include palliative medicine in the curriculum of nursing and undergraduate medical students
- Give training in palliative care to medical staff in government and private hospitals
- Set up a pain and palliative-care hospital in every district.
- Provide enough medicines for relieving pain.

The Commission ordered an action-taken report from the government within 30 days.

Contact
Pain and Palliative Care Society,
Medical College (PO),
Calicut 673008, Kerala, INDIA
Email: pain@vsnl.com
Web: www.painandpalliativecare.org/index.htm

Example 2: Litigation to ensure access to morphine in India

In 1988, a doctor took legal action to secure access to morphine for cancer patients in India.

Project type
Litigation

Health and human rights issue
In 1985, the Narcotic Drugs and Psychotropic Substances Act instituted strict controls on the distribution of morphine in India. This had tremendous impact on the use of morphine for medical purposes. Supplies of medical morphine dwindled from over 750 kilograms per year in 1985 to only 56 kilograms in 1996. Thus, while India was the major exporter of opium to the world, patients with severe pain did not have access to morphine. Moreover, a whole generation of doctors graduated without experience in its use and unaware of its potential in treating patients.

Actions taken
- Dr. Ravindra Ghooi filed a public interest litigation in the Delhi High Court on behalf of cancer patients in the country, requesting the rationalization of procedures for the supply of morphine for medical purposes.

- Dr. Ghooi filed suit after the death of his mother. His mother had breast cancer, but due to a previous history of diabetes and a stroke, she was not a candidate for aggressive cancer therapy. Nonetheless, she suffered from significant pain. Her physicians were not able to obtain even 1 mg of morphine for her treatment. Dr. Ghooi himself went through an enormous amount of bureaucratic red tape and spent his time and money meeting with government officials, but was ultimately unsuccessful.

Results
- In 1998, the High Court affirmed, "It is a right of patients to receive any medication they need, particularly morphine."

- The Court then directed the state government to speedily attend to morphine requests and to pending hospital applications for morphine licenses. It further encouraged patients to approach the court if unsatisfied.

- This court case worked in tandem with other advocacy efforts to increase access to palliative care medications. In 1993, the Pain and Palliative Care Society formed to develop community-based palliative care provision in India, and over the next seven years, the Society helped established twenty outreach palliative care programs throughout Kerala. By 2002, eight of the twenty-eight states in India amended their rules governing access to morphine.

Contact
All India Lawyer's Forum for Civil Liberties (AILFCL)
Ch.No.444, Western Wing,
Tis Hazari Court, Delhi-110 054

Example 3: Regulatory reform in Romania

Incorporating patients' rights arguments and international standards in their advocacy, a Romanian team convinced regulators of the need to reform opioid control policies to enable the provision of palliative care.

Project type
Law reform

Health and human rights issue
Romania's drug-control policies were more than 35 years old and imposed an antiquated regulatory system on pain medication based on inpatient, post-surgical management of acute pain. This restricted prescription authority, making access to opioid treatment difficult for patients with severe chronic pain due to cancer or AIDS.

Actions taken
- In 2002, a Romanian team composed of health care professionals working on cancer, HIV AND AIDS, pain, and palliative care and representatives from narcotic authorities and the ministries of health, social welfare, and insurance attended an IPCI workshop on ensuring the availability of opioid analgesics for palliative care.
- The Romanian team returned home and advocated for the creation of a national commission to reform Romania's opioid control policies.
- To convince regulators that a change in opioid law was needed, one argument the team used was to point to Romania's patient rights law, which stated, "The patient has the right to palliative care in order to die in dignity." (24/2003, Cap VI, art. 31).
- The Ministry of Health agreed to the formation of a Palliative Care Commission (PCC) to study the matter.
- Finding that Romania's opioid control policies fell short of WHO guidelines, the PCC invited the Pain & Policy Studies Group from the University of Wisconsin to collaborate in the preparation of recommendations.

Results
- Based on the resulting report, the Ministry of Health drafted legislation to replace the old narcotics law. Parliament passed this into law in 2005. The Pain and Policy Studies Group then worked with the Ministry of Health on implementing regulations.
- Under the new law, special authorization is no longer necessary to prescribe opioids for outpatients, non-specialists can prescribe after receiving certified training, and there is no dosage limitation.
- Romania is currently conducting a country-wide effort to educate healthcare professionals in the use of opioid analgesics.

Contact
Dr. Daniela Mosoiu
Hospice Casa Sperantei
Email: mosoiudaniela@xnet.ro

David Joranson and Karen Ryan
Pain & Policies Study Group
University of Wisconsin
Email: kmryan2@facstaff.wisc.edu,
Web: www.painpolicy.wisc.edu

Example 4: Integration of patients' rights standards in hospice accreditation in South Africa

The Hospice and Palliative Care Association of South Africa (HPCA) developed palliative care standards for the accreditation of hospices in South Africa, incorporating key protections for patient rights.

Project type

Development of patient care standards

Health and human rights

Founded in 1988, the Hospice and Palliative Care Association of South Africa (HPCA) is a professional membership organization for hospice and palliative care organizations. One of its core missions is to ensure professional palliative care services and to guarantee a high standard of care to patients and their families. HPCA thus wished to develop accrediting standards and procedures for hospices in South Africa. Patient rights are central to HPCA's philosophy—providers view themselves as advocates for their patients—and would thus have to figure prominently in criteria developed.

Actions taken

- In 1994, a HPCA Standards Committee was created to work with the Council for Health Services Accreditation of South Africa (Cohsasa), the accrediting body for facilities in compliance with health professional standards, to formulate comprehensive palliative care standards for hospices.
- The Committee developed standards covering 13 key areas with patient rights as one of them. Patient rights language is further embedded throughout.
- A chapter on patient rights addresses processes to: identify, protect, and promote patient rights; inform patients of their rights; include the patient and the patient's family, when appropriate, in decisions about the patient's care; obtain informed consent; educate staff about patients' rights; and guide the organization's ethical framework.

Results

- In 2005, the HPCA/Cohsasa standards for hospice accreditation were published and recognised by the International Society for Quality in Health Care Incorporated (ISQua).
- Eleven South African hospices were granted full Cohsasa accreditation in 2006, and another 26 should be fully accredited in 2007.

Contact
HPCA (Hospice Palliative Care Association of South Africa),
P.O. Box 38785, Pinelands 7430,
South Africa
Email: HPCA@IAFRICA.COM
Web: www.hospicepalliativecaresa.co.za/

Cohsasa (Council for Health Services Accreditation of South African)
P.O. Box 676, Howard Place 7450,
South Africa
Email: info@cohsasa.co.za
Web: www.cohsasa.co.za/

Where can I find additional resources on palliative care and human rights?

Resources

To further your understanding on the topic of palliative care and human rights, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions: UN
- Declarations and resolutions: non-UN
- Position statements
- Books
- Reports, key articles, and other documents
- Websites
- Training opportunities and key conferences

Declarations and resolutions: UN

- Resolution adopted by the UN General Assembly, 26th special session, Agenda item 8, S-26-2. Declaration of Commitment on HIV/AIDS. 2001.
- World Health Assembly Resolution 58.22 Cancer prevention and control, May 2005.
  Source: www.who.int/gb/ebwha/pdf files/WHA58/WHA58 22-en.pdf
- Pursuant to World Health Assembly Resolution 58.22 and the Economic and Social Council (ECOSOC) Resolution 2005/25: Joint Report of the Director-General of the World Health Organization and the President of the International Narcotics Control Board, Assistance Mechanism to Facilitate Adequate Treatment of Pain Using Opioid Analgesics, March 2007.

Declarations and Resolutions: non-UN

- Allende S, Carvell HC. Mexico. Status of Cancer Pain and Palliative Care. J Pain & Symptom Manage, Declaration of Guadalajara, 12(2)121: 123, 1996.
- Alma Ata Declaration on Health for All, 1978.
  Source: www.euro.who.int/AboutWHO/Policy/20010827_1

- American Medical Association House of Delegates, Resolution Advances Palliative Medicine as Subspecialty, 2006.
  Source: www.supportivecarecoalition.org/CoalitionEnews/E-News+July+2006.htm

- European Federation of Older Persons (EURAG) Recommendation: Making Palliative Care a Priority on the European Health Agenda and Recommendations on Developing Palliative Care in Europe. 2004.
  Source: www.eurag-europe.org

- Luczak J. The Poznan Declaration. (1998)
  Source: www.oncology.am.poznan.pl/ecept/declaration.php

- Montejo Rosas G. Mexican Declaration of Cancer Pain Relief, (1992) El enfermo con cáncer incurable y la medicina paliativa en México. *Salud Publica de México* 34(5):569-574

- Sebuyira LM, Mwangi-Powell F, Perira J and Spence C. The Cape Town Palliative Care Declaration: Home-Grown Solutions for Sub-Saharan Africa. J PLL Mws (2003) 6; 3: 341-343.

- Sen A. Elements of a theory of human rights. Philosophy of Public Affairs, 2004; 32:315-56.

- The Korean Declaration. Report of the Second Global Summit of National Hospice and Palliative Care Associations, Seoul, March 2005.
  Source: www.hpc-assocations.net.

- World Health Assembly Resolution 58.22 Cancer prevention and control, May 2005.
  Source: www.who.int/gb/ebwha/pdf_files/WHA58/WHA58_22-en.pdf

Position Statements

- Pain Management for Persons Living with HIV/AIDS. Position Statement. Association of Nurses in AIDS Care, 2005.
  Source:
  www.anacnet.org/media/pdfs/PS_ANAC_Pain_Management_Rev_01_2007.pdf

- Palliative Care. Position Statement. Association of Nurses in AIDS Care, 2006.
  Source: www.anacnet.org/media/pdfs/PS_PalliativeCare_App_9_2006.pdf

- The Care of the Dying Patients. Position Statement. American Geriatrics Society, 2002.
  Source: www.americangeriatrics.org/products/positionpapers/careofd.shtml

Books

- Berzoff J, Silverman R. (eds). *Living with Dying: A Comprehensive Resource for End-of-Life Care*. Columbia University Press, NY, 2004.
- Ferrell B, Coyle N (eds) *Oxford Textbook of Palliative Nursing*, 3rd edition, 2006.
- Goldman A, Hain R, Liben R (eds) *Oxford Textbook of Palliative Care for Children,* 2006.
- Gwyther L, Merriman A, Mpanga Sebuyira L, Shietinger H: *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa,* 2006. Source: www.apca.co.ug/publications/ClinicalGuide/index.htm
- Hanks G, Cherny N and Calman K (eds) *Oxford Textbook of Palliative Medicine,* 6th edition, 2006.
- O'Neill JF, Selwyn PA, Schietinger H. *A Clinical Guide to Supportive & Palliative Care for HIV/AIDS*, Washington, D.C.: Health Resources and Services Administration, 2003.
- Wright M, Clark D (eds). *Hospice and Palliative Care in Africa: A Review of Development and Challenges*. Oxford University Press, United Kingdom, 2006.

4

Reports, key articles, and other documents

Palliative care as a human right

- Brennan F. Palliative Care as a Human Right. *Journal of Pain and Symptom Management*. In Press, May 2007.
- Brennan F, Gwyther L, Harding R. Palliative Care as a Human Right. Background paper. New York: Public Health Program, OSI, 2008.
- California Bus. And Prof. Code, s. 2190.5, and 2313 (West 2004); Medical Treatment Act (1994) Australian Capital Territory, s 23 (1); Consent to Medical Treatment and Palliative Care Act 1995 (South Australia), s. 17 (1).
- Estate of Henry James v Hillhaven Corporation. No. 89 CVS 64 (North Carolina Superior Court Division) 1991. Source: www.painandthelaw.org/malpractice/undermedicating_cases.php
- Harding R. Palliative Care. A basic human right. Source: www.id21.org/insights/insights-h08/art00.html
- In the High Court of Delhi at New Delhi Extraordinary Civil Writ Jurisdiction Civil Writ Petition. No. 942 of 1998-Orders.

- Montreal Statement on the Human Rights to Essential Medicines (2005). Source: www.economyandsociety.org/events/Pogge_background_paper2.pdf.

- Pope Benedict XVI. Message of His Holiness Benedict XVI for the Fifteenth World Day of the Sick. December 8, 2006. Source: www.vatican.va/holy_father/benedict_xvi/messages/sick/documents/hf_ben-xvi_mes_20061208_world-day-of-the-sick-2007_en.html

- Recommendation Rec (2003)24 of the Committee of Ministers to member states on the organization of palliative care. Adopted by the European Committee of Ministers on November 12, 2003. Source: www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec(2003)24.asp

- Somerville M. Human Rights and Medicine. The Relief of Suffering. In: Cotler I and Eliadis FD, ed. *International Human Rights Law: Theory and Practice*. Pg. 505-522. Montreal: Canadian Human Rights Foundation, 1992.

- Standing Committee on Social Affairs, Science and Technology. Quality end-of-life care: the right of every Canadian; final report of the Subcommittee to update of Life and Death. Senate of Canada. June, 2000. Source: www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm

- Treatment Action Campaign v Minister of Health (Kwa-Zulu-Natal). Constitutional Court of South Africa. (2002). Source: www.tac.org.za/Documents/MTCTCourtCase/ConCourtJudgmentOrderingMTCTP-5July2002.pdf

Pain Management as a Human Right

- Brennan F. Cousins MJ. *Pain Relief as a Human Right. Pain – Clinical Updates*. Volume XII, No. 5, September 2004.

- Foley KM, Wagner JL, Joranson DE, Gelband H. Pain Control for People with Cancer and AIDS. *Disease Control Priorities in Developing Countries*. 2nd Edition. Oxford University Press, 2006; 981-994.

- Scholten W, Nygren-Krug H, Zucker HA. WHO paves the way for action to free people from the shackles of pain. Editorial. *Anesthesia & Analgesia*, special issue on pain management as a human right. Anes.Analg.2007Jul;105(1):1-4. Source: www.anesthesia-analgesia.org/cgi/content/full/105/1/1?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&author1=Scholten&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT

- World Hospice and Palliative care Day 2007, Access to Pain Relief- An Essential Human Right: The State of the World (Published by the Help the Hospices for the Worldwide Palliative Care Alliance), September 2007.
  Source: www.worldday.org/documents/access_to_pain_relief.pdf

Essential Medicines and Human Rights

- Foley KM, Wagner JL, Joranson DE, Gelband H. Pain Control for People with Cancer and AIDS. *Disease Control Priorities in Developing Countries*. 2nd Edition. Oxford University Press, 2006; 981-994.

- Ghooi RB, Ghooi SR. A Mother in Pain. *The Lancet*, 1998;352 (9138):1622.

- Ghooi RB, Ghooi SR, Chaturvedi HK. Pain Relief in India. *The Lancet* 1999; 353 (9):677.

- Hogerzeil HV. Essential Medicines and Human Rights: What Can They Learn from Each Other? Bulletin of the World Health Organization, May 2006; 84.

- Hogerzeil HV, Samson M, Casanovas JV, Rahmani L. Access to Essential Medicines As Part of the Fulfillment of the Right to Health: Is It Enforceable through the Courts? Department of Medicines Policy and Standards, World Health Organization, Geneva, 2006.

- WHO (World Health Organization) Assuring the Availability of Opioid Analgesics for Palliative Care, Report on WHO Workshop. Budapest, Hungary, 2002.
  Source: www.euro.who.int/document/e76503.pdf

Other

- African Palliative Care Association. 2006. Advocacy Workshop for Palliative Care in Africa: A Focus on Essential Pain Medication Accessibility. Uganda: APCA.
  Source: www.apca.co.ug/advocacy/workshop/index.htm

- African Palliative Care Association. 2006. The Report on Pain Relieving Drugs in 12 African PEPFAR Countries. Uganda: APCA
  Source: www.apca.co.ug/publications/painrelief.htm

- African Palliative Care Association. 2006. Mentoring for Success: A Manual for Palliative Care Professionals, Organizations and Associations. Uganda: APCA.
  Source : www.apca.co.ug/publications/mentorship.htm

- A *Journal of Pain and Symptom Management* special issue on "The Current Status of Palliative Care", May 2007.

- American Declaration of Rights and Duties of Man, O.A.S. Res. XXX, adopted by the Ninth International Conference of American States (1948).

- Guellec D. Delhi High Court's Surprise Decision, 1998.
  Source: www.Sulekha.com

- Rajagopal MR, Joranson DE, Gilson AM. Medical Use, Misuse, and Diversion of Opioids in India. *The Lancet* 2001. July 14; 358(9276):139-43.

- Singh K. In "Terminal Illness and Pain" Hindustan Times, June 27, 1998.

- Singer EJ, Zorilla C, Fahy-Chandon B, Chi S, Syndulko K, Tourtellotte WW. 1993. Painful Symptoms Reported by Ambulatory HIV-Infected Men in a Longitudinal Study. Pain 54(1):15-19.

- Stjernsward J, Clark D. 2003. Palliative Medicine: A Global Perspective. In *Oxford Textbook of Palliative Medicine*, 3rd ed., ed. D. Doyle, G.W. C. Hanks, N. Cherny, and K. Calman, 1199-222. New York: Oxford University Press.

- The International Observatory on End of Life Care to map the development of hospice and palliative care globally.
  Source: www.eolc-observatory.net

- UNAIDS (2000) AIDS Palliative Care, UNAIDS Technical Update.
  Source: data.unaids.org/Publications/IRC-pub05/JC453-PalliCare-TU_en.pdf

- UNICEF (2004) The Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS.
  Source:
  www.unicef.org/publications/files/Enhanced_Protection_for_Children_Affected_by_AIDS.pdf.

- UNODC/WHO/UNAIDS (2006) HIV Prevention, Care, Treatment and Support in Prison Settings. A Framework for an Effective National Response.

- United Nations. 1961. Single Convention on Narcotic Drugs.
  Source: www.incb.org/pdf/e/conv/convention_1961_en.pdf.

- Webster R, Lacey J, Quine. Palliative Care: A Public Health Prioirty in Developing Countries. *Journal of Public Health Policy* 2007; 28:28-39.

- WHO (World Health Organization). 2007. Cancer Control: Knowledge into Action. A Guide to Effective Programmes. Palliative Care. Geneva: WHO. In Press.
  Source: www.who.int/cancer/modules/Order%20form.pdf

- WHO (World Health Organization). 2006. 34th Report of the WHO Expert Committee on Drug Dependence. Technical Report 942. Geneva: WHO.
  Source: whqlibdoc.who.int/trs/WHO_TRS_942_eng.pdf

- WHO (World Health Organization). 2006. Palliative Care is An Essential Part of Cancer Control and Can Be Provided Relatively Simply and Inexpensively. Geneva: WHO.
  Source: www.who.int/cancer/palliative/en/

- WHO (World Health Organization). 2004. Davies E, Higginson IJ, eds. The Solid Facts: Palliative Care. Geneva: WHO.
  Source: www.euro.who.int/document/E82931.

- WHO (World Health Organization). 2004. Davies E, Higginson IJ, eds. Better Palliative Care of Older People. Geneva: WHO.
  Source: www.euro.who.int/document/E82933.pdf

- WHO (World Health Organization). 2004. Palliative Care: Symptom Management and End of Life Care. Integrated Management of Adolescent and Adult Illness. Geneva: WHO.
  Source:
  www.who.int/3by5/publications/documents/en/genericpalliativecare082004.pdf

- WHO (World Health Organization). 2000. Achieving Balance in National Opioids Control Policy: Guidelines for Assessment. Geneva: WHO.
  Source: www.painpolicy.wisc.edu/publicat/00whoabi/00whoabi.htm

- WHO (World Health Organization). 2002. A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa. Geneva: WHO.
  Source: www.who.int/cancer/publications/en/

- WHO (World Health Organization). 1996. Cancer Pain Relief: with a Guide to Opioid Availability, 2nd Edition. Technical Report. Geneva: WHO.
  Source: www.painpolicy.wisc.edu/publicat/cprguid.htm

- WHO (World Health Organization). 1990. Cancer Pain Relief and Palliative Care in Children. Geneva: WHO.
  Source:
  www.who.int/bookorders/francais/detart2.jsp?sesslan=2&codlan=1&codcol=15&codcch=459

Websites

- African Palliative Care Association
  www.apca.co.ug
- American Academy of Hospice and Palliative Medicine
  www.aahpm.org
- Asia Pacific Hospice Palliative Care Network
  www.aphn.org/content/Disarticle.asp?I=2
- Elton John AIDS Foundation
  www.ejaf.org
- European Association for Palliative Care
  www.eapcnet.org
- Foundation for Hospices in Sub-Saharan Africa
  www.fhssa.org
- Help the Hospices
  www.helpthehospices.org.uk
- Hospice Information Service
  www.hospiceinformation.info
- Hospice Africa Uganda
  www.hospiceafrica.or.ug
- International Association for Hospice and Palliative Care
  www.hospicecare.com
- International Network for Cancer Treatment and Research
  www.inctr.org
- International Observatory on End of Life Care
  www.eolc-observatory.net
- International Palliative Care Initiative, Public Health Program, Open Society Institute
  www.soros.org/initiatives/health/focus/ipci
- Latin American Association for Palliative Care
  www.cuidadospaliativos.org
- National Hospice and Palliative Care Organizations
  www.nhpco.org/templates/1/homepage.cfm

- Pain and Policy Studies Group
  www.painpolicy.wisc.edu

- Palliative Care Initiative, The Diana, Princess of Wales Memorial Fund
  www.theworkcontinues.org/microsite_palliative.shtml

- Palliative Care. The Solid Facts
  www.euro.who.int/document/E82931.pdf

- The International Association for the Study of Pain
  www.iasp-pain.org

- World Health Organization: National Cancer Control Programmes – Policies and Managerial Guidelines.
  www.who.int/cancer/publications/en/#guidelines

- Worldwide Palliative Care Alliance
  www.wwpca.net

Training opportunities and key conferences

- African Palliative Care Association, Advocacy Workshop, Accra, Ghana: May 8-10, 2007.
  Source: www.apca.co.ug/index.htm

- 2nd African Palliative Care Association Conference—Nairobi, Kenya: September 19-21, 2007.
  Source: www.apca2007nairobi.com/index.htm

- Asia Pacific Hospice Conference—Manila, Philippines: September 27-29, 2007.
  Source: www.aphc2007.com

- Cardiff University, Diploma in Palliative Medicine
  Source: www.pallium.cardiff.ac.uk

- Certificate in Palliative Care, University of Wales, College of Medicine Palliative Care Education Unit
  Email: Dippallmed@velindre-tr.wales.nhs.uka

- Clinical Palliative Care--Short Course, Long Course, Hospice Africa Uganda
  Source: www.hospiceafrica.or.ug

- Diploma in Palliative Care, Coventry University, UK
  Email: hssgen@coventry.ac.uk

- Diploma in Palliative Care Course, University of Gloucestershire, School of Health & Social Sciences, Francis Close Hall, Swindon Road, Cheltenham, UK
  Email: shss@glos.ac.uk

- Diploma in Supportive and Palliative Care,
  Sheffield Hallam University, Sheffield, UK
  Email: admissions@shu.ac.uk
  Source: www2.shu.ac.uk/prospectus/op_pglookup1.cfm?id_num=HSC011

- Distance Learning Diploma Course, Makerere University and Hospice Africa Uganda
  Source: www.hospiceafrica.or.ug

- Distance Learning Course in Palliative Medicine, University of Dundee
  Source:
  www.dundee.ac.uk/prospectus/distlearning/deptprofiles/palliative.htm

- Distance Learning Course in Symptom Control, Beth Israel Medical Center, Department of Pain Medicine and Palliative Care
  Source:
  www.stoppain.org/for_professionals/content/education/elearning.asp

- End of Life Palliative Care Education Resource Center (EPERC)
  Source: www.eperc.mcw.edu

- End of Life Nursing Education Consortium (ELNEC) Core Syllabus
  Source: www.aacn.nche.edu/elnec/index.htm

- Fellowship in Palliative Medicine
  Contact Prof. Reena George (palcare@cmcvellore.ac.in)

- Finding our Way: Living with dying in America
  Source: itrs.scu.edu/fow/pages/FOWCOURSEINDEX.html

- Free online course for nurses and carers
  Source: www.cancernursing.org

- Guide I: Become and Effective Online Educator in Palliative Care
  University of Calgary in partnership with IAHPC
  Email: palacios@ucalgary.ca

- International Observatory on End of Life Care Summer School Social Research Methods, Bowland Tower East, Lancaster University, RU
  Email: hargreaves@lancaster.ac.uk
  Source: www.eolc-observatory.net

- Introduction to Palliative Care Nursing Course
  Source: www.CancerNursing.org

- Master of Science in Palliative Care
  Graduate Certificate in Health (Palliative Care)
  Graduate Certificate in Pediatric Palliative Care
  Graduate Diploma in Palliative Care
  Master of Palliative Care
  Graduate Certificate in Palliative Care in Aged Care
  Graduate Diploma in Palliative Care in Aged Care and
  Master of Palliative Care in Aged Care
  Flinders University, Adelaide, Australia
  Source: www.flinders.edu.au

- Master of Science in Palliative Care
  King's College London
  Department of Palliative Care and Policy
  Email: jonathan.s.koffman@kcl.ac.uk
  Source: www.kcl.ac.uk/palliative

- MPhil in Palliative Medicine, University of Cape Town
  Source: www.uct.ac.za/students/degrees/health/postgraduate/

- MSc Diploma and Certificate in Palliative Medicine, Kings College London
  Source: www.kcl.ac.uk/schools/medicine/depts/palliative/spc/

- Palliative Care Resource Training Center: Hungarian Hospice Foundation
  Source: www.hospicehaz.hu/eng/

- Palliative Care Education Resource Team for Nursing Homes Curriculum
  Source: www.swedishmedical.org/PERT/curriculum.htm

- Palliative Care Resource Training Center: Hospice Casa Sperantei
  Source: hospice.ong.ro/e_index.htm

- Palliative Care in HIV Management
  Global AIDS Learning & Evaluation Network (GALEN)
  International Association of Physicians in AIDS Care (IAPAC)
  Source: www.hospicecare.com/resources/pdf-docs/galen-pallcare-eng.pdf

- Palliative Care Research: Strategic Training Program
  Universite Laval, McGill University, University of
  Ottawa, Canadian Institutes of Health Research, National Cancer
  Institute of Canada
  Email: saode.savary@mcgill.ca
  Source: www.mcgill.ca/cihr-pcresearch

- Palliative Care Resource Training Center: Hospice Palium
  Source: hospice.ong.ro/e_index.htm

- Postgraduate Diploma in Palliative Medicine, University of Cape Town
  Source:
  www.uct.ac.za/downloads/uct.ac.za/apply/handbooks/fac_health.pdf

- Postgraduate Diploma in Palliative Care, Newcastle University
  Source: www.ncl.ac.uk/postgraduate/taught/course/23

- The Initiative for Pediatric Palliative Care: IPPC Curriculum and Video Series
  Source: www.ippcweb.org

- Third Worldwide Summit for National Associations of Hospice and Palliative Care. Nairobi, Kenya: September 17-18, 2007
  Source: www.fedcp.org/pdf_congressi/Kenya.pdf

- University of Washington, Seattle, Center for Palliative Care Education
  Source: depts.washington.edu/pallcare/training/index.shtml

What are key terms related to palliative care and human rights?

Glossary

A variety of terms is used in palliative care and human rights work.

A

Acute pain
Pain that has a known cause and occurs for a limited time. It usually responds to analgesic medications and treatment of the cause of the pain.

Addiction
A commonly-used term describing a pattern of drug use that indicates physical or mental dependence. It is not a diagnostic term and no longer used by the World Health Organization (WHO).

Advance medical directives
Used to give other people, including health care providers, information about a patient's own wishes for medical care. Advance directives are important in the event patients are not physically or mentally able to speak for themselves and make their wishes known. The most common types of advance directives are the living will and the durable power of attorney for health care. A Do Not Resuscitate (DNR) is also a form of an Advance Medical Directive.

Analgesic medications
Medications used to prevent or treat pain.

B

Bereavement
The act of grieving the loss of a significant other.

C

Cancer
An abnormal growth of cells which tend to proliferate in an uncontrolled way and, in some cases, to metastasize (spread).

Caregiver
Any person who provides care for the physical, emotional, or spiritual needs of a family member or friend.

Chronic pain
Pain that occurs for more than one month after an injury has healed, that occurs repeatedly over months, or is due to a lesion that is not expected to heal.

Complementary therapies
Approaches to treatment that are outside of mainstream medical practices. Complementary therapy treatments used for pain and/or comfort include: acupuncture, low-level laser therapy, meditation, aroma therapy, Chinese medicine, dance therapy, music therapy, massage, herbal medicine, therapeutic touch, yoga, osteopathy, chiropractic treatments, naturopathy, and homeopathy.

Community based care
Medical and social service care often provided by volunteer trained members of the community.

D

Death
The end of life in a biological organism, marked by the full cessation of its vital functions.

Do-Not-Resuscitate (DNR) orders
A DNR is a medical directive that gives consent from the patient, his/her advocate or from a Medical Physician that the patient is not to be treated for cardiac or respiratory arrest. This directive is used when treatment of the patient will not be beneficial or successful to the quality or longevity of the patients' life. This is usually the case in the seriously and terminally ill, and/or the frail and elderly. These directives do not mean that comfort measures will be withheld.

Dignity
The quality of being worthy, honored, or esteemed. Human rights are based on inherent human dignity and aim to protect and promote it.

Durable power of attorney
A person who is dying may appoint someone else to manage their finances and to make economic decisions on their behalf. This person is referred to as the "agent."

E

End-of-life care
Doctors and caregivers provide care to patients approaching the end of life that is focused on comfort, support for the family, and treatment of psychological and spiritual concerns.

Essential medicines
Medicines that satisfy the priority health-care needs of the population. Essential medicines are intended to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.

Ethics
A system of moral principles and rules that are used as standards for professional conduct. Many hospitals and other health care facilities have ethics committees that can help doctors, other healthcare providers, patients, and family members in making difficult decisions regarding medical care. This may vary with religious and cultural backgrounds.

G

Grief
The normal process of reacting to a loss. The loss may be physical (such as a death), social (such as divorce), or occupational (such as a job). Emotional reactions of grief can include anger, guilt, anxiety, sadness, and despair. Physical reactions of grief can include sleeping problems, changes in appetite, physical problems, or illness.

H

HAART
Highly active anti-retroviral therapy.

Health care proxy
A written instrument in which an individual legally delegates authority to another person to make certain health related decisions on their behalf.

Home based care
Medical and social care provided by trained health care professionals or volunteers in a person's home.

Hospice
A care program that provides a centralized program of palliative and supportive services to dying persons and their families, in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in specialized inpatient settings.

Hospice care
Care designed to give support to people in the final phase of a terminal illness, and focused on comfort and quality of life, rather than a cure. The goal is to enable patients to be comfortable and free of pain so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they sometimes provide services away from home -- in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to treat the whole person by providing support for the patient's emotional, social, and spiritual needs, as well as addressing medical symptoms.

I

Informed consent
The process of making decisions about medical care that is based on factual, open and honest communication between the health care provider and the patient and/or the patient's family members.

L

Life-limiting illness
An illness with a prognosis of a year or less to live.

Life-threatening illness
An illness serious enough in which a patient may die.

Living will
A legal document which outlines the direction of medical care a patient wishes to have or not to have. The living will is used only if the patient becomes unable to make decisions for him/herself, and will be carried out as the patient has directed in the document.

M

Medical power of attorney
A document that allows any individual to appoint another person to be their agent and make decisions for them should they become unable to make decisions for themselves.

Multidisciplinary team
A group of individuals representing different medical disciplines who work together to care for a patient and family.

N

Nursing home
A residential facility for persons with chronic illness or disability, particularly older people who have mobility and eating problems. This is also called a convalescent home or long-term care facility.

Nutrition Hydration
Intravenous (IV) fluid and nutritional supplements given to patients who are unable to eat or drink by mouth, or those who are dehydrated or malnourished.

O

Opioid
A type of medication related to opium. Opioids are analgesics used in acute and chronic pain. Opioids include morphine, codeine, and a large number of synthetic (man-made) drugs like methadone and fentanyl.

Opportunistic infections
Infections caused by organisms that usually do not cause disease in a person with a healthy immune system, but can affect people with a poorly functioning or suppressed immune system.

P

Pain
An unpleasant feeling that may or may not be related to an injury, illness, or other bodily trauma. Pain is complex and differs from person to person, as related to the individual's pain threshold.

Palliative care
An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care for children
Represents a special, albeit closely related field to adult palliative care for children with life threatening or chronic disorders and their families. Includes active total care of the child's body, mind, and spirit; family support; and a multidisciplinary approach that includes the family and makes use of available community resources.

Palliative care standards
Standards reflecting the level of care a patient and family can expect to receive when dealing with a diagnosis of a life-limiting illness.

Permanent guardianship of minor children
Offers a parent the option of permanently placing their child (a minor) in the care of another person.

Power of attorney for personal care
A legal document that specifies one or more individuals a patient would like to make medical decisions on his/her behalf if unable to do so on their own.

Psychology
Science dealing with phenomena of the mind, the conscious subject, or self.

Psychosocial care
Care given to meet a constellation of social, mental health, and emotional needs.

R

Rehabilitation
Treatment for an injury, illness, or pain with the goal of restoring partial or full function.

S

Social work
Work carried out by professionals concerned with social problems, their causes, their solutions, and their human impacts. Social workers work with individuals, families, groups, organizations, and communities, as members of a profession committed to social justice and human rights.

Spiritual care
Providing the necessary resources to address and support people's values and beliefs, provided these values and beliefs place no individuals at risk. It is based on treating each person with respect and dignity, promoting love, hope, faith, and helping vulnerable people to find the strength to cope at times of life crises when overcome by despair, grief and confusion.

Suffering
Absence of any power to control or to meaningfully influence a perceived process of one's own disintegration.

Symptom management
Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called palliative care, comfort care, and supportive care.

T

Terminal
A progressive disease that is expected to cause death.

Treatment withholding
When treatment is considered to be ineffective, disproportionate, or of no value to the patient's quality of life, it may be withdrawn or withheld.

Treatment withdrawal
The ending of treatment that is medically futile in promoting an eventual cure or possible control of the disease.

W

Will
A legal document that allows a person to leave any portion of his/her estate and any specific positions to any other person or organization.

Withholding care
Not offering a specific treatment to a patient.

Withdrawing care
Withdrawing a treatment that has already started in a patient.

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Photo: Quentin Deltour, courtesy of the International Committee on the Rights of Sex Workers in Europe, street demonstration in Brussels, Belgium October 2005

Chapter 5 Sexual Health and Human Rights

"The correct understanding of fundamental human rights principles, as well as existing human rights norms, leads ineluctably to the recognition of sexual rights as human rights."

Paul Hunt, United Nations Special Rapporteur on the Human Right to the Highest Attainable Standard of Health

Contents

5

Introduction

This chapter will introduce you to key issues and resources in **sexual health and human rights**, with a particular focus on **l**esbian, **g**ay, **b**isexual and **t**ransgender (LGBT) persons and sex workers. These two populations are priorities for OSI's work on sexual health and rights. The broader field of sexual health and rights includes women's sexual reproductive health, adolescent sexual and reproductive health, and the sexual and reproductive health of racial, ethnic, and indigenous minorities.

The chapter is organized into six sections that answer the following questions:[1]

- **How** is sexual health a human rights issue for LGBT and sex workers?
- **What** is OSI's work in the area of sexual health and human rights for LGBT and sex workers?
- **Which** are the most relevant international and regional human rights standards related to the sexual health of LGBT and sex workers?
- **What** are some examples of effective human rights programming in the area of sexual health for LGBT and sex workers?
- **Where** can I find additional resources on sexual health and human rights for LGBT and sex workers?
- **What** are key terms related to sexual health and human rights for LGBT and sex workers?

As you read through this chapter, consult the **glossary of terms**, found in the last section, *What are key terms related to sexual health and human rights for LGBT and sex workers?*

5

[1] Some of these questions are also addressed in Chapter 2, HIV/AIDS and Human Rights.

How is sexual health a human rights issue for LGBT and sex workers?

What is sexual health?

Sexual health is not merely the absence of disease, but **a state of physical, emotional, mental and social well-being** in relation to sexuality. According to the World Health Organization, "sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, **the sexual rights of all persons must be respected, protected and fulfilled**."[2]

Socially marginalized groups such as **sex workers** and **lesbian, gay, bisexual, and transgender (LGBT) persons** are especially vulnerable to violations of their sexual rights, and are priority target populations for OSI's Sexual Health and Rights Program. Other groups that suffer disproportionately from violations of sexual rights include young people, female injecting drug users, Roma women, and people living with HIV and AIDS.

What are sexual rights?

Sexual rights derive from human rights that are recognized in national, regional, and international human rights laws. Sexual rights include the right of all persons, free of coercion, discrimination and violence, to:

- The highest attainable standard of sexual health, including access to sexual and reproductive health care services
- Seek, receive and impart information related to sexuality
- Sexuality education
- Respect for bodily integrity
- Choice of one's partner or partners
- Decision whether to be sexually active or not
- Consensual sexual relations
- Consensual marriage
- Decision whether or not, and when, to have children; and
- Pursue a satisfying, safe, and pleasurable sexual life.

[2] WHO Defining Sexual Health, Report of a Technical Consultation 2002.

Did you know?

- More than 80 countries prohibit sexual relations between consenting adults of the same sex. At least 7 countries make homosexual activity punishable by death.

- A study of men who have sex with men (MSM) in Senegal found that 43 percent of MSM had been raped at least once outside of the family home. 13 percent of MSM reported having been raped by a policeman.[3]

- According to the NGO Transgender Day of Remembrance, one transgender person is killed every month in the United States.[4]

- A study in India revealed that 70 percent of sex workers from 13 districts in Tamil Nadu had been beaten by police. More than 80 percent had been arrested without evidence.[5]

- In a study in Cambodia, 97 percent of 1,000 sex workers interviewed reported having been raped in the previous year.[6]

- When sex workers face violence at the hands of clients or pimps, they often cannot report it or seek a remedy because of anti-prostitution laws or laws against brothel-keeping and living off the earnings of prostitution.

- Laws against "trafficking in persons" can have the unintended result of closing borders to migrant workers, driving sex workers into dangerous underground situations, and undermining efforts to reach out to trafficked persons with HIV-prevention and other health services.[7]

- Even in countries where prostitution is legal, sex workers can be detained under laws against brothel-keeping, living off the earnings of prostitution, or simply being present in a residence where prostitution is taking place.[8]

Human rights violations against sex workers and LGBT communities not only have serious consequences for individuals. They can also threaten public health by driving marginalized groups' further underground and impeding their access to HIV-prevention and other health services.

[3] Population Council Horizons Project, Meeting the Sexual Health Needs of Men who Have Sex with Men in Senegal, 2001.
[4] Transgender Day of Remembrance, www.gender.org/remember/day/.
[5] Sangram, Point of View and VAMP Newsletter, 2002.
[6] C. Jenkins, "Violence and Exposure to HIV among Sex Workers in Phnom Penh, Cambodia" (Policy Project c/o Futures Group, Washington, DC, 2006). Found at: www.researchforsexwork.org/downloads/Jenkins-CambodiaFinal.pdf.
[7] Open Society Institute, Fostering Enabling Legal Environments for Sex Workers' Health and Human Rights, 2006.
[8] Canadian HIV/AIDS Legal Network, Criminalization of sex work(ers): The human rights case for law reform, 2006.

What is OSI's work in the area of sexual health and human rights for LGBT and sex workers?

OSI's work in sexual health and human rights focuses on the human rights of socially marginalized groups—particularly sex workers and lesbian, gay, bisexual, and transgender persons—in relation to HIV and AIDS. The main Network Program supporting work in this area is the **Sexual Health and Rights Project (SHARP).**

OSI also supports LGBT rights through the **Human Rights and Governance Grants Program (HRGGP)**, which provides funding to groups combating discrimination against the LGBT community in Central and Eastern Europe and the former Soviet Union. HRGGP support has helped groups to decriminalize homosexuality, document and legally challenge rights abuses, and monitor the extent to which states are effectively implementing domestic and international non-discrimination standards. In addition, HRGGP provides support to a number of efforts promoting reproductive rights through a combination of litigation and advocacy in Central and Southeastern Europe.

Some examples of projects supported by SHARP include:

- **Reports**
  - A regional report on barriers to sex workers' human rights by the Central and Eastern European Harm Reduction Network, 2005.
  - Support for ground-breaking reports on the health of LGBT people in Central and Eastern Europe and sex workers, LGBT and MSM in Thailand.

- **Convening**
  - "Fostering Enabling Legal Environments for Sex Workers' Health and Human Rights", a global meeting in June 2006 to articulate a global vision for human rights approaches to sex workers' health.
  - Support for a European Conference on the Rights of Sex Workers, which adopted a Manifesto and Declaration on the Rights of Sex Workers.

- **Training**
  - A week-long training and hands-on advocacy workshop at the African Commission of Human and Peoples Rights, Banjul for self-identified LGBT rights advocates and their allies, May 2006.

- **Networking**
  - Networking, community building sessions, and venues for people in sex work and LGBT advocates at the 2006 International AIDS Conference (IAC), including a regular conference digest, "IAC in SHARP Focus."
  - A coalition-building project to support allies in sex work, women's rights, health and human rights working together to educate media and policy makers globally and in US foreign policy and funding.

For more information, visit SHARP's website:
www.soros.org/initiatives/health/focus/sharp

Which are the most relevant international and regional human rights standards related to the sexual health of LGBT and sex workers?

Overview

A variety of human rights standards at the international and regional levels applies to sexual health. These standards can be used for many purposes:

- **To document** violations of sexual rights
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To complain** to regional and international human rights bodies.

In the tables on the following pages, **examples** of human rights violations related to sexual health are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** interpreting each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
• Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
• Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	• Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on sexual health and human rights.

Abbreviations

In the tables, the seven treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (**ICCPR**)	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**)
European Social Charter (**ESC**)	European Committee of Social Rights (**ECSR**)

Also cited are the former Commission on Human Rights (**CHR**) and various UN Special Rapporteurs (**SR**) and Working Groups (**WG**).

Table 1: Sexual health and the right to life

Examples of Human Rights Violations	
• A penal code imposes the death penalty for (homosexual or heterosexual) sex outside of marriage, or for sex work or related acts such as pimping. • Police officers rape or violently assault a homeless transgender person. • Sex workers or LGBT communities are denied access to services to prevent HIV, a fatal disease. • Police fail to investigate murders of people in sex work, whether, male, female or trans-identified.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life. **(2)** In countries which have not abolished the death penalty, sentence of death may be imposed only for the most serious crimes in accordance with the law in force at the time of the commission of the crime and not contrary to the provisions of the present Covenant and to the Convention on the Prevention and Punishment of the Crime of Genocide. This penalty can only be carried out pursuant to a final judgment rendered by a competent court. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law. ***See also:*** • CRC 6	**CHR:** has acknowledged that sexual orientation is grounds for concern for application of the death penalty or extrajudicial execution. **HRC:** has linked denial of the right to life to execution for same sex or other sexual behavior outside marriage; has also linked prostitution to increased susceptibility to violence, threatening sex workers' right to life {**Colombia** 1997} **CEDAW Committee** has repeatedly called for protection of sex workers' right to life through access to reproductive health services (e.g., **Armenia** (1997), **Azerbaijan** (1998), **Namibia** (1997), **Cameroon** (2000), **DR Congo** (1999) **CRC:** "The obligation to realize the right to life, survival and development also highlights the need to give careful attention to sexuality as well as to the behaviors and lifestyles of children, even if they do not conform with what society determines to be acceptable under prevailing cultural norms" {General Comment 3, Paragraph 9} **SR Arbitrary and Extrajudicial Executions:** have noted that capital punishment should not be applied to "morals" offences, and also called on states to prevent and investigate the killing of sexual minorities by non-state actors.

Table 2: Sexual health and freedom from torture and cruel, inhuman and degrading treatment, including in prisons

Examples of Human Rights Violations	
• A psychiatrist provides "treatment" to an LGBT person with electric shock or hormone therapy without consent. • A gay man in prison is denied a bed and repeatedly assaulted and raped by cell mates, with the complicity or inaction of prison guards and correctional officials. • A sex worker is raped by police in detention with no investigation or remedy. • Police officials fail to investigate the sexual assault of a woman who uses drugs.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. **ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment ***See also:*** • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment (1987) • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (1989) • Code of Conduct for Law Enforcement Officials (1979)	**HRC, CAT:** have condemned the torture and ill-treatment of persons in detention based on their sexual orientation or gender identity. **CEDAW Committee:** has noted that sex workers "are at increased risk of violence and need equal protection of laws against rape and other forms of violence." {General Recommendation 19} **ECtHR:** has considered the rape of a woman in detention as torture and CID {Aydin v. **Turkey**, 1997}. **SR Torture:** has expressed concern at torture and CID directed at persons because of their sexual orientation or gender identity or expression, noting that torture and CID protections apply in criminal detention as well as to health and immigration facilities.

Table 3: Sexual health and freedom from slavery and servitude

Examples of Human Rights Violations	
• A child is recruited and taken from his or her home for the purposes of sexual exploitation. • A man or woman is tricked into forced prostitution by the promise of work abroad. • A migrant worker is held against his or her will in a brothel and forced into sexual servitude.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 8 (1) No one shall be held in slavery; slavery and the slave-trade in all their forms shall be prohibited. **(2)** No one shall be held in servitude. **ECHR 4 (1)** No one shall be held in slavery or servitude. **ACHPR 5** All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. ***Note:*** These provisions should not interfere with freedom of movement and to choose one's residence. Consenting adults who migrate for work, including sex work, are not necessarily victims of slavery, servitude, or trafficking. ***See also:*** • CEDAW 6 (prevention of prostitution and trafficking) • CRC 34 (protection from sexual exploitation) • Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, Supplementing the United Nations Convention against Transnational Organized Crime (2001) • UN Principles and Guidelines on Human Rights and Trafficking (2003)	**HRC:** has emphasized governments' duty to prosecute procurers of forced prostitution {**Lithuania**, 1997}. **CAT:** has defined trafficking in women as a form of violence, within CAT's mandate **Greece** (2001), **Georgia** (2001). **CEDAW Committee:** has defined trafficking as violence and a clear violation of women's rights {General Recommendation 19}; has noted that "States parties should ensure, without prejudice and discrimination, the right to sexual health information, education and services for all women and girls, including those who have been trafficked, even if they are not legally resident in the country" (General Recommendation 24); has urged States to decriminalize or review laws that criminalize prostitution, e.g., **China** (1999) and **Sweden** (2001), and to enforce anti-prostitution laws in a non-discriminatory way or change laws that punish sex workers but not procurers, e.g., **Hong Kong** (1999), **Egypt** (2001), **Guyana** (2001), **India** (2000), **Indonesia** (1998), **Lithuania** (2000). **SR Human Rights Aspects of Trafficking:** recommended that "potential victims of trafficking and exploitation, including women that have contracted HIV/AIDS or other sexually transmitted diseases, must not be immediately deported but given adequate legal, medical and social assistance, including access to interpretation in language they understand" {**Lebanon**, 2006}.

Table 4: Sexual health and freedom from arbitrary arrest and detention

Examples of Human Rights Violations	
• Police arbitrarily arrest sex workers for violating municipal laws against public loitering. • A gay man is arrested without charge by undercover police officers in a "cruising" area. • A lesbian adolescent is detained without charge after her parents discover her sexual orientation and call the police. • A transgender or transvestite person is detained at a border for "suspicious behavior." • A woman using drugs is detained in the hospital after giving birth and denied custody of her child.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 9(1) Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law. **ACHPR 6** Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained. **ECHR 5(1)** Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law: ***See also:*** • Code of Conduct for Law Enforcement Officials (1979) • Basic Principles on the Use of Force and Firearms by Law Enforcement Officials (1990)	**ACHPR:** asked **Cameroon** in 2006 about the arrest and detention of men for their alleged homosexuality. **ACHPR Womens' Protocol:** has recognized gender-specific protections for women's "life, integrity and security of the person." **WG Arbitrary Detention:** issued view that the arrest and detention of men for having sex with men was an arbitrary act by the **Egyptian** police, not justified by claims of morality; also considered the detention of men in **Cameroon** a violation.

Table 5: Sexual health and the right to privacy

<table>
<tr><th colspan="2">Examples of Human Rights Violations</th></tr>
<tr><td colspan="2">

A penal code punishes non-marital sex or non-reproductive sex, such as any form of anal or oral sex, same-sex sexual behavior, commercial sex, sex with a condom, masturbation.
A doctor discloses a patient's sexual history, health status, or sexual partner without consent.
Police officials keep lists of "suspected homosexuals" with photographs and fingerprints.
A newspaper publishes an article condemning the sexual orientation of a teacher or journalist.
Police raid a suspected brothel without evidence or judicial authorization.
Health care workers require young people to obtain parental consent as a condition of receiving sexual health services.

</td></tr>
<tr><th>Human Rights Standards</th><th>Precedents and Interpretations</th></tr>
<tr><td>
ICCPR 17(1) No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.

ECHR 8(1) Everyone has the right to respect for his private and family life, his home and his correspondence.

See also:

• CRC 16
</td><td>
HRC: established for the first time under an international treaty that the penalization of same sex behaviour is a violation of privacy and non-discrimination under ICCPR articles 2 and 17 {Toonen v. Australia, 1994}.

CEDAW Committee: since Toonen, has used privacy as the basis for numerous comments on sexual rights {see, e.g., CEDAW General Recommendation 24, 2000}.

ECtHR: affirmed that the penalization of same sex behaviour violates the right to privacy (Dudgeon v. UK and later cases), and protected the right to transition from one gender to another, although not to remain between genders {Goodwin v. UK, 2002}.
</td></tr>
</table>

Table 6: Sexual health and freedom of expression and information

Examples of Human Rights Violations	
• Young people are denied information about HIV and AIDS, safer sex, and condoms, as well as about sexual behaviors such as homosexuality. • A state agency in charge of newspaper distribution refuses to distribute an LGBT publication. • A transvestite student is forced by school authorities to dress according to his "biological sex". • Nongovernmental organizations are compelled to adopt a policy "opposing prostitution" as a condition of government funding for work on HIV and AIDS or anti-trafficking.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice. **ACHPR 9 (1)** Every individual shall have the right to receive information. **ECHR 10(1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises. **(2)** Every individual shall have the right to express and disseminate his opinions within the law. ***See also:*** • ICESCR 13 (right to education) • CRC 13 (right to education)	**CRC:** concluded that adolescent's right to information about HIV and AIDS is part of the right to information {General Comment 3, Paragraph 4, 2003}. **SR Education:** has noted the need for sexuality education in schools, and for schools to ensure the safety of gay and lesbian students. **SR Freedom of Expression and Information:** has commented on or expressed concern about: the abuse of the rights of sex workers and LGBT persons; restrictions on public speech and denial of HIV and AIDS information to these communities; detention of persons in **Kuwait** because of a letter mentioning a lesbian relationship, and the arrests and harassment of two gender-non-conforming women in **Uganda**. **SR Human Rights Defenders, SR Racism, SR Violence against Women, and SR Health:** collectively criticized a Bill in **Nigeria** that would criminalize persons seeking same sex relationships and marriage, as well as organizations working on or speaking about such issues (2007).

Table 7: Sexual health and freedom of assembly and association

Examples of Human Rights Violations	
• A government prohibits and criminalizes any associations for promotion of LGBT rights, or refuses to register an LGBT association. • A gay pride parade is banned by city authorities. • A sex worker group is denied the right to register as an NGO on the grounds that it is "promoting criminality". • In order to discourage prostitution, a government prohibits sex workers from forming a union or professional association.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 21 The right of peaceful assembly shall be recognized. **22(1)** Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests. **(2)** No restrictions may be placed on the exercise of this right other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order (*ordre public*), the protection of public health or morals or the protection of the rights and freedoms of others. **ACHPR 10** Every individual shall have the right to free association provided that he abides by the law. **11** Every individual shall have the right to assemble freely with others. The exercise of this right shall be subject only to necessary restrictions provided for by law in particular those enacted in the interest of national security, the safety, health, ethics and rights and freedoms of others. **ECHR 11** Everyone has the right to freedom of peaceful assembly and to freedom of association with others, including the right to form and to join trade unions for the protection of his interests.	**Various mechanisms:** have noted denial of LGBT rights to public assembly and marching as well as related violations to their security and safety. **SR Human Rights Defenders, SR Racism, SR Violence against Women, and SR Health:** collectively criticized a Bill in **Nigeria** that would criminalize persons seeking same sex relationships and marriage, as well as organizations working on or speaking about such issues (2007). **ECtHR**: declared ban on LGBT pride march in Warsaw in 2005 illegal and discriminatory {Baczkowski and Others v. **Poland**, 2007}.

Table 8: Sexual health and the right to marry and found a family

Examples of Human Rights Violations	
• A government refuses to accord to unmarried same-sex couples the same rights and responsibilities it accords to unmarried different-sex couples • A lesbian woman is denied the right to artificial insemination services • A single gay man is denied the right to adopt a child • A woman living with HIV is forced to terminate her pregnancy or abandon her child • Sex workers are denied legal and social status for their families • The law prevents adult children of sex workers from living with their parents, on the grounds this constitutes "living off the avails of prostitution."	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 23(2) The right of men and women of marriageable age to marry and to found a family shall be recognized. **ECHR 12** Men and women of marriageable age have the right to marry and to found a family, according to the national laws governing the exercise of this right. ***See also:*** • CEDAW 16.1 • African Women's Protocol 14	No UN-based expert has specifically applied this right to LGBT identified persons, same-sex relationships, or sex workers who have faced abuses of their family rights including respect for marriage and parental rights. However: **HRC:** found **Australia's** failure to ensure same sex pension rights violated the right to equal protection under law {Young v. **Australia**}. **ECtHR:** found Portugal's denial of custody rights to a biological father in a same-sex relationship violated rights of privacy and family life {*da Silva Mutua v.* ***Portugal***}; also found **UK's** restricting two transsexual women from marrying violates privacy and family rights if the state does not recognize their new identity {Goodwin v. **UK** and I. v. **UK**}. **ECtHR**: decided that the state cannot justify discrimination of unmarried same-sex couples by "protection of traditional family", thus saying that the state should give same rights to same-sex and different-sex unmarried couples (Karner v. **Austria**, 2003) **SR Human Rights Defenders, SR Racism, SR Violence against Women, and SR Health:** collectively criticized a Bill in **Nigeria** that would criminalize persons seeking same sex relationships and marriage, as well as organizations working on or speaking about such issues (2007).

Table 9: Sexual health and right to bodily integrity

Examples of Human Rights Violations	
• A transsexual or transgender person is raped or assaulted by police. • A lesbian is raped by family friends to "make her straight". • The police fail to investigate beatings and sexual assaults of men having sex with men. • Schools fail to protect students from attacks for sexual or gender non-conformity. • Police fail to investigate the rape of a sex worker, claiming she "asked for it". • An HIV-positive woman is sterilized against her will.	
Human Rights Standards	**Precedents and Interpretations**
ACHPR 4 Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. ***Note:*** The right to bodily integrity is not specifically recognized under the **ICCPR** or **ICESCR**, but has been interpreted to be part of the right to security of the person, to freedom from torture and cruel, inhuman, and degrading treatment, and the right to the highest attainable standard of health. Similarly, the right to bodily integrity is not specifically recognized in **CEDAW**, although CEDAW has been widely interpreted to include the right to protection from violence against women. ***See also:*** • CRC 19.1 • CEDAW 5(a) • African Women's Rights Protocol 3, 4, 5	**CEDAW Committee:** has noted that sex workers "are at increased risk of violence and need equal protection of laws against rape and other forms of violence." {General Recommendation 19} **WG Enforced or Involuntary Disappearances:** has noted that, "An aspect of disappearances that has been underreported in the past and continues at the present time relates to the way in which acts of disappearance are perpetrated in conjunction with other gross violations, with targets drawn from among the most vulnerable groups in society. . . . Common examples brought to our notice were: disappearances, combined with "social cleansing," the urban poor, the unemployed, and the so-called "undesirables," including *prostitutes, petty thieves, vagabonds, gamblers and homosexuals as the victims*" [emphasis added].

Table 10: Sexual health and the right to non-discrimination

Examples of Human Rights Violations	
• A person is denied a job, housing, health care, education, or access to goods and services because of sexual orientation, gender identity or expression, or being a sex worker. • A TV program is prohibited by authorities because it features a same-sex kiss while allowing different-sex kisses to be aired regularly. • An organization for boys (e.g., "Boy Scouts") denies membership to LGBT people. • A young woman is expelled from school because of pregnancy.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 2(1) Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICCPR 26** All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ACHPR 2** Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, colour, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. **ECHR 14** The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. For a similar provision, Protocol 12 of **ECHR 1**, "other status" has been interpreted by the **ECtHR** to include sexual orientation.	**HRC:** has recognized the right to non-discrimination on the basis of sexual orientation in relation to privacy {Toonen v. **Australia**} and access to benefits {Young v. **Australia**}, but not access to marriage {Joslin v. **New Zealand**}; has also observed importance of non-discrimination on the basis of sexual orientation and gender identity or expression in access to health care and housing, as well as freedom of speech, freedom from torture, and right to life. ***Note:*** UN treaty bodies have not determined whether to criticize laws against adultery, sodomy, and fornication, rather than recommending *equal penalties* for men and women under these laws {see, e.g., HRC concluding comments to **Egypt**, 2002}. **CEDAW Committee:** has noted impact of prostitution laws on stigma and violence against sex workers, but has not questioned laws themselves. **CRC:** has considered the equal right of adolescents on the basis of sexual orientation and health status to gain access to HIV-prevention tools {General Comment 4, 2003}.

Table 11: Sexual health and right to the highest attainable standard of health

Examples of Human Rights Violations	
• A national health system fails to provide anti-retroviral treatment to LGBT people or sex workers, while making it accessible to others. • Perceived LGBT persons are treated with stigma and judgmental attitudes in the health system. • Police confiscate condoms from sex workers, claiming they are evidence of illegal activity. • A woman living with HIV is denied condoms or services to prevent mother-to-child transmission of HIV, and instead discouraged from having sex.	
Human Rights Standards	**Precedents and Interpretations**
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. **12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: . . . (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases. **ACHPR 16 (1)** Every individual shall have the right to enjoy the best attainable state of physical and mental health. **(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick. ***See also:*** • CEDAW 12(1) • CRC 24(1) • ESC (1)	**CESCR:** has urged governments to protect sex workers' right to health as part of overall public health {**Dominican Republic**, 1997}. **CEDAW Committee:** has called for access to access to sexual health information, education, and services for all women {General Recommendation 24}; in **Uganda** (2002) and **Cameroon** (2000), has recommended that the government ensure health services for sex workers so as to curb rise in HIV andAIDS; has repeatedly called for protection of sex workers' right to health through access to reproductive health services {e.g., **Armenia** (1997), **Azerbaijan** (1998), **Namibia** (1997), **Cameroon** (2000), **DR Congo** (1999)}. **SR Health:** Included freedom of sexual orientation in report on fundamental principles in sexual and reproductive rights (2004); expressed concern that stigma against sex workers and injecting drug users in health facilities poses a barrier to services {Report of Mission to **Romania**, 2005}. **SR Violence Against Women, Torture, Freedom of Expression:** have all addressed barriers faced by sexually stigmatized people in receiving health care with respect and safety.

What are some examples of effective human rights programming in the area of sexual health for LGBT and sex workers?

Introduction

In this section, you are presented with **four examples** of effective activities in the area of sexual health and human rights. These are:

1. Reforming Federal Prostitution Laws in **New Zealand**
2. Organizing to End Abuse of Sexual and Gender Minorities in **India**
3. Gay Rights Advocacy in **Romania**
4. Lesbian Rights as Women's Rights in **Namibia**.

Right-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such an activity **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this activity?
- What **barriers** need to be overcome to ensure its successful replication?

Example 1: Reforming federal prostitution laws in New Zealand

In 2003, New Zealand, an island country of about 4 million persons, reformed its sexual offences law to legalize some forms of prostitution and brothel-keeping. Leading the effort were the members of New Zealand Prostitutes' Collective, an organization made up of current and past sex workers.

Project type
Law reform

Health and human rights issue
Sex workers in New Zealand sought a safe work environment to protect their rights. Health and human rights advocates argued that criminal laws encouraged operators of massage parlours, escort agencies, and brothels to go underground. This made operators unwilling to display safer sex literature and other products, impeded sex workers' access to sexual health information, and allowed unacceptable working conditions—including unfair dismissals, withholding payment, and denial of the right to refuse clients—to persist.

Actions taken
NZPC took a series of actions to reform the law to allow some forms of prostitution and brothel-keeping. Specifically, they:

- Formed a participatory law reform coalition made up sex workers, health professionals, HIV/AIDS groups, human rights groups, some professional women's groups (including the YWCA), parliamentarians, and civil servants
- Developed carefully-researched arguments for how reforming prostitution laws would contribute to the protecting the rights of people in prostitution, ending the exploitation of adults, and keeping children out of prostitution
- Developed relationships with the media, so that journalists asked NZPC for its opinion anytime they reported on the reform of prostitution laws.

Results and lessons learned
- The coalition recruited a diverse membership, proving that sex workers can be leaders in a law reform effort. However, the coalition had difficulty attracting street-based (as opposed to brothel-based) sex workers.
- NZPC emerged as a respected voice in the media on the issue of prostitution laws in New Zealand. However, sensational stories about prostitution continued and undermined the case for law reform.
- In 2003, the national law was reformed to allow some forms of prostitution and brothel-keeping. However, the intent of the reform has been undermined at the local level, as municipal authorities have resisted its implementation and found other ways to crack down on sex work.

Contact
New Zealand Prostitutes Collective
National Office, P.O. Box 11-41
Wellington, New Zealand
Tel: +64-4-382-8791
Web: www.nzpc.org.nz

Example 2: Organizing to end abuse of sexual and gender minorities in India

SANGAMA, a queer resource centre in Bangalore, and the People's Union for Civil Liberties-Karnataka (PULC-K), a well-known human rights group in India, released two reports that became the basis of a many different actions in support of the health and human rights.

Project type
Documentation and advocacy; legal services

Health and human rights issue
Sexual and gender minorities in Bangalore, India faced ongoing police abuse, discrimination, and criminalization under anti-sodomy and anti-trafficking laws. Particularly vulnerable were *hijras*, a group of people born as men but who dress as women and enact some women's roles as well as a culturally-specific third-gender role. Outreach workers providing these communities with HIV-prevention services were also targets of police abuse.

Actions taken
With leadership from affected communities, SANGAMA and PULC-K undertook a documentation project to build the case for human rights protections for sexual and gender minorities and sex workers. Specifically, they:

- Formed effective collaborations with a human rights organization, a feminist collective, and lawyers working with sexual and gender minorities
- Conducted extensive interviews with victims and perpetrators of human rights abuses, and documented human rights violations
- Initiated direct interventions such as providing legal services "on-call" to persons in detention and persons facing abuse.

Results and lessons learned
- Due to the participatory and collaborative nature of the project, new leaders from the LGBT and *hijra* communities began to emerge and to influence prominent national campaigns for the repeal of sodomy laws. Advocates from diverse fields—health, women's rights, Dalit rights—began to work together for the first time. This leadership was difficult to sustain, however, due to low budgets, stigma, and the mobility of marginalized groups.
- Through interviews, many human rights violations that had not previously been documented were finally exposed. This placed several human rights issues—such as rape of sexual minorities and the right to sexuality information—"on the map." Researchers and advocates began to criticize a range of laws affecting the health and rights of marginalized groups.
- At the local level, the conduct of police, family members, and medical professionals was publicly challenged. However, health professionals were reluctant to accept that their conduct toward sexual minorities was abusive. Local challenges, moreover, were not enough to influence national and international laws and policies.

Contact
SANGAMA, Flat 13, 3rd Floor, Royal Park Apartments, 34 Park Road
Tasker Town, Bangalore 560051
Web: www.sangama.org

Example 3: Gay rights advocacy in Romania

Through a pair of influential human rights reports, as well as leveraging European Union accession and HIV/AIDS arguments, a gay rights group in Romania won reform of the penal code and the adoption of legislation prohibiting discrimination on the basis of sexual orientation.

Project type
Law reform, documentation and advocacy

Health and human rights issue
LGBT persons in Romania faced rampant discrimination and state-sponsored homophobia. Until 2001, the Romanian Penal Code penalized same-sex relations with 1-5 years in prison, with the support of religious and nationalist groups. One of the effects of the law was to drive same-sex activity underground and to impede HIV-prevention and outreach efforts among men having sex with men.

Actions taken
Romanian and international groups working to protect the rights and health of LGBT populations developed a range of claims within European and international rights frameworks. Specifically, they:

- Issued two major reports on LGBT rights in Romania, one by Human Rights Watch and the International Gay and Lesbian Human Rights Commission, and the other commissioned by UNAIDS
- Registered the LGBT rights group, ACCEPT, as a non-governmental organization (the NGO had to register as a human rights organization, not an LGBT organization, because the law denied LGBT persons the right to freedom of assembly and association)
- Pressured Romania to conform to European Union and Council of Europe standards on non-discrimination on the basis of sexual orientation, as part of Romania's process of accession to the EU.

Results and lessons learned
- The penal code of Romania was amended in 2000 and further revised again in 2001. With guidance from the EU, Romania adopted comprehensive anti-discrimination mechanism that includes protection from discrimination on the grounds of both sexual orientation and HIV status.
- ACCEPT successfully registered as a human rights group. While it was illegal to advocate for LGBT rights, it made arguments and alliances with other human rights groups around freedom of expression and association. It has been less successful at connecting to advocacy against gender inequality, violence against women, and transgender rights.
- Accession to the EU and pressure to prevent HIV/AIDS—especially when voiced by international agencies—provided important leverage for reforming the penal law. However, some religious and political leaders continue to foment anti-gay prejudice and violence.

Contact
The Bucharest Acceptance Group (ACCEPT)
CP 34-56, Bucharest, Romania
Email: florentina@accept-mail.ro

Example 4: Lesbian rights as women's rights in Namibia

In the Southern African country of Namibia, a network of women's organizations led by the NGO Sister Namibia included lesbian rights in a national Manifesto on women's rights. Many political attacks followed, but the network continued to advocate for lesbian rights as part of women's rights.

Project type
Networking and coalition-building

Health and human rights issue
The elimination of all forms of discrimination against women, the protection of gender equality, and the promotion of women's health must include lesbian as well as heterosexual women. Yet it can be challenging to include lesbians in the women's movement, particularly when they are politically useful targets for politicians claiming to protect "national values."

Actions taken
Sister Namibia, a collective of women committed to gender and racial equality, undertook a series of actions to include lesbian rights in their advocacy. Specifically, they:

- Included references to lesbian rights in a 90-page Manifesto on women's rights, following a broad national consultation beginning in 1999
- Challenged numerous attacks by the dominant political party in Nambia (SWAPO, the South West African People's Organization) that lesbians and homosexuals are selfish, individualistic, and anti-Namibian—including from women's rights advocates in the government
- Continued to advance the rights of lesbians, including by creating a lesbian working group to work with Black women in townships, beginning a continent-wide Coalition of African Lesbians, and exploring how the Women's Protocol to the ACHPR can be used to advance lesbian rights.

Results and lessons learned
- The government attacks had the ironic effect of creating more support for lesbian rights, and increasing solidarity among women's rights and lesbian rights advocates. At workshops in rural areas, participants found new and creative arguments to defend the Manifesto and the rights of lesbians.

> *"They are our daughters, our mothers and our sisters, we can't just throw them out; they pay taxes like everyone else; we know who is leading the women's movement here and fighting for all women's rights."*

- However, advocacy for lesbian rights has not attracted the same attention in Africa as advocacy against sodomy laws and for the rights of gay men.
- Lesbians become politically useful targets when governments—including some feminist-identified government officials who are anti-lesbian—want to claim to protect "African values."

Contact
Sister Namibia, P.O. Box 40092
Windhoek, Namibia
Tel: +264 61 230 618
Email: sister@iafrica.com.na

Where can I find additional resources on sexual health and human rights for LGBT and sex workers?

Resources

To further your understanding on the topic of sexual health and human rights, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions: UN
- Declarations and resolutions: non-UN
- Books
- Reports, key articles, and other documents
- Health guidelines
- Periodicals
- Websites
- Blogs, wikis, search engines, and list-serves
- Training opportunities

When applicable, resources for this chapter have been further divided into three areas of sexual rights work:

- LGBT rights
- Sex workers' rights
- Sexual and reproductive health

Declarations and resolutions: UN

- Fourth World Conference on Women (Beijing 1995)

  The Platform for Action of the Beijing Conference states that "the human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence."
  Source: www.un.org/womenwatch/daw/beijing/platform/index.html

- International Conference on Population and Development (Cairo 1994)
  The Programme of Action of the ICPD does not refer to sexual rights, but it contains references to the link between sexuality, sexual health, and reproductive health, and to the right of adolescents to information about sexuality and sexual health.
  Source: www.unfpa.org/icpd/summary.htm

Declarations and Resolutions: non-UN

LGBT rights

- ADEFRA Declaration on Violence Against Lesbian Women in Africa
  Source: www.ilga.org/news_results.asp?LanguageID=1&FileCategoryID=1&FileID=901&ZoneID=4/

- American Psychological Association Policy Statement on Discrimination against Homosexuals
  Source: Conger, J.J. (1975). Proceedings of the American Psychological Association, Incorporated, for the year 1974: Minutes of the annual meeting of the Council of Representatives. American Psychologist, 30, **620-651**. www.apa.org/pi/lgbc/policy/discrimination.html.

- European Parliament Resolutions on Racism and Homophobia (January 2006)
  Source: www.ilga.org/news_results.asp?FileID=736

- Petition: Putting Sexuality on the Agenda (NGO petition to put sexuality on the agenda at the Fourth World Conference on Women in Beijing, 1995)
  Source: www.qrd.org/qrd/orgs/LAMBDALETTERS/1995/un.womens.conf-02.95

- Recommendation 1474, Parliamentary Assembly of the Council of Europe ("Situation of Lesbians and Gays in the Council of Europe Member Sates")
  Source: assembly.coe.int/main.asp?Link=/documents/adoptedtext/ta00/erec1474.htm

- The Montreal Declaration (adopted by the International Scientific Committee of the International Conference on LGBT Human Rights, July 2006)
  Source: www.declarationofmontreal.org

- Transfeminist Manifesto by Emi Koyama
  Source: www.eminism.org/readings/index.html

- Yogyakarta Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity
  Source: yogyakartaprinciples.org, released March 26, 2007 by a group of 29 international human rights experts

Sex workers' rights

- A Declaration on the International Day to End Violence against Sex Workers (Zi Teng, Hong Kong, 2005)
  Source: www.ziteng.org.hk/news_e.html

- Declaration on the Rights of Sex Workers (International Committee on the Rights of Sex Workers in Europe, 2005)
  Source: www.sexworkeurope.org

- Durbar Mahila Samanwaya Committee Manifesto for Sex Workers' Rights. (1997)
  Source: www.nswp.org

- Sex Workers in Europe Manifesto (International Committee on the Rights of Sex Workers in Europe, 2005)
  Source: www.sexworkeurope.org

- Sisonke Sex Worker Movement Mission Statement (South Africa, 2004)
  Source: www.sweat.org.za

- World Charter for Prostitutes Rights (International Committee for Prostitutes Rights, Amsterdam 1985)
  Source: www.walnet.org/csis/groups/icpr_charter.html

Sexual and reproductive health and rights

- Adolescent Sexual and Reproductive Health Rights Document (National Adolescent Friendly Clinic Initiative)
  Source: www.lovelife.org.za

- A New Bill of Sexual Rights and Responsibilities (American Humanist Association, 1976)
  Source: www.americanhumanist.org/about/sexual-rights.html.

- Charter on Sexual and Reproductive Rights (International Planned Parenthood Federation, March 2000 update)
  Source: www.ippf.org/NR/rdonlyres/6C9013D5-5AD7-442A-A435-4C219E689F07/0/charter.pdf

- Declaration of Sexual Rights (XIV World Congress of Sexology, 1999)
  Source: www.worldsexology.org/about_sexualrights.asp.

- HERA: Health, Empowerment, Rights & Accountability (Women's Sexual and Reproductive Rights and Health Action Sheets, 1998)
  Source: www.iwhc.org/resources/heraactionsheets.cfm

- SexPanic! (A Declaration of Sexual Rights, 1997)
  Source: www.worldsexology.org/about_sexualrights.asp

Books

General

- Altman, D. *Global Sex*. The University of Chicago Press, Chicago, IL. 2001.

- Correa, S. "From Reproductive Health to Sexual Rights: Achievements and Future Challenges." Abstract available at www.siyanda.org/search/summary.cfm?nn=2073&ST=SS&Keywords=correa&SUBJECT=0&Donor=&StartRow=1&Ref=Sim.

- Duggan, Lisa and Nan Hunter. *Sex Wars: Sexual Dissent and Political Culture*. New York: Routledge, 1995.

- Esplen, E. *Gender and Sexuality: Supporting Resources Collection*. BRIDGE Development and Gender. Brighton, UK: University of Sussex Press, 2007.
  Source: www.bridge.ids.ac.uk/reports/CEP-Sexuality-SRC.doc

- Mann, Jonathan, Daniel J.M. Tarantola, and Thomas W. Netter (eds.), *AIDS in the World: A Global Report*. Cambridge, MA: Harvard University Press, 1992.

- Misra, G. and R. Chandiramani, *Sexuality, Gender, and Rights: Exploring Theory and Practice in South and Southeast Asia*. New Delhi, India: Sage, 2005.

- Parker, R. Barbosa, R. and Aggleton, P. eds. *Framing the Sexual Subject: The Politics of Gender, Sexuality and Power*. Berkeley: University of California Press, 2000.

LGBT rights

- Currah, P., Juang, R.M., Price Minter, S. eds. *Transgender Rights*. Minneapolis, MN: University of Minnesota Press, 2006.

- Eskridge, W. and Hunter, N. *Sexuality, Gender, and the Law*. New York: Foundation Press, 2004.

- Feinberg, L. *Transgender Warriors: Making History from Joan of Arc to Dennis Rodman*. Boston: Beacon Press, 1996.

- Heinze. E. *Sexual Orientation: A Human Right*. The Hague: Martinus Nijhoff Publishers, 1995.
- Israel, Gianna E.; Tarver, Donald E. and Shafer, Dianne. *Transgender Care: Recommended Guidelines, Practical Information and Personal Accounts*. Philadelphia, PA: Temple University Press, 1998.
- Meyer, I.H. & M. E. Northridge, eds. *The Health of Sexual Minorities: Public Health Perspective on Lesbian, Gay, Bi-Sexual and Transgender Populations* Kluwer/Spinger Press, 2007.
- Stryker, Susan and Whittle, Stephen. *The Transgender Reader*. New York and London: Routledge, 2006.
- Wintemute, R. *Sexual Orientation and Human Rights: The United States Constitution, the European Convention, and the Canadian Charter*. Oxford, England: Clarendon Paperbacks, 1995.

Sex workers

- Alexander, P. and Delacoste, F. eds. *Sex Work*. Seattle, WA: Cleis Press, 1988.
- Brussa, Licia, ed. *Health, Migration and Sex Work: The Experience of TAMPEP*. Amsterdam: TAMPEP International, 1999.
- Ditmore, Melissa, ed. *Encyclopedia of Prostitution and Sex Work*. Westport, CT: Greenwood Press, 2006.
- Kempadoo, K. and Doezema, J. eds. *Global Sex Workers*. New York and London: Routledge, 1998.
- Kempadoo, K., et al eds. *Prostitution and Trafficking Reconsidered*. Boulder, CO: Paradigm Publishers, June, 2005.
- Mann, Jonathan, Daniel J.M. Tarantola, and Thomas W. Netter (eds.), *AIDS in the World: A Global Report*. Cambridge, MA: Harvard University Press, 1992. See especially discussions of sex work, pp. 344-345, 372-381.
- Overs, C. and Longo, P. *Making Sex Work Safe*. London: Russell, 1997. Source: www.nswp.org
- Pheterson, G. *The Prostitution Prism*, Amsterdam, The Netherlands: University of Amsterdam Press. June, 1996.
- Pheterson G ed. *Vindication of the Rights of Whores*. Seattle, WA: Seal Press, 1989.

- Vanwesenbeeck, Ine, *Prostitutes' Well-Being and Risk*. Amsterdam: VU University Press, 1994.

Sexual and reproductive health

- Chavkin, W. and Chesler, E. 2005. *Where Human Rights Begin – Health, Sexuality, and Women in the New Millennium*. New Brunswick, NJ: Rutgers University Press, 2005.

- Parker, R. and Aggleton, P, eds., *Culture, Society and Sexuality: A Reader, Second Edition*. London: UCL Press, 2007.

Reports, key articles, and other documents

General

- 2004 Report of the UN Special Rapporteur on the Right to Health
  Source:
  daccessdds.un.org/doc/UNDOC/GEN/G04/109/33/PDF/G0410933.pdf?OpenElement

- Fried, S. and Landsberg-Lewis, I. 2000. *Sexual Rights: From Concept to Strategy*. pp. 91-122 in K. Askin and D. Koenig, eds, Women's Human Rights Reference Guide. New York: Transnational Press.

- Lkkaracan, P. and Jolly, S. 2007. *Gender and Sexuality: Overview Report*. BRIDGE Development and Gender. Brighton, UK: University of Sussex Press.
  Source: www.bridge.ids.ac.uk/reports/CEP-Sexuality-OR.doc

- Rubin, Gayle. Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality. In Nardi, P. M. and Schneider, B.E., eds. *Social Perspectives in Lesbian and Gay Studies; A Reader*. New York: Routledge, 1984.

LGBT rights

- Amnesty International. Crimes of Hate, Conspiracy of Silence: Torture and Ill-Treatment based on Sexual Identity (London, Amnesty International Publications, 2001).

- Amnesty International. New York City: Abuse of Transgender Women by New York City Police Officers (New York, 2006).
  Source:
  www.amnestyusa.org/outfront/document.do?id=ENGAMR511642006

- Bockting, W. O. and Avery, E. (eds). Transgender Health and HIV Prevention, published simultaneously as special issue of *International Journal of Transgenderism*, Vol. 8, Issue 2/3 (2005), The Haworth Press.

- Bockting, W.O. and Kirk, S. (eds). Transgender and HIV: Risks, prevention and care. Binghamton, NY: The Haworth Press, 2001. Originally published as a special issue of *International Journal of Trangenderism* 3.1+2.

- Bockting, W. O., Rosser, B.R.S., and Coleman, E. Transgender HIV Prevention: A Model Education Workshop. *Journal of the Gay and Lesbian Medical Association* 4(4): 175-183.

- Cameron E. Sexual orientation and the constitution: A test case for human sights, in *South African Legal Journal*, Vol110 (1993), no 3, 450-472.

- Critical Health Needs for MTF Transgenders of Color - Center for AIDS Prevention Studies
  Source: www.caps.ucsf.edu/projects/TRANS/pdf/TRANScriticalneeds.pdf

- Feldman, J. and Bockting, W. Transgender Health. *Minnesota Medicine* Volume 86 (2003), July 2003.

- Gooren, Louis J. G. Hormonal Sex Reassignment. *International Journal of Transgenderism*, 3 (1999) 3.

- Gorton, N.; Buth, J, Spade, D. Medical Therapy and Health Maintenance for Transgender Men: A Guide for Health Care Providers. 2005.
  Source:
  www.nickgorton.org/Medical%20Therapy%20and%20HM%20for%20Transgender%20Men_2005.pdf

- Human Rights Watch and International Gay and Lesbian Human Rights Commission (IGLHRC), More than a Name: State-Sponsored Homophobia and Its Consequences in Southern Africa (2003).
  Source: www.iglhrc.org/files/iglhrc/reports/safriglhrc0303.pdf

- Human Rights Watch, In a Time of Torture: The Assault on Justice In Egypt's Crackdown on Homosexual Conduct (New York, 2004).
  Source: hrw.org/reports/2004/egypt0304/

- IGLHRC. Off the Map: How HIV/AIDS Programming Is Failing Same-Sex Practicing People in Africa (2007).

- IGLHRC, Making the Mountain Move: An Activist's Guide to How International Human Rights Mechanisms Can Work for You
  Source: www.iglhrc.org/files/iglhrc/reports/unguide.pdf

- Joint Statement: Four key experts (on proposed Nigerian legislation to criminalize same-sex relations, February 2007).
  Source:
  www.unhchr.ch/huricane/huricane.nsf/view01/A8F5CC6EAC2D6C52C125728B0054CD9B?opendocument

- Keatley, J. and Clements-Nolle, K. Factsheet: What are the Prevention Needs of Male-to-Female Transgender Persons? University of California, San Francisco, Center for AIDS Prevention Studies, (2001) (Spanish/Español). Source: www.caps.ucsf.edu/pubs/FS/MTF.php

- Lurie, S. Overview of Transgender Issues for College Health Centers. *College Health in Action*, Vol. 45(April/May/June 2006) 4, p. 1 and 10.

- Lurie, S. Identifying Training Needs of Health Care Providers, in Transgender Health and HIV Prevention, (2005), The Haworth Press. [PDF Document] Source: www.tgtrain.org/LurieIJTv8n2.pdf

- Macovei, M. and Coman, A. Implications for HIV/AIDS of laws affecting men who have sex with men in Romania. Bucharest Acceptance Group (ACCEPT), 1998.

- Maguen, S, Shipherd, J, Harris, H, Providing Culturally Sensitive Care for Transgender Patients. *Cognitive and Behavioral Practice* 12(2005): 479-490.

- Moore, E; Wisniewski, A; Dobs, A. Endocrine Treatment of Transsexual People: A Review of Treatment Regimens, Outcomes and Adverse Effects. *Journal of Clinical Endocrinology and Metabolism*. 88 (2003) 8 [PDF Document]

- National Coalition for LBGT Health. An Overview of US Trans Health Priorities, (2004) [PDF Document] Source: www.nctequality.org/HealthPriorities.pdf

- National LGBT health summit, London 2006. Source: www.lgbthealth.co.uk

- Norwegian Statement on ECOSOC Status for LGBT NGOs. Source: www.ilga.org/news_results.asp?LanguageID=3&FileCategoryID=46&FileID=968&ZoneID=14

- Oriel, K. A. Medical care of Transsexual Patients. *Journal of the Gay and Lesbian Medical Association* 4 (2000) 4: 185-193.

- People's Union for Civil Liberties. Human Rights Violations against the Transgender Community. Source: www.pucl.org/Topics/Gender/2003/transgender.htm

- Post, P, (2002), Crossing to Safety: Transgender Health and Homelessness, Healing Hands: A publication of the Health Care for the Homeless Clinician's Network, 6 (4), June 2002. Source: www.nhchc.org/Network/HealingHands/2002/June2002HealingHands.pdf

- Saiz, I. Bracketing Sexuality: Human Rights and Sexual Orientation-A Decade of Development and Denial at the UN (*Health and Human Rights: An International Journal*: Special Focus: Sexuality, Human Rights, and Health Vol. 7, No. 2. Cambridge, MA: Harvard University.)

- Smith, D and Walter, J. Improving Services to Transgender Students, Improving Services to All Students. *Student Health Spectrum, Special issue on Cultural Competency: A Publication of the Chickering Group*, January 2005. See pp. 29-34.

- Spack, N. Transgenderism. *Lahey Clinic Medical Ethics*, in collaboration with Dartmouth-Hitchcock Medical Center. Fall 2005, Vol. 12, Issue 3.

Sex workers' rights

- Agustín, Laura. *Conexiones Para Migrantes/Connexions for Migrants.* Source: www.nodo50.org/migrantes

- Agustín, L. 2006. The Disappearing of a Migration Category: Migrants Who Sell Sex. *Journal of Ethnic and Migration Studies*, 32, 1, 29-47.

- Agustín, Laura. *La Industria del Sexo y "Las Migrantes."* Source: www.geocities.com/litertulia/0041)_agustin.htm and www.nodo50.org/conexiones/Laura_Agustin/LAgustin_Disappearing.pdf

- Agustín, Laura. A Migrant World of Services. *Social Politics* 10 (2003): 377-96.

- Agustín, Laura. The Plight of Migrant Women: They speak, but who's listening? In *Women@Internet: Creating New Cultures in Cyberspace.* Edited by Wendy Harcourt. London: Zed Books, 1999.

- Agustín, Laura. *Sex Work & Migrations/Trabajo Sexual y Migraciones.* Source: www.swimw.org/agustin.html

- Agustín, Laura, Trabajar en la industria del sexo. *OFRIM/Suplementos,* Madrid, June 2000. Source: www.swimw.org/agustin.html (Spanish)

- Agustín, Laura and Jo Weldon. The Sex Sector: A Victory for Diversity. *Global Reproductive Rights Newsletter* 66/67 (2003): 31-34. Source: www.swimw.org/agustin.html

- Bindman, Jo, & Jo Doezema. Redefining Prostitution as Sex Work on the International Agenda. London: Anti-Slavery International, 1997. Source: www.walnet.org/csis/papers/redefining.html

- Cameron, Liz. Research: Empowering or Exploitative? *Partnership for Prevention: A Report of a Meeting Between Women's Health Advocates,Program Planners, and Scientists*. New York and Washington, D.C.: Program Council for Women's Health and the International Women's Health Coalition, 1994. Source: www.popcouncil.org/pdfs/ebert/partprev.pdf

- Canadian HIV/AIDS Legal Network. *Sex, work, rights: reforming Canadian criminal laws on prostitution,* Canadian HIV/AIDS Legal Network Source: www.aidslaw.ca/publications/publicationsEN.php?t_id=11&l_id=1&sort=date

- Central and Eastern European Harm Reduction Network, Sex Work, HIV/AIDS and Human Rights in Central and Eastern Europe and Central Asia (2005). Source: www.ceehrn.org/old_site/index.php?ItemId=7224

- Chapkis, Wendy. Trafficking, Migration, and the Law: Protecting Innocents, Punishing Immigrants. *Gender & Society*, 17 (2003): 923-37.

- Csete, J. & Seshu, M. (2004). Still Underground: Searching for Progress in Realizing the Human Rights of Women in Prostitution. *HIV/AIDS Policy and Law Review*, 9(3), 8-14. Source: www.aidslaw.ca/EN/publications/index.htm

- Ditmore, M. Trafficking in Lives: How Ideology Shapes Policy. In: Kempadoo, K., ed., *Trafficking and Prostitution Reconsidered; New Perspectives on Migration, Sex Work and Human Rights*. Boulder, CO: Paradigm Press, 2005.

- Ditmore, Melissa. L'éthique dans les Essays Incluant des Travailleuses du Sexe. Action 98 Paris, France: Act Up Paris, 2005. French.

- Ditmore, Melissa. New U.S. Funding Policies on Trafficking Affect Sex Work HIV-Prevention Efforts World Wide. *SIECUS Report* 33 (2005): 26-29.

- Ditmore, Melissa. Reaching Out to Sex Workers. *Reaching the Hardly Reached (Program for Appropriate Technology and Health)*. 2002. Source: www.path.org/files/RHR-Article-3.pdf

- Doezema, J. Forced to choose: Beyond the free v. forced prostitution dichotomy. In K. Kempadoo and J. Doezema (eds.), *Global Sex Workers: Rights, Resistance and Redefinition,* New York and London: Routledge, 1998.

- Donaldson, Stephen "Donny." In *A Million Jockers, Punks, and Queens: Sex Among American Male Prisoners and its Implications for Concepts of Sexual Orientation*. New York: Stop Prisoner Rape, 1993. Source: www.spr.org

- Global Alliance Against Trafficking in Women (GAATW). *Human Rights in Practice: A Guide to Assist Trafficked Women and Children*. Bangkok: GAATW, 1999.

- Goldman, E. (1917). The traffic in women. Reprinted in Anarchism and Other Essays, 177-194, Drinnon, R., ed. Dover: 1969.
  Source:
  dwardmac.pitzer.edu/Anarchist_Archives/goldman/aando/traffic.html

- International Labour Organisation. *The Sex Sector: The economic and social bases of prostitution in Southeast Asia* edited by Lin Lean Lim, International Labour Office, Geneva, 1998.

- Kao, Tha, Chuon Srey Net, Sou Sotheavy, Pick Sokchea, and Chan Sopheak. "The Tenofovir Trial Controversy in Cambodia." *Research for Sex Work* 7 (2004): 10-11.

- Kempadoo, K. Introduction: Globalizing Sex Workers' Rights. pp. 1-28 in K. Kempadoo and Jo Doezema, eds. *Global Sex Workers: Rights, Resistance, and Redefinition*. New York: Routledge, 1998.

- Kempadoo, K. Slavery or Work? Reconceptualizing Third World Prostitution. positions, 7(1999) 225-238.

- Leigh, C. Inventing sex work. In Nagle, J., ed. *Whores and Other Feminists*. NY: Routledge, 1997.

- Lerum, Kari. Sexuality, Power, and Camaraderie in Service Work. *Gender & Society*, 18 (2004): 756-76.

- Lim, L. Lean. Introduction. The Sex Sector: The Economic and Social Bases of Prostitution in Southeast Asia. Geneva: International Labour Organization, 1998.

- Loff, Bebe, Carol Jenkins, Melissa Ditmore, Cheryl Overs and Rosanna Barbero. Unethical Clinical Trials in Thailand: a Community Response. *The Lancet* 6 (May 2005): 1618-1619.

- Longo, Paulo. From Subjects to Partners: Experience of a project in Rio de Janeiro, Brazil. *Research for Sex Work* 7 (2004).
  Source: www.nswp.org/r4sw/

- Montgomery, Heather. Children, Identity and Child Prostitution In a Tourist Resort in Thailand. In Global Sex Workers: Rights, Resistance and Redefinition. Edited by Kamala Kempadoo and Jo Doezema. London: Routledge, 1998.

- Morgan Thomas, Ruth. AIDS Risks, Alcohol, Drugs, and the Sex Industry: A Scottish Study. In Martin Plant, ed., *AIDS, Drugs, and Prostitution*. London: Tavistock/Routledge, 1990.

- Morgan Thomas, Ruth. HIV and the Sex Industry. In Bury, J., Morrison, V. and McLachlan, S., eds., *Working with Women & AIDS: Medical, social, & counselling issues*. London: Tavistock/Routledge, 1992. Morgan Thomas is a member of the International Network of Sex Work Projects and founder of Scot-PEP, in Edinburgh.

- Murray, Alison. Debt Bondage and Trafficking: Don't Believe the Hype. In *Global Sex Workers: Rights, Resistance, and Redefinition*. Kamala Kempadoo and Jo Doezema, eds. New York and London: Routledge, 1998, pp. 51-64.

- NSW Rape Crisis Center. I am a Sex Worker.
  Source: www.nswrapecrisis.com.au/Information%20Sheets/I-am-a-sex-worker.htm

- Open Society Institute Public Health Program. Fostering Enabling Legal and Policy Environments for Sex Workers' Health and Human Rights. July, 2006. CD-ROM

- Pheterson, Gail, The Category "Prostitute" in Scientific Inquiry. *The Journal of Sex Research* August 1990 27(3):397-407. Also, in Pheterson, Gail, *The Prostitution Prism*. Amsterdam: Amsterdam University Press, 1996.

- PIVOT Legal Society, *Beyond Decriminalisation: Sex Work, Human Rights, and a new Framework for Law Reform*, 2006. PIVOT Legal Society, Vancouver, Canada.

- Saunders, P. with Miller, A. Harm Reduction, Health and Human Rights, and Sex Work, unpublished paper commissioned by the Open Society Institute, June 2006.

- Stella, l'amie de Maimie. EXXXpressions: Forum XXX Proceedings. May, 2005. CD-ROM.

- Thukral, Juhu & Melissa Ditmore. *Revolving Door: An Analysis of Street-based Prostitution in New York City*. Report issued by the Sex Workers Project at the New York: Urban Justice Center, 2005.
  Source: www.sexworkersproject.org/downloads/RevolvingDoor.pdf

- Thukral, Juhu, Melissa Ditmore and Alexandra Murphy. *Behind Closed Doors: An Analysis of Indoor Sex Work in New York City*. New York: Urban Justice Center, 2005.
  Source: www.urbanjustice.org/sexworkersproject and www.sexworkersproject.org/reports

- Vanwesenbeeck, I. (2001). Another decade of social scientific work on sex work: A review of research, 1990 – 2000. *Annual Review of Sex Research*, *12*, 242-289.

- Vanwesenbeeck, I. (2005). Burnout among indoor female sex workers. *Archives of Sexual Behavior, 34*, 627 – 639.

- Weitzer, R. (2005). Flawed theory and method in studies of prostitution. *Violence Against Women, 11*, 934-949.

Sexual and reproductive health

- Center for Reproductive Rights (2002). Bringing rights to bear: An advocate's guide to the UN treaty monitoring bodies on reproductive and sexual rights. Source: www.reproductiverights.org/pdf/pub_bp_brb.pdf

- Litigating Reproductive Rights: Using Public Interest Litigation and International Law to Promote Gender Justice in India. Source: www.reproductiverights.org/pdf/media_bo_India1215.pdf

- Miller, A. 2000. Sexual but Not Reproductive: Exploring the Junctions and Disjunctions of Sexual and Reproductive Rights. *Health and Human Rights*, v. 4, no. 2: 68-109.

- Realizing sexual rights: A Project of the Institute of Development Studies. Source: www.bridge.ids.ac.uk/reports/CEP-Sexuality-OR.doc

- The Application of Human Rights to Reproductive and Sexual Health: A Compilation of the Work of the European Human Rights System. Source: www.astra.org.pl/tor/index_1.html

- The Application of Human Rights To Reproductive & Sexual Health: A Compilation of the Work of International Human Rights Treaty Bodies (3rd Edition). Source: www.acpd.ca/compilation/2006/index.htm

- The Lancet, Sexual and Reproductive Health Series (A six-part series of commissioned papers November 2006). Source: www.who.int/reproductive-health/donateresearch.htm

- The Swedish Association for Sexuality Education (RFSU), 2004. Breaking Through: A Guide to Sexual and Reproductive Health and Rights. Source: www.crlp.org/pub_bo_breakingthrough.html

- World Health Organization, Defining Sexual Health: Report of a Technical Consultation (28-31 January 2002, Geneva). Source: www.who.int/reproductive-health/gender/sexual_health.html

Health guidelines

Health protocols for LGBT and intersex people

- Callen-Lorde Community Health Center, New York City

  Many community clinics use a combination of Tom Waddell Health Center and Callen-Lorde CHC Protocols. The Callen Lorde Protocols are only available by direct request (use link for request form). Providers like them because they are visit-by-visit specific and have a strong informed consent component. [PDF Document]
  Source: www.callen-lorde.org/documents/TG_Protocol_Request_Form2.pdf

- Shifting the Paradigm of Intersex Treatment - Key Points of Comparison Between the Concealment-centered Model and the Patient-centered Model. Prepared by Dr. Alice Dreger for the Intersex Society of North America. [includes link to PDF Document]
  Source: www.isna.org/compare.

- Standards of Care for Gender Identity Disorders, Sixth Version. Harry Benjamin International Gender Dysphoria Association (February 20, 2001). [PDF Document]
  Source: www.wpath.org/Documents2/socv6.pdf.

- Tom Waddell Health Center Transgender Clinic, Protocols for Hormonal Reassignment of Gender, 2001.
  Source: www.tgtrain.org/healthresources.html

- Understanding the Challenges Facing Gay and Lesbian South Africans: Some Guidelines for Service Providers.
  Source: www.out.org.za/Documentation/Booklet%20for%20service%20providers.pdf

Occupational safety standards for sex workers

- "A Guide to Best Practice: Occupational Health and Safety in the Australian Sex Industry." 2000. Website of the Australian Federation of AIDS Organizations.
  Source: www.afao.org.au/view_articles.asp?pxa=ve&pxs=100&pxsc=&pxsgc=&id=204

- "A Guide to Occupational Health and Safety in the New Zealand Sex Industry." Website of the Department of Occupational Safety and Health of New Zealand, 2004.
  Source: www.osh.dol.govt.nz/order/catalogue/235.shtml

Periodicals

- Health and Human Rights: An International Journal: Special Focus: Sexuality, Human Rights, and Health Vol. 7, No. 2.
  Source: www.hsph.harvard.edu/fxbcenter/v7n2.htm

- *Research for Sex Work* is the annual journal of the Network of Sex Work Projects.
  Source: www.researchforsexwork.org, www.nswp.org/r4sw/index.html

Websites

General

- Amnesty International
  www.amnesty.org

- Human Rights Watch
  www.hrw.org

- Canadian HIV/AIDS Legal Network
  www.aidslaw.ca/EN/index.htm

- Open Society Institute Sexual Health and Rights Project (SHARP)
  www.soros.org/initiatives/health/focus/sharp

LGBT rights

- Africa: Behind the Mask
  www.mask.org.za

- "A Human Rights Investigation in the Medical "Normalization" of Intersex People" [PDF]. The product of years of work, this long-awaited report was released on May 5, 2005 by the San Francisco Human Rights Commission.
  www.isna.org/files/SFHRC_Intersex_Report.pdf

- ARC International
  www.arc-international.net/index.html

- Asian & Pacific Islander Wellness Center Transgender Page
  www.apiwellness.org/transgen.html

- Center for Research and Comparative Legal Studies on Sexual Orientation and Gender Identity
  www.cersgosig.informagay.it/inglese/progetto.html

- Emi Koyama's website www.eminism.org, and resource page. Eminism.org is the web site for Emi Koyama, the activist/author/academic working on intersex, sex workers' rights, (queer) domestic violence, gender queer, anti-racism, and other issues.
  www.eminism.org/readings/index.html

- Equality and Parity: A Statewide Action for Transgender HIV Prevention and Care - Transcripts and audio recordings from conference held in San Francisco, May 5, 2005.
  hivinsite.ucsf.edu/InSite?page=cftgcare-00-00

- *Europe:* European Region of the International Lesbian and Gay Association
  www.ilga-europe.org

- Gender Identity Project
  www.gaycenter.org/program_folders/gip/index_html/program_view

- Hudson's FTM Resource Guide
  www.ftmguide.org

- International Gay and Lesbian Human Rights Commission
  www.iglhrc.org

- International Lesbian and Gay Association
  www.Ilga.org

- Pacific AIDS Education and Training Center transgender training resources Powerpoint slideshows available for download
  www.ucsf.edu/paetc/resources/index.html#transgender

- Russian LGBT Network
  www.lgbtnet.ru

- Southeastern Europe Queer Network
  www.seequeer.net

- Survivor Project - Non-profit organization for intersex and trans survivors of domestic and sexual violence
  www.survivorproject.org

- The Sylvia Rivera Law Project works to guarantee that all people are free to self-determine gender identity and expression, regardless of income or race, and without facing harassment, discrimination or violence.
  www.srlp.org/ and www.srlp.org/index.php?sec=03A&page=issues.
  Training materials: www.srlp.org/index.php?sec=03L&page=trainingmat

- Transgender Awareness Training and Advocacy
  www.tgtrain.org

- Transgender Care Project from the Transgender Health Program in Vancouver, Canada
  www.vch.ca/transhealth/resources/tcp.html

- Trans-health.com - a volunteer-run website providing information on health and fitness for trans people.
  www.trans-health.com

- TS Roadmap.com - Resources focused on MTF transition concerns.
  www.tsroadmap.com

- Transsexual Women's Resources by Anne Lawrence
  www.annelawrence.com/twr

- UCSF Center for AIDS Prevention Studies: TRANS Research
  caps.ucsf.edu/projects/TRANS/transresearch.php

Sex workers' rights

- Bay Area Sex Worker Advocacy Network. This is sex worker and activist Carol Leigh's website.
  www.bayswan.org

- Central and Eastern European Harm Reduction Network and allied organization (SWAN/HCLU)
  www.ceehrn.org/old_site

- HOOK Online is "an informative 'zine and program by, for and about men in the sex industry."
  www.hookonline.org

- International Committee for the Rights of Sex Workers in Europe
  www.sexworkeurope.org

- International Union of Sex Workers
  www.iusw.org

- Network of Sex Work Projects
  www.nswp.org

- Scarlet Alliance
  www.scarletalliance.org.au

- Sex Worker Rights Advocacy Network (SWAN)
  www.tasz.hu/index.php?op=contentlist2&catalog_id=2735&cookielanguage=en

- TAMPEP
  www.tampep.com

- The Asia Pacific Network of Sex Workers site features extensive information about rights violations in 100% Condom Use Programs and information for transgender sex workers.
  www.apnsw.org

- UNAIDS
  www.unaids.org/en/Issues/Affected_communities/sex_workers_and_clients.asp

Sexual and reproductive health and rights

- Africa Regional Sexuality Resource Centre
  www.arsrc.org

- Eldis – Sexual and Reproductive Health and Rights
  www.eldis.org/health/srhr/index.htm

- PEPFAR Watch
  www.pepfarwatch.org

- Reproductive Health Matters
  www.rhmjournal.org.uk

- South and South East Asia Resource Center on Sexuality
  www.asiasrc.org

- WHO
  www.who.int/reproductive-health/gender/sexual_health.html

- World Health Organization, Sexual Health Homepage
  www.who.int/reproductive-health/gender/sexual_health.html

Blogs, Wikis, and list-serves

LGBT rights

- List of gay rights organizations
  en.wikipedia.org/wiki/List_of_gay-rights_organizations

- EuroQueer (European LGBT rights listserv, used to share information and debate hot current issues, hosted by QueerNet Project)
  euro-queer-owner@groups.queernet.org

- SEEQ Network (open e-mail list of Western Balkans LGBT activists: see qmreza@yahoo.com)
  www.biresource.org/bidir-cgi/view_entry.cgi?record_id=8YWcn7a1

- SOGI (global sexual orientation / gender identity / human rights listserv) moderated by ARC International
  To join, email postmaster@list.arc-international.net

Sex workers' rights

- International Union of Sex Workers website has instructions for joining their listserv.
  www.iusw.org

- Laura Agustín maintains a romance-language listserv.
  To join, write to laura@nodo50.org explaining why you would like to join.

- Sex Worker Rights Advocacy Network (SWAN) Newsletter
  To subscribe or unsubscribe to SWAN News, send a message to swan-subscription@tasz.hu with the following text in the subject line: "Subscribe SWAN News"

- Sex Workers Present is the video blog of the Network of Sex Work Projects
  sexworkerspresent.blip.tv

- The Network of Sex Work Projects maintains various listservs, one general, and others regional.
  - There are two African lists, one using French and one using English.
  - To join, write to secretariat@nswp.org, including your reasons for wanting to join.
  - The Asia Pacific Network of Sex Workers listserv uses English. To join, write to apnswbkk@gmail.com.

Sexual and reproductive health and rights

- Family Care International. "Sexual and Reproductive Health: Presentation Tools." 2001. CD-ROM.

- *Global Reproductive Health Forum*: A research library with bibliographic references on sexual rights.
  www.hsph.harvard.edu/organizations/healthnet (This site is unavailable at this writing.)

- Reproductive and Sexual Health law list-serv ((REPROHEALTHLAW-L): an electronic mailing list managed by the Reproductive and Sexual Health Law Programme at the University of Toronto.
  To subscribe, email reporhealth.law@utoronto.ca

- *Women's Human Rights Resources*: Annotated bibliographic references on a wide range of topics, including sexual orientation, reproductive rights, violence against women, health and well-being, among others.
  www.law-lib.utoronto.ca/Diana

Training opportunities

- CREA Sexuality and Rights Institute
  Source: www.sexualityinstitute.org/home.htm

- François-Xavier Bagnoud (FXB) Center for Health and Human Rights, Harvard University, *Health and Human Rights Conference List*: An on-line listing of news, meetings and events, and information and resources.
  Source: www.fxb.org

- Goodrum, Alexander John. Gender Identity 101: A Transgender Primer.
  Source:
  sagatucson.org/saga/index.php?option=com_content&task=view&id=42&Itemid=94

- Program for the Study of Sexuality, Gender, Health, and Human Rights, Columbia University, New York. Program description, seminar listings, fellowship applications and other resources.
  Source: cpmcnet.columbia.edu/dept/gender/

- SIDA, LGBT and Human Rights – 2007 Training Curriculum.
  Source:
  app.rfsl.se/apa/19/public_files/Sida_LGBT_and_Human_Rights_2007.pdf

- Summer Institute on Sexuality, Culture and Society, University of Amsterdam, The Netherlands.
  Source: www.ishss.uva.nl/SummerInstitute

- The South and Southeast Asia Resource Centre on Sexuality.
  Source: www.asiasrc.org

- The Swedish Association for Sexuality Education (RFSU)
  Source: www.rfsu.se/training_programmes.asp

- TARSHI South and South East Asia Training
  Source: www.asiasrc.org/regional-institute.php

What are key terms related to sexual health and human rights for LGBT and sex workers?

Glossary

A variety of terms is used in sexual health and human rights work. In this section, the terms are organized into the following categories:

- Terms related to sex and sexuality
- Terms related to gender and gender identity
- Terms related to sexual orientation
- Terms related to prostitution and sex work

Terms related to sex and sexuality

I

Intersex

Refers to a variety of conditions in which an individual is born with aspects of reproductive/sexual anatomy or physiology that do not fit the conventional assignment of having only a male or only female body.

M

MSM (Men who have sex with men)

A public health term describing any man who has sex with another man, whether occasionally, regularly, or as an expression of a gay identity. The term is meant to be *descriptive* without attaching an identity or meaning to the behaviour, so that health interventions—especially HIV/AIDS education and services—can be directed to persons on the basis of need. While useful, it can also be used to avoid or deny a right to an identity. Some men have begun to refer to themselves as "MSM," suggesting the term is developing as an identity.

S

Sex

Refers to the biological characteristics that are used to define humans as female or male. Some individuals possess both female and male biological characteristics.

Sexual health
A state of physical, emotional, mental, and social well-being in relation to sexuality. Like health generally, it is not merely the absence of disease, but encompasses positive and complex experiences of sexuality as well as freedom to determine sexual relationships, as well as the possibility of having pleasurable sexual experiences, free of coercion, discrimination and violence.

Sexual minorities
A catch-all phrase referring to any group that adopts a sexual identity, gender identity, sexual orientation, or sexual behaviour that differs from a defined "majority." Thus, in various cultural contexts, it may refer to homosexual or trans persons, or even persons who sell sex or practice sado-masochistic sex. It is always important to clarify which kind of people or practices are included in the "sexual minority" being referred to.

Sexual rights
Human rights that are already recognized in national laws, international human rights documents and other consensus statements. Important sexual rights include the right to sexual and reproductive health services, sexuality education, respect for bodily integrity, rights of privacy and non-discrimination and expression that encompass the choice of sexual partner, consensual sexual relations, and consensual marriage without discrimination and the means to effect these decisions. *For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled.*

Sexuality
Consists of thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships related to sex, erotic desire. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

T

Transsexual (or "trans")
Individuals who identify with a different sex than that associated with the biological sex that was ascribed to them at birth. A transsexual person can be male-to-female or female-to-male. Transsexual persons can have a homosexual, heterosexual, or bisexual orientation.

Transvestite
Persons who, to different extents and with different regularity, dress in clothes traditionally ascribed to persons of the different sex. Transvestites may have a homosexual, heterosexual or bisexual orientation. Transvestites are sometimes called cross-dressers. See also transgender below.

Terms related to gender and gender identity

G

Gender expression
A broader term than gender identity, referring to masculine or feminine expressions such as dress, mannerisms, role-playing in private or social groups, or speech patterns. Gender expression is not always associated with a fixed gender identity and often changes.

Gender identity
A personal identity each persons create from their deeply felt sense of being a man, a woman, or an identity spanning both or aspects of each, which may not correspond to their body. *Gender identity is distinct from sexual orientation.*

T

Transgender
Most commonly used as the umbrella term for people whose gender identity and/or gender expression differs from the sex they were assigned at birth. The term may include, but is not limited to: transsexuals, intersex people, cross-dressers, and other gender variant people. **Transgender** (or "trans") persons are those who move across genders, meaning their gender identity may span identities associated with men or women, or change between the two. Transgender persons are sometimes but not always transsexual (see above): they may transition by medical means (altering their physiology or hormones), or by way of dress, roles, or behaviour. Trans people can have any sexual orientation.

Terms related to sexual orientation

B

Bisexual
Refers to an emotional, affective and sexual attraction to persons of both the same or a different sex/gender.

G

Gay
Can refer to either male or female-identified persons with homosexual orientations. In some cultural contexts the term gay only refers to male homosexuals.

H

Heterosexual
Refers to an emotional, affective and sexual attraction to persons of a different sex/gender.

Homophobia
Typically used in a disapproving sense to refer to policies and individuals who display fear, avoidance, prejudice, or condemnation of same-sex sexual practices or homosexuality in general.

Homosexual
Refers to an emotional, affective and sexual attraction to a person of the same sex/gender.

L

Lesbian
While the term gay can refer to either male or female-identified persons with homosexual orientations, many prefer the term **lesbian** for homosexual women, in part to ensure women's visibility in LGBT rights advocacy.

LGBT
An acronym that groups together sexual orientation-based identities (**l**esbian, **g**ay, **b**isexual) with a non-sexual orientation created category (**t**ransgender or transsexual). In some contexts and policy documents a broader acronym LGBTIQ or LGBTIQQ is used (**i**ntersex and **q**ueer and/or **q**uestioning).

Q

Queer
A term often used to refer to LGBT persons. Depending on the use, the term may be perceived as derisive or offensive, or as self-empowering.

Questioning
Refers to a person who is questioning their sexuality, gender, gender identity, or sexual orientation.

S

Sexual orientation
One of the components of sexuality distinguished by an enduring emotional, romantic, sexual or affectional attraction to individuals of a particular gender. Sexual orientation is different from sexual behavior because it refers to feelings and self-concept. Persons may or may not express their sexual orientation in their behaviors. The main terms used to describe sexual orientation are **homosexual, gay, lesbian, straight, and bisexual.**

Terms related to prostitution and sex work

C/D

Criminalization/Decriminalization (of prostitution)

Criminalization is the inclusion of prostitution or related activities in the criminal legal code. This is different from the inclusion of prostitution in business or other regulatory or civil legal codes.

Decriminalization is the removal of prostitution and related activities from the criminal legal code. This is the legal approach to prostitution recommended by most sex worker organizations and advocates of sex workers' rights.

P

Penalization (of prostitution)

Applying criminal punishments to person engaged in the exchange of sexual services for money. The **penalization** can be applied to sellers or buyers only, or both, or to the range of activities connected with living on sex work.

Prostitution

Refers to exchanging sexual services for material compensation.

R

Regulation (of prostitution)

The application of rules and laws to sex work, conditioning the legality of the work on the obedience to specific criteria and tests, often mandatory health checks for sex workers. Regulatory systems exist side by side with sex work that remains criminal because persons do not fit the criteria to register (women only, health test, nationals only etc).

S

Sex work

Refers to varied forms of sexual commerce engaged in by adults. Some forms of sex work are more informal and occasional; others are more regular and organized. Many who work in sexual commerce resist the term "prostitute" because of the stigma associated with it. This is especially true for those who are engaged in forms of sex work, such as telephone sex and stripping, which are not covered by legal prohibitions against prostitution. LGBT as well as conventional heterosexual persons can all engage in sex work.

Swedish model

Refers to a law passed in 1999 in Sweden that penalizes "[t]he person who, for payment, obtains a casual sexual relationship… with fines or imprisonment for a maximum of 6 months." Swedish legislators believed that prostitution would be reduced if the purchasers of sexual services, as opposed to sex workers themselves, could be deterred from exchanging money for sex. There have been attempts to replicate the Swedish model in other countries.

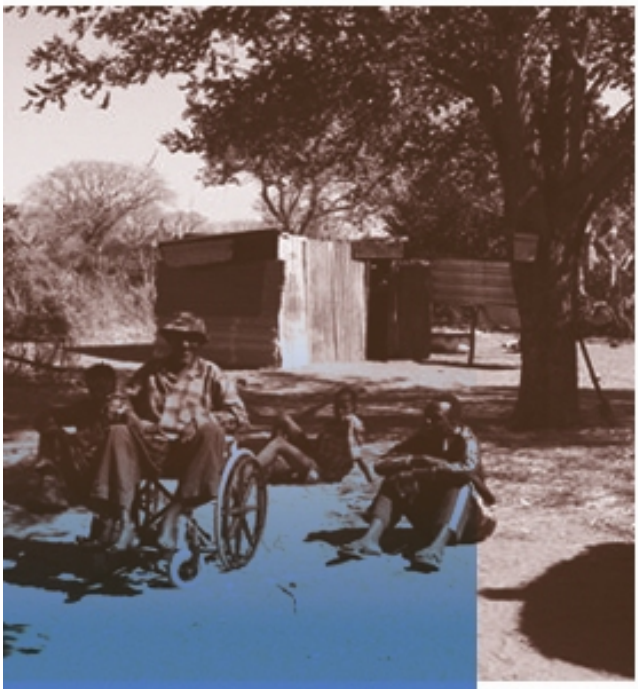
T

Trafficking

Under current international law, **trafficking** is the coerced or fraudulent movement of any person into a position of exploitation, including into domestic work, sex work, agricultural or factory work etc. However, the historical association of 'trafficking' solely with the movement of girls and women into prostitution means that many national laws and policies still treat trafficking and all movement into prostitution as if they were the crime of trafficking.

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains
International Centre for Human Rights Education



Photos courtesy of Open Society Institute

Chapter 6 Health and Human Rights in Minority Communities: *The Roma and San*

"It's not simply that poor material circumstances are harmful to health; the social meaning of being poor, unemployed, socially excluded, or otherwise stigmatized also matters."

WHO: the Solid Facts,
Richard Wilkinson and Michael Marmot

Contents

Introduction

This chapter will introduce you to key health and human rights issues facing ethnic, racial, or indigenous minorities, particularly the **Roma** communities in Central and Eastern Europe and the Newly Independent States and **San** communities in Southern Africa.

The chapter is organized into seven sections that answer the following questions:

- **How** is minority health a human rights issue?
- **What** is OSI's work in the area of health and human rights in minority communities?
- **Which** are the most relevant international and regional human rights standards related to the health of minority communities?
- **What** are some examples of effective human rights programming in the area of minority health, in particular the Roma and San communities?
- **What** steps can government and key stakeholders take to improve the health status of minority populations?
- **Where** can I find additional resources on health and human rights in Roma and San communities?
- **What** are key terms related to Roma and San health and human rights?

As you read through this chapter, consult the **glossary of terms** found in the last section, "*What are key terms related to Roma and San health and human rights*?

How is minority health a human rights issue?

What are minority health rights?

It is widely recognized that ethnic, racial, or indigenous minorities often suffer increased illness and greater mortality in comparison to the majority ethnic population in the same region and socio-economic class. This disparity signals a health inequity, defined by the European Office of the World Health Organization as "differences in health which are not only unnecessary and avoidable but, in addition, are . . . unfair and unjust." [1] In other words, even if all individually determined risk factors for poor health were equal, minorities would still suffer from poorer health status.

Major factors contributing to the poorer health of minorities are discrimination, social exclusion, and an overrepresentation of minorities in the ranks of the poor. The right to the highest attainable standard of health recognizes the importance of broader social determinants of health, such as a respect for human rights.[2] Thus, public health and human rights approaches are inseparable in addressing the disparate health situation of minorities.

The human rights of minorities impacting the protection and promotion of health include:

- Freedom from discrimination in all areas including health, education, employment, housing, and social services
- Equal access to health care and social services
- Freedom from any distinction, exclusion, restriction, or preference based on race, color, national or ethnic origin, language, religion, birth, or any other status, which has the purpose or effect of impairing the enjoyment of human rights and fundamental freedoms
- Equal recognition as a person before the law, equality before the courts, and equal protection of the law
- Equal participation in shaping decisions and policies concerning their group and community at local, national, and international levels
- The right to maintain and enjoy their culture, religion, and language
- The requirement not only to respect and protect fundamental rights, but also to fulfill them, for all persons.

Who are the Roma?

Roma are a diverse people originally of Indian origin who make up the largest ethnic minority in Europe, estimated at up to 9 million people.[3] Approximately 70% of Roma live in Central, Eastern, and South-East Europe and constitute between 6-11% of the populations of Bulgaria, Former Yugoslav Republic,

[1] Whitehead, M. *The concepts and principles of equity and health.*: WHO/EURO, Copenhagen, 1991.
[2] CESCR General Comment 14, The Right to the Highest Attainable Standard of Health, para. 4.
[3] For further details, see the World Bank website on Roma.

Macedonia, Romania, and the Slovak Republic.[4] The term Roma refers to persons describing themselves as Romas, Gypsies, Travellers, Manouches, and Sinti. The Roma language, Romanis, is an Indic language closely related to Hindi. Many dialects exist, but there is broad recognition of the unity of Romanis.

The history of the Roma in Eastern and Central Europe is marked by racism and human rights abuses. State policies towards the Roma have vacillated between intense assimilation efforts (forced sterilization, removal of children to state institutions) and social exclusion. Massive social and economic transitions in the region since 1989 have brought about a resurgence of anti-Roma sentiment and a worsening of their social and economic standing. Western Europe has also seen a rise in anti-Roma violence as a reaction to real and perceived increased migration. Despite centuries of discrimination and attempts at forced assimilation, many Roma communities have maintained a distinct identity characterized by strong extended-familial bonds and an adherence to traditional cultural practices. The discrimination and abuses against Roma continue to be one of the gravest human rights dilemmas facing Europe.[5]

Who are the San?

The San are the oldest inhabitants of Southern Africa, where they resided in the Kalahari Desert—now divided between Angola, Botswana, Namibia, and South Africa. They lived there for at least 20,000 years, and sources trace San communities to as early as 8000 BC. Bantu-speaking peoples from East and Central Africa arrived in San territory around the 15th century to be followed by European colonists in the 17th to 19th centuries. San today number close to 100,000, and around 80% live in Botswana and Namibia. The San are also known, somewhat derogatively, as Basarwa,[6] Khwe, and Bushmen. Despite their popular image as leather-clad hunters and gatherers, hardly any San today subsist entirely through these traditional means.

Marginalized and displaced from their land, the San suffer from a host of social problems. Access to resources is low, as is the availability of social and medical services. Education facilities are poor, and illiteracy rates are high. Many have been relocated from their land through a mixture of force and bribery.[7] Perceived as childlike, the San have little say in policy decisions. As a result, the San are plagued by high unemployment, poverty, alcohol abuse, and drug dependency—bringing with them domestic violence and petty crime.[8]

Did you know?

[4] European Commission. *Roma in an Enlarged European Union*. DG Employment and Social Affairs of the European Commission, Brussels, October 2004.
[5] For further information, see the report The Situation of Roma in an Enlarged European Union: ec.europa.eu/employment_social/publications/2005/ke6204389_en.pdf.
[6] Basarwa is a Tswana word meaning "inanimate (not quite human) original dwellers." Hugh Brody, "Botswana, the Bushmen/San, and HIV/AIDS," p. 2, August 2003.
[7] In 2002, the government of Botswana expelled the San from their ancestral land in the Central Kalahari Game Reserve and placed them in resettlement villages. International observers pointed to prospective diamond mining as motivating the expulsion, while the government claimed it was bringing the San into the modern age. Conditions in the resettlement villages were poor, and the health of displaced San suffered. The San filed suit, and in December 2006, the High Court of Botswana ruled that they were illegally expelled and entitled to return to their home in the Central Kalahari Game Reserve. For more information, please see *Roy Sesana and Ke/wa Setlohobogwa and Others v. The Attorney General*, Misca. No. 52 of 2002 (Dec. 13 2006).
[8] For more information, please see SUZMAN, J. "An assessment of the status of the San in Namibia." Regional assessment of the status of the San in Southern Africa. Report series 4 of 5 (2001). Legal Assistance Centre, Windhoek; Megan Biesele, Robert K.Hitchcock, Richard B. Lee, "The San of Southern Africa: A Status Report," 2003.

About Roma health

- A representative survey in Hungary found that 25% of Roma interviewed reported having faced discriminatory treatment in hospitals and other health care institutions, and 44.5% reported discriminatory treatment by general practitioners.[9]

- Until 1990, the Czechoslovak government sterilized Roma women programmatically as part of policies aimed at reducing the "high, unhealthy" birth rate of Roma women. This practice has been documented in the Czech Republic and Slovakia as late as 2004.[10]

- In late 2001, more than half of all Roma in Serbia did not have a birth certificate or any document proving their citizenship. Almost one-third did not possess a health card.[11]

- In Bulgaria, the World Bank estimates that though Roma account for only 8.8% of the population, they make up almost half (46%) of the country's poor.[12]

- Poverty among the Roma in Serbia is between 4 and 5 times higher than among the general population.[13]

- The majority of Roma in South East Europe (53%) reported going hungry in the previous month, compared with only 9% in average population. Almost twice as many of the Roma children have low weight at birth compared with the national average population.[14]

- Data from the Czech Republic indicated that 64% of Roma children in primary schools are in special schools, in comparison with 4% for the total population. In Hungary, Roma make up approximately half the number of students enrolled in special schools.[15]

[9] Delphio Consulting. *Cigányok Magyarországon – szociális-gazdasági helyzet, egészségi állapot, szociális és egészségügyi szolgáltatásokhoz való hozzáférés*. Budapest 2004, p.6. Available at: www.delphoi.hu/download-pdf/roma-szoc-eu.pdf. See also European Roma Rights Centre. *Ambulance not on the way: the Disgrace of Health Care for Roma in Europe*. Open Society Institute 2006, p. 39.

[10] European Roma Rights Centre. *Ambulance not on the way: the Disgrace of Health Care for Roma in Europe*. Open Society Institute 2006, p. 42.

[11] Cameron, L. 'The Right to an Identity'. *Roma Rights Quarterly*. European Roma Rights Centre, 2007. The article is available at www.errc.org/cikk.php?cikk=1066

[12] World Bank. *Bulgaria: Poverty Assessment*. Washington, DC, 2002 p.xi.

[13] E/C.12/1/ADD.108 (CESCR, 2005).

[14] UNICEF. *Breaking the Cycle of Exclusion: Roma Children in South East Europe*. Belgrade, February 2007, P. 7 Available at www.unicef.org/ceecis/070305-Subregional_Study_Roma_Children.pdf

[15] World Bank. *Roma in an Expanding Europe*,. Washington, DC, 2005, p. 45.

About San health

- The San are the only ethnic group in Namibia whose health and economic status have declined since independence. San life expectancy is 22% below the national average.[16]

- Maternal and infant mortality is extremely high. About 40% of all deaths of women of childbearing age are related to sexual and reproductive rights.[17]

- Namibia has highest tuberculosis rate in the world. In parts of Tsumkwe where the San reside, rates of more than 1,500 TB cases per 100,000 people were recorded in 2004.[18]

- Access to health information and services is very low in San communities. Three quarters of respondents in Tsumkwe indicated that there is "little that a person can do to prevent getting malaria" and that "health workers cannot do a lot for malaria."[19]

- Namibia has an HIV prevalence rate of 21.3%. 80% of females in Tsumkwe did not know if HIV/AIDS was a problem in their community, 85% responded "do not know" when asked about their risk of infection, while 26% had their first sexual contact under age 15.[20]

- Alcohol-related violence in San communities is responsible for a substantial number of injuries to women, children, and men. The San also suffer from a high prevalence of folate, thiamin, and iron deficiency, likely linked to alcohol consumption.[21]

[16] Indigenous Peoples – Health Issues. Summary of Presentation at Indigenous Peoples and Socioeconomic Rights Expert Workshop March 20th and 21st. <www.cpsu.org.uk/downloads/Health%20Issues.pdf>.
[17] Ibid.
[18] Health Unlimited 2004.
[19] Health Unlimited 2003.
[20] Health Unlimited 2003-2004.
[21] Robert K. Hitchcock & Patricia Draper, Health Issues among the San of Western Botswana.

What is OSI's work in the area of health and human rights in minority communities?

OSI's Public Health Program (PHP) works to promote the health of minority communities facing stigma and discrimination. A goal of the program is to enable minority communities to better participate in decision-making for health policy by ensuring they have the skills and resources to identify health issues and advocate for programs tailored to their needs. OSI works extensively with Roma communities in Central and Eastern Europe/ South Eastern Europe (CEE/SEE), and the Open Society Initiative of Southern Africa is starting a new project to address the needs of the San in Southern Africa. The following is a selection of work undertaken by OSI's Roma Health Project (RHP).

- **Convenings**
  - TB and Social Exclusion in Eastern Europe (2/07), Salzburg, Austria – OSI's Roma Health Project and the International Union Against Tuberculosis and Lung Disease sponsored the gathering of 42 national health planners, TB coordinators, and representatives of civil society to discuss the response to TB in marginalized and minority communities throughout Central and Eastern Europe and make concrete recommendations to improve strategies.
  - Left Out: Access of Roma to Health Care (3/07), Bratislava, Slovakia – OSI sponsored a panel discussion at the annual European Public Health Alliance Conference, "Health in an Enlarged EU," featuring Roma health service and advocacy projects by OSI grantees.

- **Reports**
  - *Confronting a Hidden Disease: TB in Roma Communities* outlines the available literature and data on Roma and TB in Central and Eastern Europe and current efforts by governments and NGOs to address TB in Roma communities. The report aims to bring research needs and program opportunities to the attention of key stakeholders.
  - *Ambulance Not on the Way:The Disgrace of Health Care for Roma in Europe*, published by OSI grantee the European Roma Rights Centre (ERRC), explores major systemic causes for exclusion of Roma from access to health care and documents inferior medical services and other forms of human rights abuse in health care provision.

- **Capacity building and partnerships**
  - OSI provides core institutional support to organizations working on programming and policy initiatives to improve access to health care for Roma women. The grants include a training component to strengthen the capacity of organizations to address minority health issues.
  - OSI gives grants to harm reduction organizations for outreach to Roma communities to increase the availability and access of HIV/AIDS prevention and treatment services. OSI is planning a conference in the fall of 2007 with Roma activists on drug use in Roma communities and approaches to protect individuals from HIV/AIDS, including a harm reduction approach.

For more information, please visit the RHP website at:
www.soros.org:80/initiatives/health/focus/roma

In addition, the Human Rights and Governance Grants Program (HRGGP) provides institutional support to many of the leading Roma rights organizations in Central and Eastern Europe and the former Soviet Union whose work includes promoting access to health care. Many of these organizations are also leading efforts to ensure that state commitments made in the framework of the Decade for Roma Inclusion are honoured. HRGGP support focuses on groups providing legal aid, monitoring and reporting on abuses, and taking strategic litigation to protect the rights of vulnerable minority communities.

Which are the most relevant international and regional human rights standards related to the health of minority communities?

Overview

A wide of variety of human rights standards at the international, regional, and national levels applies to health and human rights in minority communities. These standards can be used for many purposes:

- **To document** violations of the human rights of the Roma and San people
- **To advocate** for the cessation of these violations
- **To sue** governments for violations of national human rights laws
- **To report** to regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, **examples** of human rights violations against minority communities, in particular the Roma and San are provided. Relevant human rights **standards** are then cited, along with examples of legal **precedents** interpreting each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on health and human rights in minority communities.

Abbreviations

In the tables, the ten treaties and their corresponding enforcement mechanisms are referred to with the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights (**ICCPR**)	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
International Convention on the Elimination of all forms of Racial Discrimination (**ICERD**)	Committee on the Elimination of Racial Discrimination (**CERD**)
Convention concerning Indigenous and Tribal Peoples in Independent Countries (**ILO Con**)	International Labour Organization (**ILO**)
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**)
European Social Charter (**ESC**)	European Committee of Social Rights (**ECSR**)
Framework Convention for the Protection of National Minorities (**FCNM**)	Committee of Ministers of the Council of Europe & Advisory Committee (**AC**)

Also cited in this report is the Special Rapporteur on the situation of human rights and fundamental freedoms of indigenous people (**SR**).

Table 1: Minority health and the right to non-discrimination and equality

Examples of Human Rights Violations	
• Housing policies force Roma communities into separate settlements that lack basic infrastructure and render inhabitants more vulnerable to illness and disease. • Roma members are further more likely to be evicted from their homes and left to fend for themselves on the street. • San communities have been expelled from their land and forced into settlements with inadequate facilities. • Hospitals place Roma women in a separate maternity ward.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 26 All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICERD 2(1)** States condemn racial discrimination and undertake to pursue by all appropriate means a policy of eliminating racial discrimination in all its forms. **2(2)** State Parties shall . . . take . . . special and concrete measures to ensure the adequate development and protection of certain racial groups or individuals belonging to them, for the purpose of guaranteeing them the full and equal enjoyment of human rights and fundamental freedoms. **3** States particularly condemn racial segregation and apartheid and undertake to prevent, prohibit and eradicate all practices of this nature in territories under their jurisdiction. **5** State Parties undertake to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of . . . (e) . . . [t]he right to housing; [t]he right to . . . social services.	**HRC:** referring to ongoing discrimination faced by the Roma in **Hungary** in almost all aspects of life covered by the ICCPR. [CCPR/CO/74/HUN (HRC, 2002), para. 7]. **CESCR:** noting persistent discrimination against the Roma in **Greece**, **Lithuania**, and **Serbia** in the fields of housing, health, employment, and education. [E/C.12/1/ADD.97 (CESCR, 2004), para. 11; E/C.12/1/ADD.96 (CESCR, 2004), para. 9; e/c.12/1/ADD.108 (CESCR, 2005) para. 13]. **CESCR:** noting that many Roma settlements in Serbia lack access to basic services such as electricity, running water, sewage facilities, medical care, and schools. [E/C.12/1/ADD.108 (CESCR, 2005), para. 30]. **CERD:** urging the **Czech Republic** to ensure that domestic legislation clearly prohibits racial discrimination in the enjoyment of the right to housing and protects the Roma from evictions. [CERD/C/CZE/CO/7, March 2007]. **CERD:** linking the critical health situation of Roma communities in **Lithuania** to their poor living conditions and calling for addressing issues of drinking water supplies and sewage disposal systems in Roma settlements. [CERD/C/LTU/CO/3 (CERD, 2006), para. 22].

Table 1: Minority health and the right to non-discrimination and equality, **continued**

Human Rights Standards	Precedents and Interpretations
ILO Con 2 Governments shall have the responsibility for . . . [a]ssisting the members of the peoples concerned to eliminate socio-economic gaps that may exist between the indigenous and other members of the national community, in a manner compatible with their aspirations and ways of life. **3(1)** Indigenous and tribal peoples shall enjoy the full measure of human rights and fundamental freedoms without hindrance or discrimination. **4(1)** Special measures shall be adopted as appropriate for safeguarding the persons, institutions, property, labour, cultures and environment of the peoples concerned. **FCNM 4(1)** The parties undertake to guarantee to persons belonging to national minorities the right of equality before the law and of equal protection of the law. In this respect, any discrimination based on belonging to a national minority shall be prohibited. **4(2)** The parties undertake to adopt . . . adequate measures in order to promote, in all areas of economic, social, political and cultural life, full and effective equality between persons belonging to a national minority and those belonging to the majority. ***See also:*** • ICCPR 2(1) • CEDAW 2(a),(e) • ACHPR 2 • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 2 (elimination of discrimination against women) • European Race Directive 2000/43/EC	**CEDAW Committee:** referring to the multiple forms of discrimination faced by Roma women and girls in **Romania**, who remain marginalized with regard to their education, health, housing, employment, and participation in political and public life. [CEDAW/C/ROM/CO/6 (CEDAW, 2006), para. 26]. **CRC Committee:** remarking that children in Roma communities in **Greece** are exposed to substandard living conditions, including inadequate housing, poor sanitation and waste disposal, and no running water. [CRC/C/15/ADD.170 (CRC, 2002), para. 64].

Table 2: Minority health and the right to the highest attainable standard of health

Examples of Human Rights Violations	
• Doctors and health facilities are not located in or in close proximity to Roma and San neighbourhoods. • Roma and San patients are refused treatment, given inferior care, or abused in public health facilities. • Roma and San women lack access to maternal and reproductive health services. • Social policies disproportionately exclude Roman individuals from access to health insurance. • Displaced from their lands, the San have been deprived of their traditional livelihood, and their health has suffered.	
Human Rights Standards	**Precedents and Interpretations**
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. **12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right 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. **ICERD 5** State Parties undertake to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of . . . **(e)** . . . [t]he right to public health, medical care, social security and social services. **ILO Con 25(1)** Governments shall ensure that adequate health services are made available to the peoples concerned, or shall provide them with resources to allow them to design and deliver such services under their own responsibility and control, so that they may enjoy the highest attainable standard of physical and mental health.	**CESCR:** "States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds." [CESCR GC 14, para. 19]. **CESCR:** "[I]ndigenous peoples have the right to specific measures to improve their access to health services and care. . . . [D]evelpment-related activities that lead to the displacement of indigenous peoples against their will from traditional territories and environment, denying them their sources of nutrition and breaking their symbiotic relationship with their lands, has a deleterious effect on their health." [CESCR GC 14, para. 27]. **CESCR:** explaining that "the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment." [CESCR GC 14, paras 4, 11, 12]. **CESCR:** calling for the Roma's inclusion in **Serbia's** health insurance scheme. [E/C.12/1/Add.108, June 2005, para. 60]. **CERD:** encouraging the implementation of programs to improve Roma health in **Lithuania**, bearing in mind their disadvantaged situation resulting from extreme poverty and low levels of education. [CERD/C/LTU/CO/3 (CERD, 2006), para. 22].

Table 2: Minority health and the right to the highest attainable standard of health, **continued**

Human Rights Standards	Precedents and Interpretations
CEDAW 12(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health services, including those related to family planning. **12(2)** State Parties shall ensure to women appropriate services in connection with pregnancy, confinement and post-natal period. **14(2)(b**) To have access to adequate health care facilities including information, counselling and services family planning. **CRC 24(1)** States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. **ACHPR 16(1)** Every individual shall have the right to enjoy the best attainable state of physical and mental health. **16(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick. **ESC 11** – The right to protection of health With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed . . . **(2)** to provide advisory and educational facilities for the promotion of health . . . ***See also:*** • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 14(1): "State Parties shall ensure the right to health of women, including sexual and reproductive health is respected and promoted." • African Charter on the Rights and Welfare of the Child 14 (child's right to the highest attainable standard of health)	**CEDAW Committee:** noting the Roma women's marginalization and lack of access to health care and calling upon **Macedonia** to provide information on concrete projects to address these problems. [CEDAW/C/MKD/CO/3, Feb 2006, para. 28]. **CRC Committee:** noting the limited access to health services for Roma children in **Hungary**. [CRC/C/HUN/CO/2 (CRC, 2006), para. 41] **SR Indigenous:** recommending that **South African** social services, health, and education departments give high priority attention to San needs and grievances. [E/CN.4/2006/78/Add.2 (SR Indigenous, 2005), para. 92].

Table 3: Minority health and the right to information

Examples of Human Rights Violations	
• There are fewer health facilities in Roma and San communities, and there is little attempt to provide them with basic health information. • Due to poor educational facilities in San communities, illiteracy rates are high, and children are unable to access important health information. • Roma children are channeled into "special schools," which provide an inferior education and limit their access to health information. • Roma women lack access to information on sexual and reproductive health. • Data on Roma and San health is inadequate, hindering the development of policies to address the needs of these communities.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 19(2) Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice. **ICESCR 13(1)** The State Parties . . . recognize the right of everyone to education. . . . [E]ducation shall be directed to the full development of the human personality and the sense of its dignity. **ILO Con 26** Measures shall be taken to ensure that members of the peoples concerned have the opportunity to acquire education at all levels on at least an equal footing with the rest of the national community. **CEDAW 10(h)** Access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning. **16(1)(e)** The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.	**HRC:** noting the "grossly disproportionate" number of Roma children assigned to special schools and urging **Slovakia** to take immediate steps to eradicate this segregation. [CCPR/CO/78/SVK (HRC, 2003), para. 18]. **CESCR:** urging the elimination of discrimination against Roma children in the **Czech Republic** by removing them from special schools and integrating them into the mainstream educational system. [E/C.12/1/ADD.76 (CESCR, 2002), para. 44] **CERD:** calling upon the **Czech Republic** to promptly eradicate racial segregation and the placement of a disproportionate number of Roma children in special schools. [CERD/C/304/ADD.109 (CERD, 2001), para. 10]. **CERD:** noting that cultural and linguistic rights of the San are not fully respected in educational curricula in **Botswana**. [A/57/18(Supp) (CERD, 2001), para. 305]. **CEDAW Committee:** noting the lack of information on Roma women and their access to health services in **Hungary**; recommending data collection disaggregated by sex and the implementation of health awareness campaigns. [A/57/38(SUPP), Aug 2002, para. 332]. **CEDAW Committee:** urging the collection of statistical information on the health of Roma women and girls in **Romania** in order to develop policies responsive to their needs. [CEDAW/C/ROM/CO/6 (CEDAW 2006) para. 27].

Table 3: Minority health and the right to information, **continued**

Human Rights Standards	Precedents and Interpretations
CRC 28 States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, **ACHPR 9 (1)** Every individual shall have the right to receive information. **ECHR 10 (1)** Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises. **10(2)** Every individual shall have the right to express and disseminate his opinions within the law. **FCNM 9(1)** The Parties undertake to recognize that the right to freedom of expression of every person belonging to a national minority includes freedom to hold opinions and to receive and impart information and ideas in the minority language. **12(3)** The Parties undertake to promote equal opportunities for access to education at all levels for persons belonging to national minorities. ***See also:*** • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 14(2)(a) (right to health education and information) • African Charter on the Rights and Welfare of the Child 11 (right to education);	**CRC Committee:** calling upon **Moldova**, **Poland**, and the **Ukraine** to develop and implement a plan aimed at integrating all Roma children into mainstream education and prohibiting their segregation into special classes. [CRC/C/15/ADD.191 (CRC, 2002), para. 75; CRC/C/15/ADD.194 (CRC, 2002), para. 53; CRC/C/15/ADD.192 (CRC, 2002), para. 50]. **CRC Committee:** urging **South Africa** to guarantee the rights of San children, particularly concerning language and access to information. [CRC/C/15/ADD.122 (CRC, 2000), para. 41]. **AC:** highlighting the need for data to assess Roma (and particularly Roma women's) access to health services and education in **Slovakia**; data would have to be provided voluntarily, and Roma communities should be informed about the methods and purpose of data collection. [ACFC/OP/II(2005)004, May 2005, para. 11].

Table 4: Minority health and the right to participate in public life

Examples of Human Rights Violations	
• Roma members are unable to obtain citizenship papers and a health card, leaving them without access to social and health services. • Labeled child-like, San members have little say in policy decisions affecting their health and well-being. • Roma, particularly women, are unable to participate in public life and access needed social services.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 25 Every citizen shall have the right and the opportunity, without . . . distinctions . . . **(a)** To take part in the conduct of public affairs, directly or through freely chosen representatives. **ICERD 5(c)** States will guarantee political rights, in particular the right to take part in the Government as well as in the conduct of public affairs at any level and to have equal access to public services. **5(d)** States guarantee the right to nationality. **ILO Con 6(1)** Governments shall . . . **(b)** [e]stablish means by which these peoples can freely participate . . . at all levels of decision-making in elective institutions and administrative and other bodies responsible for policies and programmes which concern them. **7(1**) The peoples . . . shall have the right to decide their own priorities for the process of development . . . and to exercise control, to the extent possible, over their economic, social and cultural development. **CEDAW 7** State Parties shall take all appropriate measures to eliminate discrimination against women in the political and public life of the country and, in particular, shall ensure to women, on equal terms with men, the right: . . . **(b)** [t]o participate in the formulation of government policy and the implementation thereof.	**HRC:** calling for the removal of all administrative obstacles and fees to enable the Roma in **Bosnia** to obtain personal documents necessary for them to access health insurance and other basic rights. [CCPR/C/BIH/CO/1 (HRC, 2006), para. 22]. **HRC:** urging **Slovenia** to enhance Roma participation in public life. [CCPR/CO/84/SVN (HRC, 2005), para. 16]. **CESCR:** stressing the importance of "participation in political decisions relating to the right to health taken at both the community and national levels." [CESCR GC 14, para. 17]. **CERD:** expressing concern that a lack of identification documents effectively deprive the Roma in the **Ukraine** of their right to equal access to health care, housing, social security, education, and the legal system. [CERD/C/UKR/CO, August 2006, para. 11]. **CERD:** indicating that the Roma Council in **Bosnia** does not have sufficient funding or resources to fulfill its mandate and is rarely consulted by the Council of Ministers. [CERD/C/BIH/CO/6 (CERD, 2006), para. 14]. **CERD:** noting the cultural, social, economic, and political exclusion of San peoples in **Botswana**. [A/57/18(SUPP) (CERD, 2001), para. 301]. **CEDAW Committee:** calling for the immediate issuance of identity documents to Roma women in **Romania**.[CEDAW/C/ROM/CO/6 (CEDAW 2006) para. 27].

Table 4: Minority health and the right to participate in public life, **continued**

Human Rights Standards	Precedents and Interpretations
FCNM 15 The Parties shall create the conditions necessary for the effective participation of persons belonging to national minorities in cultural, social and economic life and in public affairs, in particular those affecting them. **African Women's Protocol 9(1)** States Parties shall take specific positive action to promote participative governance and the equal participation of women in the political life of their countries. ***See also:*** • **CEDAW** 14(2)(a) (right of rural women to participate in development planning) • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 9(1): "States Parties shall take specific positive action to promote participative governance and the equal participation of women in the political life of their countries." • European Convention on Citizenship and the Convention Relating to the Status of Stateless Persons	**CRC Committee:** noting that Roma children in **Bosnia** are often not registered due to the parents' lack of identification documents. [CRC/C/15/Add.260 (CRC, 2005), para. 32]. **SR Indigenous:** highlighting that the San are not sufficiently empowered to impact government decisions regarding allocation of limited resources in **South Africa**. [E/CN.4/2006/78/Add.2 (SR Indigenous, 2005), para. 75]. **AC:** noting the "weak and ineffective participation by the Roma community" in design and implementation of health strategies in **Romania**. [ACFC/OP/II(2005)007, Nov 2005, para. 54].

Table 5: Minority health and the right to bodily integrity

Examples of Human Rights Violations
• Roma children are disproportionately targeted by police officers and subjected to ill-treatment and abuse. • Roma women are coercively sterilized without their fully informed consent. • Roma and San women and children are frequent victims of domestic violence due to extreme living conditions such as land dispossession, community isolation, high unemployment, poverty, and alcohol abuse. • Due to discriminatory attitudes, police are especially reluctant to interfere when Roma women are victims of domestic violence.

Human Rights Standards	Precedents and Interpretations
ICERD 5 State Parties undertake to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of . . . **(b)** [t]he right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **FCNM 6(1)** The parties undertake to take appropriate measure to protect persons who may be subject to threats or acts of discrimination, hostility or violence as a result of their ethnic, cultural, linguistic or religious identity. *Note:* The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, or European conventions, but has been interpreted to be part of the right to security of the person (ICCPR 9, ECHR 5), the right to freedom from torture and cruel, inhuman, and degrading treatment (ICCPR 7, ECHR 3), and the right to the highest attainable standard of health (ICESCR 12, ESC 11). The CESCR remarked that a "major goal" under the right to health should be "protecting women from domestic violence." [CESCR GC 14, para. 21]. Although CEDAW does not specifically address bodily integrity, the CEDAW Committee indicated that the "definition of discrimination includes gender-based violence." [CEDAW Committee, General Rec. 19, paras 6-7].	**CESCR:** noting police violence against the Roma in **Greece**, including sweeping arrests and arbitrary raids of Roma settlements. [E/C.12/1/ADD.97 (CESCR, 2004), para. 11]. **CERD:** remarking on police brutality against the Roma in the **Ukraine**, including arbitrary arrests and illegal detention. [A/56/18(SUPP) (CERD, 2001), para. 373]. **CERD:** noting that Roma members, especially the young, in **Albania** are subjected to ill-treatment and improper use of force by police officers. [CERD/C/63/CO/1 (CERD, 2003), para. 18]. **CERD:** recommending that **Slovakia** take all necessary measures to end forced sterilization, including the adoption of a new health care law, and ensure victims just and effective remedies. [CERD/C/65/CO/7, 10 December 2004]. **CEDAW Committee:** noting the continuing gender-based discrimination and violence that Roma women face in their own communities in **Sweden**. [A/56/38(SUPP) (CEDAW, 2000), para. 356]. **CEDAW Committee:** calling upon the **Czech Republic** to provide redress to Roma women victimized by coercive sterilization and to prevent further involuntary sterilizations. [CEDAW/C/CZE/CO/3 (CEDAW, 2006), para. 24]. **CEDAW Committee:** decision calling for compensation to a victim of coerced sterilization in **Hungary** and a review of legislation to ensure informed consent for sterilization. [12 February 2004].

Table 5: Minority health and the right to bodily integrity, **continued**

Human Rights Standards	Precedents and Interpretations
See also: • CRC 19(1) (protecting the child from all forms of physical or mental violence) • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1): "Every woman shall be entitled to respect for her life and the integrity and security of her person." • European Convention on Human Rights and Biomedicine, art 5: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it."	**CRC Committee:** observing continued allegations of ill-treatment and torture by the police of Roma children in the **Ukraine** and urging investigation. [CRC/C/15/ADD.191 (CRC, 2002), para. 36]. **AC:** pointing to cases of abusive behavior, hostile attitudes, and violence by police against Roma members in **Romania**. [ACFC/OP/II(2005)007, November 2005].

What are some examples of effective human rights programming in the area of minority health, in particular the Roma and San communities?

Introduction

In this section, you are presented with **four examples** of effective activities addressing health and human rights in minority communities. These are:

1. Justice for Roma women coercively sterilized in central Europe
2. A shadow report on women's double discrimination in **Serbia**
3. San health care through rights protection and community participation in **Namibia**
4. Health and human rights nexus: mediators and monitors in **Romania**

Rights based programming

As you review each activity, as yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include participation by affected communities, civil society, marginalized groups, and others? Is it situated in close proximity to its intended beneficiaries?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, and prisoners?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?

Finally, ask yourself whether the activity might be replicated in your country:

- Does such an activity **already exist** in your country?
- If not, should it be **created**? If so, does it need to be **expanded**?
- What **steps** need to be taken to replicate this activity?
- What **barriers** need to be overcome to ensure its successful replication?

Example 1: Justice for Roma women coercively sterilized in Central Europe

The European Roma Rights Centre, a Roma NGO, and a Roma victim advocacy group worked together on a litigation and advocacy campaign to secure public recognition and compensation for harms suffered by coercively sterilized Roma women.

Project type

Ombudsman compliant; Litigation; CEDAW Committee advocacy

Health and human rights issue

From the 1970s until 1990, the Czechoslovak government sterilised Roma women programmatically aiming to reduce the "high, unhealthy" birth rate of Roma women. Coercive sterilization has been documented as late as 2004. Cases have also occurred in Hungary, Romania, and Slovakia. Hundreds of Roma women await justice.

Actions taken

- In 2004, The European Roma Rights Center (ERRC), and Life Together, a Roma-Czech NGO, documented cases of coercive sterilization and filed complaints with the Ombudsman—the Czech Public Defender of Rights.
- In 2005, Roma women established a Czech victim advocacy group, the Group of Women Harmed by Sterilisation (GWHS), to push the government and medical authorities for a formal apology and to establish a compensation fund.
- GWHS used demonstrations and awareness campaigns, and in 2006, a member testified before the CEDAW Committee.
- In 2004, ERRC helped file a complaint with the CEDAW Committee on behalf of a Hungarian Roma woman, coercively sterilized when she sought treatment for a miscarriage.

Results and lessons learned

- In 2005, the Ombudsman undertook an investigation and published a report recognizing coercive sterilization and racial targeting in the Czech medical community. The report recommended changes in domestic law to ensure informed consent and the simplification of compensation procedures.
- The Ombudsman also filed 54 criminal complaints with the local prosecuting office, but many have been dismissed.
- The 2006 CEDAW report to the Czech government expressed concern over cases of coercive sterilization and recommended the adoption of legislative changes to ensure informed consent and victim compensation.
- In 2006, the CEDAW Committee found Hungary in violation and likewise called for informed consent and compensation legislation.
- International treaties and standards were critical to the litigation to complement the scant domestic laws relevant to patients' rights.
- Patients whose rights have been violated are the best advocates for change. Collaborations between legal service providers, patient advocates, and Roma activists brought attention to the matter and helped address larger issues.

Contact
European Roma Rights Centre
Naphegy ter 8, 1016 Budapest, Hungary
Tel: (36 1) 41 32 200
Email: office@errc.org
Web: www.errc.org

Life Together, 30. dubna 3, 70200
Moravaská Ostrava, Czech Republic
Tel: (420) 596-130-715

Example 2: A shadow report on Roma women's double discrimination in Serbia

The European Roma Rights Centre and six Serbian NGOs partnered to gather data on double discrimination faced by Roma women in Serbia. They submitted a shadow report to the UN CEDAW Committee, bringing attention to these issues and launching an advocacy campaign.

Project type

Human rights documentation; International advocacy

Health and human rights issue

Roma women living in Serbia face double discrimination as female members of an ethnic minority. This is a leading factor responsible for their significantly lower health status, as compared with the majority population. Roma and health activists have recognized domestic violence, access to health insurance, and discrimination in health care settings as major issues affecting Roma women's health. However, little data and documentation existed to bring these concerns to human rights monitors.

Actions taken

- In 2006-2007, six women from the European Roma Rights Centre (ERRC) and the Roma Serbian NGOs: Bibija, Eureka, and Women's Space undertook research to document abuses against Roma women.
- This NGO partnership then submitted a shadow report to the CEDAW Committee, which will be presented at Serbia's May 2007 review.

Results and lessons learned

- Less than half of the 198 women interviewed agreed to talk about domestic violence. Of the remaining 81 women, the majority experienced domestic violence. Issues particular to Roma women included police non-responsiveness or an inappropriate response due to discriminatory attitudes and criteria at safe-houses disproportionately excluding Roma women.
- Discrimination against Roma women is especially evident in most commonly used health services—in the areas of reproductive and maternal health and emergency care.
- Project partners hope to follow up on research findings with advocacy on the most pertinent and strategic issues.
- A partnership between an international human rights organization, well-versed in the CEDAW process, and local NGOs with an understanding of the community can be particularly effective.

Contact
European Roma Rights Centre
Naphegy ter 8, 1016 Budapest, Hungary
Tel: (36 1) 41 32 200
Email: office@errc.org
Web: www.errc.org

Example 3: San health care through rights protection and community participation in Namibia

Health Unlimited has worked in partnership with remote San communities and the Ministry of Health in Namibia to ensure the provision of basic health services through community education and participation in health care delivery.

Project type
A rights approach to the delivery of health services

Health and human rights issue
In recent years, the growing threat of HIV and AIDS is combining with TB and malaria to present a real threat to San survival. San access to basic health care is constrained by financial, geographic, and cultural barriers. Moreover, rural communities are low on governments' priority lists as services in remote areas are difficult and costly to provide. Where services are available, the San are often reluctant or afraid to use them due to staff discrimination and insensitivity.

Actions taken
- Health Unlimited (HU), an international NGO, is working in partnership with the San in Omaheke and Otjozondjupa ("Bushmanland") and the Namibian Ministry of Health to help ensure basic health services in these remote communities and access to state health care.
- The partnership established Namibia's first community based screening and treatment programmes for TB. Trained San volunteers help identify and treat patients in their villages, eliminating the need for treatment at clinics many miles away.
- The partnership also initiated a health training program for Community Based Resource Persons, or volunteers acting as a link between local health services and communities to facilitate communication and ensure needs are met.
- In 2006, the partnership started a project to improve San adolescent sexual and reproductive health in the remote Omaheke and Tsumkwe regions. Village health committee representatives, teachers, and peer counsellors will be trained to encourage discussions in the local community on adolescent health, STIs, and HIV and AIDS and to help reduce stigma and discrimination against those affected.

Results
- The community based screening and treatment program for TB has led to an over 80% cure rate.
- The Community Based Resource Persons were able to create a mutually supportive relationship in communities where before there was antagonism and mistrust.

Contact
Health Unlimited, Namibia
P.O. Box 1467
Gobabis
Tel: +264-62-56-3604
Fax: +264-62-56-4469
E-mail: general@healthunlimited.org
Web: www.healthunlimited.org

Example 4: Health and human rights nexus: mediators and monitors in Romania

Romani CRISS developed a program in Romania whereby health mediators helped improve communications between the Roma community and health providers and referred cases of abuse and discrimination in health facilities to human rights monitors for documentation and legal advocacy.

Project type
Human rights documentation and advocacy

Health and human rights issue
Roma are disproportionately excluded from accessing health care services and encounter prevalent discrimination by providers. In a 2005 survey among 717 Romanian Roma women, 70% reported discrimination from health providers based on their race/ethnicity. Particular problems faced by Roma women include coerced sterilization and separate maternity wards. There is no administrative mechanism to address these abuses against the Roma and other vulnerable groups.

Actions taken
- In the early 1990's, the Romanian human rights NGO, Romani CRISS, developed a health mediator program to facilitate Roma access to health care. Mediators are from Roma communities but situated in health clinics to improve communications with providers. They educate communities on how to access health services and sensitize doctors on Roma health needs.
- Romani CRISS also has a network of human rights monitors responsible for documenting cases of discrimination and violence against Roma.
- In 2007, Romani CRISS initiated a program to create a link between health mediators and the human rights monitors. Health mediators were trained in human rights and human rights monitors were trained in health issues. This way, the mediators knew to refer cases of discrimination or abuse to the monitors for documentation, and they could also sensitize communities on human rights issues. The monitors would then document cases of discrimination in health care settings and bring them for redress before the National Council to Combat Discrimination, the College of Physicians, and other institutions.

Results and lessons learned
- Currently, approximately 200 mediators work in 39 communities and 20 human rights monitors in 15 counties.
- The roles of health mediators and human rights monitors must be kept separate to maintain the independence of monitors and mediators' facilitating role with health service providers. This separation is particularly important as the Ministry of Health has funded many of the mediators since 2006.
- Legal advocacy work must be combined with an effective outreach and advocacy campaign targeted at policy makers and the public.

Contact
Romani CRISS - Roma Centre for Social Intervention and Studies
Phone 004 021 231 41 44
Fax 004 021 231 41 44
Web: www.romanicriss.org

What steps can government and key stakeholders take to improve the health status of minority populations?

The preceding case studies are concrete examples of projects using human rights mechanisms to improve access to health care and the health status of minority individuals and communities. The spectrum of barriers to health care for minority populations is broad, including discrimination in health care settings, a legacy of ineffective public policies, and geographic isolation. The table below presents some steps that governments and other key stakeholders can take immediately to begin to overcome these obstacles.

Ten steps for overcoming barriers to health care for minority populations:

Governments:

1. Appoint minority representatives to participate in the design, implementation, and evaluation of health programs and policies that affect their lives.
2. Ensure that policies and legislation address social factors that determine health and the needs of minorities. Interventions that aim to improve housing, for example, are critical to reducing TB infections.
3. Support the collection of ethnically disaggregated data and, based on this data, allocate resources to populations most in need of basic health services. Communities should be involved in the data collection and analysis process.
4. Train health care workers in communicating and working with minority and marginalized populations.
5. Establish an ombudsman office or other monitoring mechanism in health care systems to follow up reports of abuse or discrimination in health care settings.
6. Grant under- represented minority students incentives and assistance to enter health care professions.

Civil society, donors, researchers, media:

7. Civil society should become more familiar with instruments designed to protect and promote human rights, including the right to health for minorities.
8. Donors should invest in the institutional and capacity development of Roma leadership to engage effectively on policy issues affecting access to health and social services.
9. Academic, government, and other research communities should explore the inequities in access to health care for minorities and other marginalized populations.
10. Media should investigate and report systemic causes of the inequity in health status between minorities and the majority population in a balanced and fair manner.

Source: Open Society Institute Public Health Program. Left Out: Roma and Access to Health Care in Eastern Europe and South Eastern Europe, 2007.

Where can I find additional resources on health and human rights in Roma and San communities?

Resources

To further your understanding on the topic of health and human rights in minority communities, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations and resolutions
- European regional instruments
- Books
- Reports, key articles, and other documents
- Websites

Declarations and Resolutions: UN

- Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities
  Source: www.ohchr.org/english/law/minorities.htm
- Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief
  Source: www.unhchr.ch/html/menu3/b/d_intole.htm
- Declaration on Race and Racial Prejudice
  Source: www.ohchr.org/english/law/race.htm
- World Conference against Racism, 2001 - Durban Declaration and Programme of Action
  Source: www.unhchr.ch/html/racism/02-documents-cnt.html
- International Labour Organization conventions on labour standards and non-discrimination in employment
  Source: www.ilo.org/ilolex/english/convdisp1.htm
- Jakarta Declaration on Leading Health Promotion into the 21st Century (WHO)
  Source: www.who.int/hpr/NPH/docs/jakarta_declaration_en.pdf

European regional instruments

European Union

- European Commission Racial Equality Directive
  ec.europa.eu/employment_social/fundamental_rights/pdf/legisln/2000_43_en.pdf

- European Commission Employment Framework Directive
  Source:
  ec.europa.eu/employment_social/fundamental_rights/pdf/legisln/2000_78_en.pdf

- European Commission website on action against discrimination
  Source:
  ec.europa.eu/employment_social/fundamental_rights/legis/lgdirect_en.htm

- The Charter of Fundamental Rights of the European Union
  Source: www.europarl.europa.eu/charter/default_en.htm

Council of Europe treaties and recommendations

- Council of Europe's treaties
  conventions.coe.int/Treaty/Commun/ListeTraites.asp?CM=8&CL=ENG

- Convention for the Protection of Human Rights and Fundamental Freedoms
  conventions.coe.int/Treaty/en/Treaties/Html/005.htm

- European Charter for Regional or Minority Languages
  conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=148&CL=ENG

- European Social Charter and Revised Social Charter
  conventions.coe.int/treaty/en/Treaties/Html/163.htm

- Framework Convention for the Protection of National Minorities
  conventions.coe.int/treaty/en/Treaties/Html/157.htm

- Oviedo Convention on Human Rights and Biomedicine (Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine)
  www.coe.int/t/e/legal_affairs/legal_co-operation/bioethics/Texts_and_documents/1Treaties_COE.asp

- Recommendation (2006)10 of the Committee of Ministers to member states on better access to health care for Roma and Travellers in Europe
  www.coe.int/t/dg3/romatravellers/documentation/recommendations/CMRec(2006)10accesshealth_en.asp

- Recommendation (2001)17 on improving the economic and employment situation of Roma/Gypsies and Travellers in Europe
  www.coe.int/T/DG3/RomaTravellers/documentation/recommendations/recemployment200117_en.asp

- Recommendation (2000)4 of the Committee of Ministers to member states on the education of Roma/Gypsy children in Europe
  www.coe.int/T/DG3/RomaTravellers/documentation/recommendations/receducation20004_en.asp

- Recommendation (2005)4 of the Committee of Ministers to member states on improving the housing conditions of Roma and Travellers in Europe www.coe.int/T/DG3/RomaTravellers/documentation/recommendations/rechousing20054_en.asp

Other relevant commitments

- Decade of Roma Inclusion (2005-2015) and the National Action Plans for Health.
  www.romadecade.com

- Guiding Principles for Improving the Situation of Roma in Candidate Countries
  www.coe.int/t/dg3/romatravellers/documentation/recommendations/MiscCOCENguidelineseu_en.asp

- Millennium Development Goals
  www.un.org/millenniumgoals/

Books

General

- Hills, LeGrand and Piachaud. *Understanding Social Exclusion*. Oxford: Oxford University Press, 2002.

Roma

- Crowe, D. and J. Kolsti (eds) *The Gypsies of Eastern Europe*. ME Sharpe INC., 1991.

- Crowe, D. M. *A History of the Gypsies of Eastern Europe and Russia*. New York: St. Martin's Griffin, 1996.

- Finnish National Board of Education. *The Roma and Health Services: A Guide for Healthcare Professionals*. Helsinki: National Board of Education, 2000.

- Liegeois, J-P. and N. Gheorghe. *Roma/Gypsies: A European Minority*. London: Minority Rights Group, 1995.

- Majtényi, B. and B. Vizi (eds). *A Minority in Europe: Selected International Documents regarding the Roma*. Budapest, Gondolat-RIENM, 2006.

- McDonald, C., Kovács, J. and Cs. Fényes. *The Roma Education Resource Book*. Open Society Institute, 2001.

- Stewart, M. The Time of the Gypsies: *Studies in the Ethnographic Imagination*. Boulder, Colorado: Westview Press, 1997.

- Zamfir, C. and M. Preda (eds) *Roma in Romania*. Bucharest; Expert Publishing House, 2002.

- Zoon, I. On the Margins: Roma and Public Services in Romania, Bulgaria, and Macedonia. Open Society Institute, 2001.

San

- Anaya, J. *Indigenous Peoples in International Law*, Oxford University Press, 1996.
- Hohmann, T. *San and the State: An Introduction in San and the State. Contesting land, development identity and representation*. Rüdiger Köppe Verlag Köln (ASCL 33846), 2003.
- Lee, Richard F. The !Kung San: Men, Women and Work in a Foraging Society, Cambridge University Press, Cambridge, 1979.
- Leffers, Arno. *Gemsbok Bean and Kalahari Truffle: Traditional Plant Use by Ju/'hoansi in North-Eastern Namibia*, Gamsberg Macmillan, Windhoek, 2003.
- Malan, J.S. *The Peoples of Namibia*. Rhino Publishers, 1995.
- Marshall, L. *The !Kung of Nyae Nyae*. Harvard University Press, Cambridge Mass., 1976.
- McNeil, Kent. *Common Law Aboriginal Title*. Oxford University Press 1989.
- Mendelsohn, John. *Selma el Obeid and Carole Roberts, A Profile of North Central Namibia*. Gamsberg Macmillan, Windhoek, 2000.
- Mendelsohn, John and el Obeid, Selma. *The Communal Lands in Eastern Namibia*. Namibian Nature Foundation Windhoek, 2002.
- Mendelsohn, John et al. *Atlas of Namibia*. David Philip, Cape Town, 2002.
- Shostak, M. *Nisa: the Life and Words of a !Kung Woman*. Cambridge, MA: Harvard University Press, 1981.
- Widlock, Thomas. *Living on Mangetti: Bushman Autonomy and Namibian Independence*. Oxford University Press, 1999.

Reports, key articles, and other documents

General

- European Commission Directorate General of Employment and Social Affairs. *Equality and non-discrimination in an Enlarged European Union*. Green Paper. Brussels, 2005.
  Source: europa.eu/scadplus/leg/en/lvb/l14157.htm
- European Commission. *Joint Report by the Commission and the Council on Social Exclusion*. Brussels, 2004.
- Institute of Medicine of the National Academies. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington DC, 2001.
  Source: www.iom.edu/?id=4475&redirect=0

- Whitehead, Margaret *The concepts and principles of equity and health.* WHO/EURO, Copenhagen, 1991.

Roma

- Antic. *Roma and the Right to Health Care in Serbia.* Minority Rights Center, Belgrade, 2005.

- Bodewig, C. and A. Sethi. *Poverty, Social Exclusion and Ethnicity in Serbia and Montenegro: The Case of the Roma.* World Bank, 2005.

- Council of Europe. *Breaking the Barriers: Romani Women and Access to Public Health Care.* Office for Official Publications of European Communities: Luxembourg, 2003.

- Delphio Consulting. *Cigányok Magyarországon – szociális-gazdasági helyzet, egészségi állapot, szociális és egészségügyi szolgáltatásokhoz való hozzáférés.* (Roma in Hungary: Social-economic condition, health status and acccess to health services) Budapest 2004.
  Source: www.delphoi.hu/download-pdf/roma-szoc-eu.pdf

- European Centre for Minority Issues. *Roma on Integration: Analysis and Recommendations.* ECMI Monograph No. 3, 2005.

- European Centre on Health and Societies in Transition, LSHTM & Department of Social Medicine and Health Care, Masaryk University. *Health Needs of the Roma Populations in the Czech and Slovak Republics: a Literature Review.* World Bank.
  Source: www.lshtm.ac.uk/ecohost/roma.pdf

- European Commission against Racism and Intolerance. *Third Report on Bulgaria. Situation of the Roma Community in Bulgaria.* Strasbourg, 2003.
  Source: www.macedonianhr.org.au/ECRI_Bulgaria_Report3.pdf

- European Commission, Directorate General for Employment and Social Affairs. *The Situation for Roma in an Enlarged European Union.* Brussels, 2005.

- European Roma Rights Centre. *Ambulance not on the way: the Disgrace of Health Care for Roma in Europe.* Open Society Institute, 2006.

- Fundacion Secretariado General Gitano y Ministerio de Sanidad y Consumo. *Health and the Roma Community: Analysis of Action Proposals.* Ministry of Health and Consumer Affairs, Madrid, 2005.
  Source: www.msc.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/docs/Health_and_the_Roma_Community.pdf

- Kostadinova, G. *Substantive Equality, Positive Action and Roma Rights in the European Union.* Minority Rights Group International, London, 2006.
  Source: www.minorityrights.org/admin/Download/pdf/MRG_RomaBriefing2006.pdf

- Open Society Institute Public Health Program. *Mediating Romani Health: Policy and Program Opportunities.* Open Society Institute, 2005.
- Resource Center for Roma Communities and Open Society Institute EU Monitoring and Advocacy Program and Roma Participation Program. *Monitoring the Local implementation for the Government Strategy for the Improvement of the Condition of Roma.* Open Society Institute, 2004.
- Ringold, D., Orenstein, MA, and E. Wilkens. *Roma in an Expanding Europe: Breaking the Poverty Cycle.* Washington DC: World Bank, 2006.
- Rorke, B. and A. Wilkens (eds). *Roma Inclusion: Lessons Learned from OSI's Roma Programming.* Open Society Institute, 2006.
- Schaaf, M. *Confronting a Hidden Disease: TB in Roma Communities.* Open Society Institute, 2007.
- Surdu, L. and M. Surdu. *Broadening the Agenda: The Status of Romani Women in Romania.* Open Society Institute, 2006.
- UNDP-Romanian Country Office. *Social Assessment of Roma and HIV/AIDS in Central East Europe.* Bucharest, 2003.
- UNICEF. *Breaking the Cycle of Exclusion: Roma Children in South East Europe.* Belgrade, February 2007.
  Source: www.unicef.org/ceecis/070305-Subregional_Study_Roma_Children.pdf
- United Nations Development Program. *Avoiding the Dependency Trap: the Roma Human Development Report.* 2003.
  Source: www.romanothan.ro/engleza/reports/docs/Avoiding%20theDependency%20Trap.pdf

San

- Becker, H. The Least Sexist Society? Perspectives on Gender, Change and Violence among southern African San. *Journal of Southern African Studies* 29(1): 5–23, 2003.
- Bennett, T.W. and Powell, C.H. Aboriginal Title in South Africa Revisited, *South African Journal of Human Rights*, Vol. 15, p. 449, 1999.
- Bishop, Kristyna. Squatters in their Own Land: San Territoriality in Western Botswana, Comparative and International Law Journal of Southern Africa, Vol. 31, pp. 96-97, 1998.
- Boden, Gertrud. Caught in the Middle: Impacts of State Decisions and Armed Conflicts on Khwe Economy and Society in West Caprivi between 1998 and 2002, in Thekla Hohmann, *San and the State: Contesting Land, Development, Identity and Representation*, Rudiger Koppe Verlag, Köln, pp. 161-204, at 171-175, 2003.

- Brenzinger, Matthias. Moving to Survive: Kxoe Communities in Arid Lands, Working Paper No. 2, Khoisan Forum, University of Cologne, Germany, 1997.
- Chan, T.M. The Richtersveld Challenge: South African Finally Adopts Aboriginal Title, in Robert Hitchcock and Diana Vinding, *Indigenous Peoples' Rights in Southern Africa*, International Work Group for Indigenous Affairs, Copenhagen, pp. 114-133, at 121, 2004.
- Communal Land Holders: Resolving the Inconsistency Between Article 16, Article 100 and Schedule 5", *South African Journal on Human Rights*, Vol. 12 (1996), p. 467.
- Curry, James. The Promise and Performance of Community Conservation. Oxford, 2001, pp.38-58.
- Dieckmann, Ute. Hai//om: Between the "Bushman Problem" and San Activism, Colonial Imaginations and Postcolonial Appropriations of Ethnicity in Namibia, PhD dissertation, University of Cologne, 2005.
- Felton, S. and Becker, H. A Gender Perspective of the status of the San in Southern Africa. Regional assessment of the status of the San in Southern Africa. Report series no 5 of 5. Legal Assistance Centre, Windhoek, 2001.
- Geingos, V. and Brörmann, M. *San, Land Rights and Development: Can San survive without land?* Working Group of Indigenous Minorities in Southern Africa (WIMSA) Namibia. Paper submitted at Indigenous Rights in the Commonwealth Project Africa Regional Expert Meeting. Indigenous People of Africa Coordinating Committee (IPACC) South Africa, Cape Town, South Africa October 2002.
- Gordon, Robert. Can Namibian San Stop Dispossession of their Land, in Edwin N. Wilmsen, *We Are Here: Politics of Aboriginal Land Tenure*, Berkeley: University of California Press, pp. 138-154, 153, 1989.
- Gordon, Robert. The Bushman Myth: The Making of a Namibian Underclass, Westview, 1992.
- Griffin, Graham. Welcome to Aboriginal Land: Anangu Ownership and Management of Ulura-Kata National Park, in Dawn Chatty and Marcus Colchester, *Conservation and Mobile Indigenous Peoples: Displacement, Forced Settlement and Sustained Development*, Berghahn Books, New York, 2002, pp. 362-376.
- Harring, Sidney L. Indigenous Land Rights and Land Reform in Namibia, in Robert Hitchcock and Diana Vinding, Indigenous Peoples' Rights in Southern Africa, International Working Group for Indigenous Rights, Copenhagen, 2004, pp. 63-81.

- Harring, Sidney L., and Odendaal, Willem. One Day We Will Be Equal: A Socio-Legal Perspective on the Namibian Land Reform and Resettlement Process, Legal Assistance Centre, Windhoek, 2002.

- Harring, Sidney L. and Odendaal, Willem. Our land they took: San land rights under threat in Namibia. Legal Assistance Centre, Windhoek, 2006

- Health Unlimited. Baseline assessment for two Health Unlimited project areas in eastern and north Namibia. Knowledge, Intention to act and behavior review. (Unpublished), 2003.

- Health Unlimited. Follow-up assessment for two Health Unlimited Project areas in Eastern and North Namibia. Knowledge, Intention to act and behaviour review. (Unpublished), 2004.

- Health Unlimited. Namibia Community Health Programme (NCHP). Tsumkwe Project. Evaluation of TB interventions in the period 1995-2003. (Unpublished), 2004.

- Hitchcock, Robert J. Communities and Consensus: An Evaluation of the Activities of the Nyae Nyae Farmers Cooperative and the Nyae Nyae Development Foundation in Northeastern Namibia, report to the Ford Foundation and the Nyae Nyae Development Foundation of Namibia, 1992.

- Hitchcock, R.K. and Draper, P. Health Issues Among the San of Western Botswana, 2003.
  Source: www.kalaharipeoples.org/documents/San-heal.htm

- Jones, Brian and Murphree, Marshall. The Evolution of Policy on Community Conservation in Namibia and Zimbabwe, in David Hulme and Marshall Murphree, *African Wildlife and Livelihoods*.

- Koot, Stasja P. Resettlement in Tsintsabis: Namibian Bushmen in a Changing World, thesis,University of Utrecht, 2000.

- Lee, R.B. & Susser, I. The San of Southern Africa: A Status Report. American Anthropology Association. Appendix 1. AIDS and the San: How Badly Are They Affected? 2003.
  Source: www.aaanet.org/committees/cfhr/san.htm

- Ministry of Lands, Resettlement and Rehabilitation (MLRR), The National Resettlement Policy,MLRR, Windhoek, 2001.

- Ministry of Lands, Resettlement and Rehabilitation, The National Land Use Policy, Windhoek, 2002.

- Molamu, J and Manyeneng, W.G. Alcohol use and Abuse in Botswana. Health Education Unit, Government of Botswana: Gaborone in Gujadhur, T (2000) Alcohol Abuse Intervention Strategies for Rural (Bushmen) Settlements Embarking on CBNRM. IUCN/SNV CBNRM Support Programme, Botswana, 1998.
  Source: www.cbnrm.net/pdf/gujadhur_t_001_alcoholabuse.pdf

- National Association of CBNRM Support Organisations (NACSO), Namibia's Communal Conservancies: A Review of Progress and Challenges, 2004.

- National Native Alcohol and Drug Abuse program. Unknown. Literature Review: Evaluation Strategies in Aboriginal Substance Abuse Programs: A Discussion. NNADAP Canada in Gujadhur, T. Alcohol Abuse Intervention Strategies for Rural (Bushmen) Settlements Embarking on CBNRM. IUCN/SNV CBNRM Support Programme, Botswana, 2000.

- National Society for Human Rights, The Rights of Indigenous Peoples: The Kxoe People of Namibia, Windhoek, 1996.

- Odendaal, Willem. Our Land We Farm, Land, Environment and Development Project of the Legal Assistance Centre, Windhoek, 2005.

- Ohenjo, N.O., Willis, R., Jackson, D., Nettleton, C., Good, K., Mugarua, B. Indigenous health in Africa. *Lancet* 2006: 367:1937-46, 2006. Source: www.thelancet.com

- Orth, Ina. Identity as Dissociation: The Khwe's Struggle for Land in West Caprivi", in Thekla Hohmann, San and the State: Contesting Land, Development, Identity and Representation, Rudiger Koppe Verlag, Köln, pp. 124-127, 2003.

- Otjozondjupa Communal Land Board, Annual Report 2004, Ministry of Lands, Resettlement and Rehabilitation, Windhoek.Richard Pakleppa, "Report on Investigations of Controversial Land Allocations in Tsumkwe District West, Namibia, between June 16 and July 4, 2002", Working Group of Indigenous Minorities in Southern Africa (WIMSA), Windhoek, 2002.

- Patemann, Helgard. Traditional Authorities in Process: Tradition, Colonial Distortion, and Reappropriation within the Secural, Democratic and Unitary State of Namibia, Centre for Applied Social Sciences (CASS), Windhoek, 2002.

- Robins, Steven, Madzudzo, Elias and Brenzinger, Matthias. An Assessment of the Status of the San in South Africa, Angola, Zambia and Zimbabwe, Legal Assistance Centre, Windhoek, 2001.

- Robins, Steven. NGOs, Bushmen and Double Vision: The ‡Khomani San Land Claim and the Cultural Politics of Community and Development in the Kalahari, in Thekla Hohmann, San and the State: Contesting Land, Development, Identity and Representation, Rudiger Koppe Verlag,Köln, 2003.

- Rousset, Karine. To be Khwe Means to Suffer: Local Dynamics, Imbalances and Contestations in the Caprivi Game Park, unpublished MA thesis, Department of Social Anthropology, University of Cape Town, March 2003.

- Stephens, C., Porter, J., Nettleton, C. and Willis, R. Disappearing, displaced, and undervalued: a call to action for Indigenous health worldwide. *Lancet* 2006; 367: 2019-28, 2006.
  Source: www.thelancet.com

- Suzman, James. An Assessment of the Status of the San in Namibia, Legal Assistance Centre,Windhoek, 2001.

- Suzman, James. Etosha Dreams: An Historical Account of the Hai//om Predicament, Journal of Modern African Studies, Vol. 42, No. 2, p. 221, 2004.

- Suzman, J. Minorities in Independent Namibia, Minority Rights Group International, 2002.
  Source: www.minorityrights.org/admin/Download/pdf/NamibiaReport.pdf

- Suzman, J. An assessment of the status of the San in Namibia. Regional assessment of the status of the San in Southern Africa. Report series 4 of 5. Legal Assistance Centre, Windhoek, 2001.

- Taylor, J. Short-term indigenous population mobility and service delivery. Centre for Aboriginal Economic Policy Research Discussion Paper 118, 1997.
  Source: www.anu.edu.au/caepr/briefs/brief13.php

- United Nations development programme. Country Fact Sheets, Namibia. The Human Development Index – going beyond income, 2005.
  Source: hdr.undp.org/statistics/data/country_fact_sheets/cty_fs_NAM.html

- Widlock, Thomas and Widlock, Dagman. The Hai//om of eastern Ovamboland and the Lands Issue, report on the national conference on the future land policy of Namibia, Windhoek, 25 June to 1 July 1991.

- Widlock, Thomas. Problems of Land Rights and Land Use in Namibia: A Case Study from the Mangetti Area, University of Namibia, Social Sciences Division, SSD Discussion Paper No. 5, March, 1994.

- Widlock, Thomas. The Needy, the Greedy and the State: Dividing the Hai//om Land in the Oshikoto Region, in Thekla Hohmann, San and the State: Contesting Land, Development, Identity and Representation, Rudiger Koppe Verlag, Köln, pp. 87-119 2003.

- Wiesnner, P. Risk, reciprocity and social influences on !Kung San economies, In *Politics and history in Band Societies*. Eleanor Leacock and Richard Lee, eds. Cambridge University Press, Cambridge. PP. 61-84, 1982.

- Wiesnner, P. Owners of the Future? Calories, Cash, Casualties and Self-Sufficiency in the Nyae Nyae Area between 1996 and 2003. *Visual Anthropology Review*. Vol 19, Issue 1-2, pages 149-159, 2003.

- Wiesnner, P. Project Proposal: The World Bank Grant Facility for Indigenous Peoples. Water, Food, and Stability In The Nyae Nyae Area: Preserving The Social Fabric, 2004.

- Williams, Frieda-Nela. Pre-Colonial Communities of Southwestern Africa: A History of Owambo Kingdoms, 1600-1920, National Archives of Namibia, pp. 51-93, 1991.

- World Wildlife Fund, Report on Mbukushu Migration to Kxoe Use Areas to the East of the Okavango River, June 1997.

Websites

General

- Center for Disease Control's Office of Minority Health

  The goal of the Center is to promote health and quality of life by preventing and controlling the disproportionate burden of disease, injury and disability among racial and ethnic minority populations.
  www.cdc.gov/omh

- European Center for Minority Issues

  The Center is an interdisciplinary institution with main activities including practice-oriented research, information, documentation and advisory services on minority-majority relations in Europe.
  www.ecmi.de

- International Society for Equity in Health (ISEqH)

  The ISEqH promotes equity in health and health services internationally through education, research, publication, communication, and charitable support.
  www.iseqh.org

- Organization for Security and Cooperation in Europe (OSCE)

  OSCE is the largest regional security organization in the world with 55 participating states from Europe, Central Asia, and North America. It works in early warning, conflict prevention, crisis management, and post-conflict rehabilitation.
  www.osce.org/index.php

- Project on Ethnic Relations

  The Project is dedicated to preventing ethnic conflict in Central and Eastern Europe, the Balkans, and the former Soviet Union.
  www.per-usa.org/per.html

- The European Union Agency for Fundamental Rights

  The Agency is a body of the European Union built upon the former European Monitoring Centre on Racism and Xenophobia (EUMC). Its main objective is to provide assistance and expertise related to fundamental rights

to institutions and authorities of the European Community and its Member States when implementing Community law.
eumc.europa.eu/eumc/index.php

Roma

- Council of Europe's Roma and Travellers Division

  The Division works on bringing about a long-term improvement in the situation of Roma and Travellers by encouraging member states to adopt a comprehensive approach in fighting racism, intolerance and social exclusion.
  www.coe.int/T/DG3/RomaTravellers/Default_en.asp

- Decade of Roma Inclusion

  The Decade of Roma Inclusion 2005–2015 is a political commitment by governments in Central and Southeastern Europe to combat Roma poverty, exclusion, and discrimination within a regional framework. The Decade is an international initiative that brings together governments, intergovernmental and nongovernmental organizations, as well as Romani civil society to accelerate progress toward improving the welfare of Roma and to review such progress in a transparent and quantifiable way. Each country has agreed to implement Health Action Plans which include indicators.
  www.romadecade.org

- Dosta

  Dosta, a Romani word meaning "enough", is an awareness raising campaign which aims at bringing non-Roma closer to Roma citizens.
  www.dosta.org/

- European Roma Information Office (ERIO)

  ERIO is an international advocacy organization promoting political and public discussion on Roma issues by serving as a policy information resource office for European Union institutions, Roma civil organizations, governmental authorities and intergovernmental bodies.
  www.erionet.org

- European Roma Rights Center

  The center is an international public interest law organization that monitors the human rights situation of Roma and provides legal defense in cases of human rights abuse.
  www.errc.org

- Fundacion Secretariado General Gitano

  The Foundation is a non-profit intercultural social organization that promotes the development of Roma communities in Spain and on the European level. FSGG has implemented and reported on a number of health programs and issues.
  www.fsgg.org

- OSI's Roma Initiatives Office (RIO)

  RIO works to guide and coordinate all aspects of OSI network programming and grant-making activity related to Roma beneficiaries, including work undertaken by other OSI initiatives and Soros foundations.

www.soros.org/initiatives/roma

- OSI's Roma Participation Program (RPP)

  RPP is an OSI grants program that supports Roma activists in Central and Eastern Europe to take charge of their lives, to participate in decisions that affect them, and to advocate for their rights as equal citizens of their own countries.
  www.soros.org/initiatives/roma/focus/rpp

- Romani CRISS - Roma Center for Social Intervention and Studies

  Romani CRISS is an NGO promoting the rights of the Roma communities in Romania by means of conflict resolution, mediation, litigation, legal aid, and advocacy. Its aim is to combat and prevent racial discrimination against Roma in all areas of public life, including health, education, employment, and housing.
  www.romanicriss.org

- The League of the Decade in Serbia

  The League is a coalition of Roma and non-Roma NGOs advocating for efficient implementation of a National Action Plan for Health by the Serbian Government for the Decade of Roma Inclusion (2005 – 2015). The League works closely with the Serbian Ministry of Health for monitoring allocation of resources to promote Roma health based on civil society research and input.
  www.romadecade.com/index.php?option=com_content&task=view&id=167&Itemid=85

- World Bank site for Roma

  The involvement of the World Bank in Roma issues stems from its agenda of economic and social development in Central and Eastern Europe. The World Bank addresses the challenges faced by Roma in its efforts to promote the process of building cohesive and inclusive societies in the region. The World Bank published the resource "Roma in an Expanding Europe – Breaking the Poverty Cycle."
  web.worldbank.org/WBSITE/EXTERNAL/COUNTRIES/ECAEXT/EXTROMA/0,,contentMDK:20333806~menuPK:615999~pagePK:64168445~piPK:64168309~theSitePK:615987,00.html

San

- Health Unlimited
  www.healthunlimited.org

- Indigenous peoples of Africa coordination committee. Who are Indigenous Peoples?
  www.ipacc.org.za/eng/who.asp

- International working group on indigenous affairs.
  www.iwgia.org

- Legal Assistance Centre

www.lac.org.na

- Survival International
  www.survival-international.org

- United nations on permanent forum on indigenous issues, Fact sheet 1. *Who are indigenous peoples?*
  www.un.org/esa/socdev/unpfii/en/session_fifth.html

- Working Group of Indigenous Minorities in Southern Africa
  www.wimsanet.org

What are key terms related to Roma and San health and human rights?

Glossary

A variety of terms is used in Roma and San health and human rights work.

C

Civil rights
Rights individuals have in their role as citizens in relation to the state.

Collective rights
Rights associated with a community or people.

D

Direct racial discrimination
Any distinction, exclusion, restriction, or preference based on race, color, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment, or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural, or any other field of public life (ICERD).

F

Forcible assimilation
Policies which seek to forcibly incorporate a minority group into the majority population by erasing any distinctiveness in culture, religion, language, or practices.

G

Gender equity
Equality in social roles and opportunities available to women and men.

H

Health equity
Concern with reducing unequal opportunities for health associated with membership in a less privileged social group, such as an ethnic minority.

Health inequality
Systematic and potentially remediable differences in one or more aspects of health across populations or population groups defined socially, economically, demographically, or geographically.

I

Indigenous people
People descended from populations which inhabited the country at the time of conquest or colonization, or the establishment of present state boundaries, and who retain some or all of their social, economic, and political institutions (ILO).

This term is somewhat problematic in the African context, where many countries define it exclusively against European colonialism and in reference to the majority Bantu population, rather than just for Khoesan populations like the San.

Indirect discrimination
An apparently neutral practice or criterion, which nonetheless places a group at social disadvantage based on group characteristics.

M

Minority
Groups with unequal power compared with the dominant majority and which may need protection from that majority (Minority Rights Group International). Minorities are defined by number (smaller than the majority population), non-dominance, and differences in ethnicity, culture, religion, or language.

Minority rights
A rights-based approach stressing the importance of cultural preservation as a means of improving the condition of minority groups. This embodies two separate concepts: first, normal individual rights as applied to members of racial, ethnic, class, religious, linguistic, or sexual minorities, and second, collective rights accorded to minority groups.

S

Self identification
Determination of belonging to a minority group made by the individuals themselves.

Social determinants of health
The broad range of factors that contribute to a person's health including nutrition, housing, education, availability of social services, income, etc.

Social exclusion
The prevention of people from participating fully in economic, social, and civil life and/or when their access to income and other resources (personal, family, social, and cultural) is so inadequate as to exclude them from enjoying a standard of living and quality of life regarded acceptable by the society in which they live.

Social integration
Policies which seek to integrate a minority without coercion into the majority society, while ensuring the protection of individual rights.

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains International Centre for Human Rights Education

Photo courtesy of Susan Shelley

Chapter 7 Mental Health and Human Rights

"Deriving from the right to health and other human rights, the right to community integration has general application to all persons with mental disabilities. Community integration better supports their dignity, autonomy, equality, and participation in society. It helps prevent institutionalization... [and] is also an important strategy in breaking down stigma and discrimination...."

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, February 2005

Contents

7

Introduction

This chapter will introduce you to key health and human rights issues facing people with **mental disabilities** (people with mental health problems and/or intellectual disabilities). Chapter 1, Human Rights in Patient Care will also be of particular relevance to people with mental disabilities.

People with mental disabilities face wide-ranging human rights abuses, such as coerced institutionalization and isolation, stigma and discrimination, and lack of access to education and employment opportunities. This chapter seeks to highlight the range of serious human rights abuses that too often occur within institutions and demonstrate the importance of developing alternatives to institutional care so that services and support are available to people in their local communities and responsive to their individual needs.

The chapter is organized into six sections that answer the following questions:

- **How** is mental disability a human rights issue?
- **What** is OSI's work in the area of mental disability and human rights?
- **Which** are the most relevant international and regional human rights standards related to mental disability?
- **What** are some examples of effective human rights programming in the area of mental disability?
- **Where** can I find additional resources on mental disability and human rights?
- **What** are key terms related to mental disability and human rights?

As you read through this chapter, consult the **glossary of terms** found in the last section, *What are key terms related to mental disability and human rights?*

How is mental disability a human rights issue?

What do we mean by "mental disability"?

Mental disability is a generic term that includes both people with mental health problems and people with intellectual disabilities:

- **Mental health problems:** (also described as "mental illness") refers to a broad range of mental and emotional conditions and diagnoses, such as anxiety, depression, and schizophrenia, that affect the way a person feels or behaves.

- **Intellectual disabilities:** (also described as "learning disabilities", "developmental disabilities", or "mental retardation") refers to a lifelong condition, usually present from birth or that develops before the age of 18. It is characterised by much lower than average intellectual ability and results in significant limitations in learning and understanding.

Although some individuals are diagnosed with both intellectual disabilities and mental health problems, there are significant differences between these conditions. However, in many countries, both groups of people face similar problems and serious human rights abuses, such as coerced institutionalization, stigma, social exclusion, and lack of access to education and employment. Paul Hunt, the United Nations' Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health ("the Special Rapporteur on the Right to Health"), has described people with mental disabilities as *"one of the most marginalized and vulnerable groups in all countries."*[1]

What are the key human rights issues for people with mental disabilities?

Unjustified Institutionalization

The most significant human rights violation facing many children and adults with mental disabilities across the world is that they are segregated in long-stay institutions such as psychiatric facilities, social care homes, and orphanages where conditions are often unacceptably poor.

The unjustified segregation of people with mental disabilities in long-stay institutions is in itself a human rights abuse. It places severe restrictions on their rights and freedoms by barring them from access to education and employment and denying them the right to choose where and how they live and with whom they associate. Furthermore, it reinforces the stigma and prejudice directed towards people with mental disabilities and perpetuates the misconceptions that they are incapable or unworthy of participating in community life.[2]

In Central and Eastern Europe and the Newly Independent States the long-stay institutions are generally situated in remote, rural areas. This means that residents rarely, if at all, receive visitors, and have little or no communication with the

[1] E/CN.4/2005/51, 11 February 2005, 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, page 7.
[2] See the United States Supreme Court decision of *Olmsted v. LC* 527 US 581 (1999).

outside world, in many cases for the rest of their lives. Numerous reports have shown that residents of such institutions are subjected to serious and sustained human rights ranging from inadequate food, heating and clothing to barbaric treatment such as the unmodified (without anaesthesia or muscle relaxants) use of electro-convulsive therapy or the use of cage beds, to sexual abuse to forced sterilisations[3].

Even in those countries that have become members of the European Union, which seeks to promote the social inclusion of disabled people, little has been done to address the institutionalisation of people with mental disabilities and new institutions for people with mental disabilities continue to be built.

Social Exclusion

The lack of community based services in many countries means that individuals who have not been placed in long-stay institutions also face social exclusion. This is because there is little or no support to facilitate their participation in community life. The ingrained societal prejudice against people with mental disabilities also bars their social inclusion. They are often kept at home by their relatives, who are either seeking to protect them from potential abuse, or wish to avoid bringing shame on the family.

Abuse of Guardianship

Both the United Nations[4] and the Council of Europe[5] have highlighted their concerns about the serious human rights violations that can arise through the use of guardianship. This is a system in which a court appoints a guardian to make decisions on behalf of a person held incapable of making decisions for him or herself. The guardian has wide-ranging powers, such as control over the person's finances and the power to decide where the person should live, with little or no safeguards. In many cases the person subject to guardianship no longer has the right to marry, vote, or work. In many countries, guardianship is used to circumvent laws governing admission to institutions with the guardian agreeing to the admission irrespective of the views or objections of the person subject to guardianship.

Education and Employment

People with mental disabilities face major challenges in exercising their fundamental rights to education and employment. In Central and Eastern Europe, thousands of children with mental disabilities are excluded from the educational system on the basis of their diagnoses alone and irrespective of their

[3] See for example, Amnesty International (2003) Bulgaria, Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities, London, Amnesty International and Mental Disability Advocacy Center (MDAC) (2003) Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries, Budapest, MDAC.

[4] *Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities*, Report of the Secretary-General, United Nations, General Assembly, A/58/181, July 2003, paragraphs 20 & 21 ('the UN Report'), *available at* http://www.un.org/esa/socdev/enable/disa58181e.htm.

[5] Office of the Commissioner of Human Rights, *The Protection and Promotion of the Human Rights of Persons with Mental Disabilities, Conclusions*, CommDH(2003)1, February 2003, *available at* http://www.coe.int/T/E/Commissioner_H.R/Communication_Unit/CommDH%282003%291_E%20.doc.

abilities. Those segregated in institutions usually receive no form of education at all. This denial of education leads to lifelong dependency, poverty, and social exclusion.

Without access to adequate education, people with mental disabilities will be unable to secure employment or engage in other meaningful activities that are crucial for every person's dignity, independence, and integration into community life. Another barrier to employment is the stigma attached to mental disabilities. Employers are often unwilling either to employ people with mental disabilities or to provide needed workplace accommodations.

What is a human rights approach to mental disability?

In recent years there has been a greater awareness of the need to protect and promote the rights of disabled people (including people with mental disabilities), leading to the adoption of the Convention on the Rights of Persons with Disabilities ("Disability Convention") by the United Nations General Assembly in December 2006. The Disability Convention applies to people with "long-term physical, mental, intellectual or sensory impairments," and seeks to "ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity"[6]. It came into force on May 3, 2008.[7]

Increasingly, it is recognized that all disabled people have the right to live in the community as equal citizens. This is made clear in the Disability Convention. Article 19 refers to 'living independently and being included in the community'. It recognizes:

> *'…the equal right of all persons with disabilities to live in the community, with choices equal to others and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'.*

Furthermore, States must ensure that:

- Disabled people have the "opportunity to choose their place of residence and where and with whom they live"
- Disabled people have access to a range of community support services, "including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community"
- Community services and facilities for the general population are "available on an equal basis to persons with disabilities and are responsive to their needs."

The Special Rapporteur on the Right to Health has highlighted the importance of developing a range of community-based support services,

[6] See Article 1
[7] As of July 23, 2008, there were 30 ratifications of the Convention. Please see: http://www.un.org/disabilities/ for an update.

"conducive to health, dignity and inclusion" as an alternative to institutional care[8]. He emphasizes that people with mental disabilities have a right to "community integration":

> *"Deriving from the right to health and other human rights, the right to community integration has general application to all persons with mental disabilities. Community integration better supports their dignity, autonomy, equality, and participation in society. It helps prevent institutionalization, which can render persons with mental disabilities vulnerable to human rights abuses and to damage their health on account of the mental burdens of segregation and isolation. Community integration is also an important strategy in breaking down stigma and discrimination against persons with mental disabilities."*[9]

The Special Rapporteur points out that even countries with very limited resources can take steps to protect the right to health of people with mental disabilities such as:

- Include the recognition, care, and treatment of mental disabilities in training curricula for all health personnel
- Promote public campaigns against stigma and discrimination of persons with mental disabilities
- Formulate modern policies and programmes on mental disabilities
- Support the formation of civil society groups that are representative of mental health care users and their families
- Downsize psychiatric hospitals and, as far as possible, extend community care.

[8] E/CN.4/2005/51, 11 February 2005, 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, paragraph 43.
[9] Report of 11th February 2005 to the United Nations General Assembly, E/CN.4/2005/51, *available at* http://daccessdds.un.org/doc/UNDOC/GEN/G05/108/93/PDF/G0510893.pdf?OpenElement.

Did you know?

- There is a high prevalence of mental health problems:
  - **One in four people will develop a mental health problem** during their lifetime.[10]
  - **One in four families** has at least **one member currently suffering from a mental health problem**.[11]
  - Mental health problems are present at any point in time in about **10% of the adult population**.[12]

- A large number of children and adults with mental disabilities are institutionalized:
  - UNICEF estimates that at least 317,000 children with disabilities live in institutions across Central and Eastern Europe and the Commonwealth of Independent States, often for life.[13]
  - Across Europe over 1.2 million disabled people are living in residential establishments for 30 people or more.[14]

- Human rights violations are rife in these institutions. A 2004 study of residential institutions in France, Hungary, Poland, and Romania found:
  - "Residents often live lives characterized by **hours of inactivity, boredom and isolation**."
  - "Contact with family, friends and community is limited," and "[s]taff members are frequently too low to provide habilitation and therapy."
  - Practices develop "such as keeping people in bed all day or the use of **cage beds to confine people**."[15]

[10] World Health Organization, The World Health Report 2001, Mental Health: New Understanding, New Hope.
[11] Ibid.
[12] Ibid.
[13] UNICEF Innocenti Centre, Innocenti Insight, Children and Disability in Transition in CEE/CIS and Baltic States, 2005, *available at* www.unicef.org.ceeis/Disability-eng.pdf.
[14] Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Deinstitutionalization and community living – outcomes and costs`; report of a European Study Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.
[15] Freyhoff G, Parker C, Coue M, and Grieg N (2004) Included in Society, Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People, Brussels 2004

What is OSI's work in the area of mental disability and human rights?

The OSI **Mental Health Initiative (MHI)** seeks to ensure that people with mental disabilities are able to live as equal citizens in the community and to participate in society with full respect for their human rights. The focus of MHI's activities is to end the end the unjustified and inappropriate institutionalization of people with mental disabilities by advocating for the closure of institutions and for the development of community based alternatives. MHI works with OSI's Human Rights and Governance Grants Program (HRGGP) and the Law and Health Initiative (LAHI) on mental health and human rights projects. Projects supported by MHI include:

- **Developing community-based alternatives to institutionalization:** In December 2006, MHI signed a Memorandum of Understanding with the Serbian Ministry of Labor, Employment and Social Policy to implement deinstitutionalization policy and develop community-based alternatives for people with intellectual disabilities. Serbia is the first state in Central and Eastern Europe to develop community-based alternative services on a national scale.

- **Providing family services to prevent institutionalization:** MHI and Habitat for Humanity and Kyrgyzstan have entered into a partnership to provide decent housing and support services to help Kyrgyz families stay together, preventing the institutionalization of family members with mental disabilities.

- **Enabling mainstream education for children with mental disabilities:** In Azerbaijan and Georgia, MHI works closely with the Ministries of Education on the reform of the segregated educational systems for children with disabilities toward inclusive education in mainstream schools.

For more information, visit MHI's website: www.osmhi.org

Which are the most relevant international and regional human rights standards for mental disability?

Overview

A wide variety of human rights standards at the international, regional, and national levels applies to mental disability. These standards can be used for many purposes:

- **To document** violations of the human rights of people with mental disabilities
- **To advocate** to end these violations
- **To sue** governments for violations of human rights laws
- **To lodge complaints with** regional and international human rights bodies about breaches of human rights agreements.

In the tables on the following pages, **examples** of human rights violations related to people with mental disabilities are provided. Relevant human rights **standards** are cited, along with examples of legal **precedents** and **provisions** from relevant charters and declarations, **interpreting** each standard.

How to read the tables

As you read through each table, ask yourself the following questions about the **violations**, **standards**, and **precedents and interpretations** that are cited:

EXAMPLES OF HUMAN RIGHTS VIOLATIONS
Do any of these violations occur in your country? Are there other violations of this human right that exist in your country?

HUMAN RIGHTS STANDARDS	PRECEDENTS AND INTERPRETATIONS
Are these violations prohibited by the "human rights standards"? Can the standards be interpreted to apply to this violation?	Do any of the "examples of precedents and interpretations" apply to this issue? Can they be interpreted to apply to this issue?

Remember that human rights law is an evolving field, and that many human rights violations are not directly addressed by existing legal standards and precedents. Through ongoing documentation of violations and advocacy at various levels, advocates can contribute to the development of jurisprudence on mental disability and human rights.

Abbreviations

In the tables, the eight treaties and their corresponding enforcement mechanisms are referred to using the following abbreviations:

Treaty	Enforcement Mechanism
International Covenant on Civil and Political Rights **(ICCPR)**	Human Rights Committee (**HRC**)
International Covenant on Economic, Social, and Cultural Rights (**ICESCR**)	Committee on Economic, Social and Cultural Rights (**CESCR**)
Convention on the Rights of Persons with Disabilities **(CRPD)**	Committee on the Rights of Persons with Disabilities **(CRPD Committee)**
Convention on the Elimination of All Forms of Discrimination Against Women (**CEDAW**)	Committee on the Elimination of All Forms of Discrimination Against Women (**CEDAW Committee**)
Convention on the Rights of the Child (**CRC**)	Committee on the Rights of the Child (**CRC Committee**)
African Charter on Human and People's Rights (**ACHPR**) & Protocols	African Commission on Human and People's Rights (**ACHPR Commission**)
European Convention for the Protection of Human Rights and Fundamental Freedoms (**ECHR**)	European Court of Human Rights (**ECtHR**) (with Committee of Ministers)
European Social Charter (**ESC)**[16]	European Committee of Social Rights (**ECSR**)

[16] This refers to the 1996 Revised European Social Charter.

Table 1: Mental disability and the right to liberty and security of the person

Examples of Human Rights Violations	
• A young man is detained against his will to a psychiatric hospital after his parents raised concerns about his behaviour. He is not told why he has been admitted. • A woman is admitted to a social care home on the authorisation of the person appointed as her guardian. She is not consulted about this decision. • Residents of an institution are not informed about their right to apply to a court or tribunal to challenge their involuntary admission/detention. • People are institutionalized indefinitely with no review of their status or of the admission decision.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 9(1) Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law. **CRPD 14(1)** State Parties shall ensure that persons with disabilities, on an equal basis with others : (a) Enjoy the right to liberty and security of person; **(2)** Are not deprived of their liberty unlawfully or arbitrarily . . . **CRC 25** States Parties recognize the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement. **ACHPR 6** Every individual shall have the right to liberty and to the security of his person. No one may be deprived of his freedom except for reasons and conditions previously laid down by law. In particular, no one may be arbitrarily arrested or detained.	**HRC:** considering that a period of 14 days of detention for mental health reasons without review by a court in **Estonia** was incompatible with ICCPR 9. [CCPR/CO/77/EST (HRC, 2003), para. 10].

Table 1: Mental disability and the right to liberty and security of the person, **continued**

Human Rights Standards	Precedents and Interpretations
ECHR 5(1) Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:… (e) the lawful detention…of persons of unsound mind **ECHR 5(4)** Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.	**ECtHR:** holding that the detention of a person on grounds of mental disorder, in addition to complying with national law, must meet the following minimum conditions: • Objective medical evidence demonstrates that the person is of 'unsound mind' • The mental disorder must be of a kind or degree that warrants compulsory confinement • The validity of the compulsory confinement depends on the persistency of the mental disorder. [Winterwerp v. **The Netherlands**, 33 Eur. Ct. H.R. (ser. A) (1979)]. **ECtHR:** establishing that there must be a regular periodic review by a court (a judicial independent body) with the power to discharge if the conditions for detention no longer apply [X v. **United Kingdom**, 46 Eur. Ct. H.R. (ser. A) (1981)].

Table 2: Mental disability and the right to bodily integrity

Examples of Human Rights Violations	
• Treatment is routinely given to people in institutions without their consent because they are automatically assumed to lack the capacity to make decisions about their treatment and care. • Patients at a psychiatric hospital are treated as part of a clinical medical trial without being informed that they are participants in the research. • Patients are given ECT (electro-convulsive therapy) which they are told is "sleep therapy." • Mentally disabled women are sterilized or given abortions without their consent.	
Human Rights Standards	**Precedents and Interpretations**
CRPD 17- Protecting the Integrity of the Person Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. *Note:* The right to bodily integrity is not specifically recognized under the ICCPR, ICESCR, or European conventions, but has been interpreted to be part of the right to security of the person (ICCPR 9, ECHR 5), the right to freedom from torture and cruel, inhuman, and degrading treatment (ICCPR 7, ECHR 3), the right to privacy (ICCPR 17, ECHR 8), and the right to the highest attainable standard of health (ICESCR 12, ESC 11). ***See also:*** • CRC 19(1) (protecting the child from all forms of physical or mental violence) • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1): "Every woman shall be entitled to respect for her life and the integrity and security of her person." • European Convention on Human Rights and Biomedicine, art 5: "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it."	**CESCR:** explaining that the right to health includes "the right to be free from non-consensual medical treatment and experimentation." [CESCR GC 14, para. 8]. **ECtHR:** "[The imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8 § 1 of the Convention" [Pretty v. **United Kingdom,** 2002]. ***See also:*** • **Council of Europe guidelines** concerning the protection of the human rights and dignity of persons with mental disorder, ("**REC(2004)10")**: a person should be subject to involuntary treatment only if the individual has a mental disorder which "represents a significant risk of serious harm to his or her health or to other persons," less intrusive means of providing appropriate care are not available, and "the opinion of the person concerned has been taken into consideration" [Article 18]. • The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, ("CPT 2001") : "[E]very competent patient…should be given the opportunity to refuse treatment or any other medical intervention. Any derogation from this fundamental principle should be based upon law and only relate to clearly and strictly defined exceptional circumstances."

Table 2: Mental disability and the right to bodily integrity, **continued**

Human Rights Standards	Precedents and Interpretations
• European Convention on Human Rights and Biomedicine, art. 7: "Subject to protective conditions prescribed by law, including supervisory control and appeal procedures, a person who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health."	• In **England,** courts have considered whether the compulsory treatment of a mentally competent patient has the potential to breach Articles 8 and 3 ECHR (even if the proposed treatment complies with the legislative requirements). Relevant factors include the consequences of the patient not receiving the proposed treatment, its possible side effects, and whether there were any other less invasive treatments. [R on the application of PS and others, 2003].

Table 3: Mental disability and the right to privacy

Examples of Human Rights Violations	
• People in institutions hide their few personal possessions in their clothing because there is no other safe place to keep them. • The medical records of people in institutions are available to all staff, including those who are not involved in their care. Diagnoses are routinely discussed in front of other residents. • People in an institution do not have their own clothes; all clothes are communal. • Women in an institution must use the toilet and take showers as a group, supervised by male staff.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 17(1) No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. **CRPD 22(1)** No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence . . . **(2)** States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others. **CRC 16(1)** No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation **ECHR 8(1)** Everyone has the right to respect for his private and family life, his home and his correspondence..	**REC(2004)10**: "All personal data relating to a person with mental disorder should be considered to be confidential. Such data may only be collected, processed and communicated according to the rules relating to professional confidentiality and personal data collection." [Article 13(1)]. **CPT 2001**: "The importance of providing patients with lockable space in which they can keep their belongings should also be underlined; the failure to provide such a facility can impinge upon a patient's sense of security and autonomy." **CPT 2001**: "[T]he practice observed in some psychiatric establishments of continuously dressing patients in pyjamas/nightgowns is not conducive to strengthening personal identity and self-esteem; individualisation of clothing should form part of the therapeutic process."

Table 4: Mental disability and freedom from torture and cruel, inhuman, and degrading treatment

Examples of Human Rights Violations	
• People in an institution are kept in cage beds and are forced to eat and use the toilet in bed. • People in a psychiatric hospital are given unmodified ECT (electro-convulsive therapy). • People in an institution who have been labelled "dangerous" by staff are tied or chained to chairs or beds for hours and even days at a time.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 7 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation. **CRPD 15(1)** No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. **CRPD 16(1)** States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, form all forms of exploitation, violence and abuse, including their gender-based aspects. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. **ECHR 3** No one shall be subjected to torture or to inhuman or degrading treatment or punishment. ***See also:*** • Convention Against Torture and Other Forms of Cruel, Inhuman, or Degrading Treatment or Punishment • Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, art. 4(1): "All forms of exploitation, cruel, inhuman or degrading punishment and treatment shall be prohibited." • European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment	**HRC:** calling for the improvement of hygienic conditions, regular exercise, and adequate treatment of the mentally ill in detention facilities in **Bosnia** and **Herzegovina** (both in prisons and mental health institutions). [CCPR/C/BIH/CO/1 (HRC, 2006), para. 19]. **ECtHR:** finding that the failure to respond adequately to the prisoners deteriorating mental health amounted to inhuman or degrading treatment or punishment. [Keenan v. **United Kingdom**, 2001]. ***See also:*** • Committee Against Torture: pointing to overcrowding, inadequate living conditions, and lengthy confinement in Russian psychiatric hospitals as "tantamount to inhuman or degrading treatment." [CAT/C/RUS/CO/4 (CAT, 2007), para. 18]. • CPT 2001: considering unmodified ECT (without anaesthetic and muscle relaxants) no longer acceptable. "Apart from the risk of fractures and other untoward medical consequences, the process as such is degrading for both the patient and the staff concerned." [Para 39].

Table 5: Mental disability care and the right to life

Examples of Human Rights Violations	
• A fire breaks out in a social care home and nearly a third of the residents die in the blaze. It later became clear that compulsory fire and safety regulations were not followed. • People in an institution die from food poisoning caused by unhygienic conditions in the kitchen. • The mortality rate in an institution is particularly high during the winter months due to poor condition of the building, inadequate sanitation and heating, and poor or no medical care. • A person in a psychiatric hospital known to be at risk of suicide is put in an isolation room and that is not monitored adequately and takes her own life.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 6(1) Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life. **CRPD 10** State Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others. **ACHPR 4** Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right. **ECHR 2(1)** Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.	**HRC:** explaining that the right to life "should not be interpreted narrowly" or "in a restrictive manner," and its protection "requires that States adopt positive measures . . . to increase life expectancy." [ICCPR GC 6, paras 1, 5]. **ECtHR**: commenting that the right to life can impose a duty to protect those in custody, including where the risk derives from self-harm. The Court will consider whether the authorities knew or ought to have known that the person 'posed a real and immediate risk of suicide and, if so, whether they did all that could have been reasonably expected of them to prevent that risk'. (Keenan v. **United Kingdom**, 3rd April 2001)

Table 6: Mental disability and the right to the highest attainable standard of health

Examples of Human Rights Violations	
• A child in a social care home becomes bedridden due to malnutrition and neglect. • People with mental disabilities are placed in an institution where they receive little or no treatment, therapy or rehabilitation. • A woman with a schizophrenia diagnosis is told by nursing staff that her abdominal pain is 'all in your head'. She is later diagnosed with ovarian cancer. • Women with mental disabilities are denied reproductive health services.	
Human Rights Standards	**Precedents and Interpretations**
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. **12(2)** The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right 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. **CRPD 25** States Parties recognize that persons with disabilities have the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability... **CRC 3(3)** States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision. **CRC 24(1)** States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.	**CESCR:** "As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality." They must also be "sensitive to gender and life-cycle requirements." [CESCR GC 14, para 12]. **CESCR:** "The right to physical and mental health also implies the right to have access to, and to benefit from, those medical and social services…which enable persons with mental disabilities to become independent, prevent further disabilities and support their social integration." [CESCR GC 5, para 34]. **CESCR:** "Women with disabilities have the right to protection and support in relation to motherhood and pregnancy… The needs and desires in question should be recognized and addressed in both the recreational and procreational contexts." [CESCR GC 5, para. 31]. **CRC Committee:** requiring **Finland** to provide timely health services to children and prevent the institutionalization of mentally ill children with adults [CRC/C/15/ADD.132 (CRC, 2000) paras 45-46].

Table 6: Mental disability and the right to the highest attainable standard of health, **continued**

Human Rights Standards	Precedents and Interpretations
ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health. **16(2)** States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick. **ESC 11** – The right to protection of health With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organisations, to take appropriate measures designed **(1)** to remove as far as possible the causes of ill health; **(2)** to provide advisory and educational facilities for the promotion of health . . . ***See also:*** • African Charter on the Rights and Welfare of the Child, art.14 (child's right to the highest attainable standard of health)	**ECtHR**: holding that states have a duty to protect the health of detainees and lack of treatment may amount to a violation of the right to freedom from torture or to inhuman or degrading treatment [Hutardo v. **Switzerland** (Series A No. 280-A, 28/01/94); Ilhan v. **Turkey**, 34 EHRR 36 (2002)]. ***See also:*** • **CPT 2001:** The provision of basic necessities of life must always be guaranteed in institutions where the State has persons under its care and/or custody. These include adequate food, heating and clothing as well as, in health establishments – appropriate medication. [Para 33].

Table 7: Mental disability and the right to dignity

Examples of Human Rights Violations	
• Staff tie a young man to his chair to stop a him from hitting his head against the wall. • People in an institution sleep in large dormitories with no private space; some have to share a bed. • People in a social care home have their heads shaved as punishment for minor infractions of the rules.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 10(1) All persons deprived of their liberty shall be treated with humanity and with respect to the inherent dignity of the human person. **CRC 37(c)** Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances. **ACHPR 5** Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited. *Note:* • ECHR, art. 8 (the right to privacy) covers a broad range of issues that are relevant to people who are detained, such as the administration of medical treatment and the provision of care. • Although the ECHR does not refer to dignity specifically the ECtHR has referred to dignity as a fundamental value. [Ahmet Ozkan v. **Turkey**, 6th April 2004].	**ECtHR:** 'The State must ensure that a person is detained in conditions which are compatible with respect for his human dignity, that the manner and method of the execution of the measure do not subject him to distress or hardship of an intensity exceeding the unavoidable level of suffering inherent in detention and that, given the practical demands of imprisonment, his health and well-being are adequately secured by, among other things, providing him with the requisite medical care.' [Ahmet Ozkan v. **Turkey**, 6th April 2004]. ***See also:*** • REC(2004)10: explaining that treatment and care should be provided to individuals with mental disorder "by adequately qualified staff and based on an appropriate individually prescribed treatment plan. Whenever possible the treatment plan should be prepared in consultation with the person concerned and his or her opinion should be taken into account. The plan should be regularly reviewed and, if necessary, revised." [Article 12]. • CPT 2001: "Provision of accommodation structures based on small groups is a crucial factor in preserving/restoring patients' dignity."

Table 8: Mental disability and the right to non-discrimination and equality

Examples of Human Rights Violations	
• People living on a locked ward in an institution are forced to wear pyjamas all day. • People in a social home do not have access to a telephone to contact friends or family. • Certain residents of a social care home are chosen by staff to punish other residents.	
Human Rights Standards	**Precedents and Interpretations**
ICCPR 26 All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. **ICESCR 2(2)** The States Parties to the present Covenant undertake to guarantee the rights enunciated in the present Covenant shall be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, birth or other status. **CRPD 1** The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. **CRPD 12(1)** States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. **(2)** States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. **(3)** States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. **(4)** States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.	**CESCR:** explaining that health facilities, goods, and services have to be accessible to everyone without discrimination "and especially to the most vulnerable and marginalized sections of the population." The Committee further urged particular attention to the needs of "ethnic minorities and indigenous populations, women, children, adolescents, older persons, persons with disabilities and persons with HIV/AIDS." [CESCR GC 14, para 12]. **CESCR:** stressing "the need to ensure that not only the public health sector but also private providers of health services and facilities comply with the principle of non-discrimination in relation to persons with disabilities." [CESCR GC 14, para 26]. **CESCR:** Defining "disability-based discrimination" as "any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights." [CESCR GC 5, para. 15]. **CESCR:** "Anti-discrimination measures should be based on the principle of equal rights for persons with disabilities and the non-disabled. . . . [A]ll resources must be employed in such a way as to ensure for every individual, opportunity for participation. Disability policies should ensure the access of [persons with disabilities] to all community services." [GC 5, para. 17].

Table 8: Mental disability and the right to non-discrimination and equality, **continued**

Human Rights Standards	Precedents and Interpretations
ACHPR 2 Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, color, sex, language, religion, political or any other opinion, national and social origin, fortune, birth or other status. ***See also:*** • European Convention on Human Rights and Biomedicine, art 3 (equitable access to health care)	***See also:*** • The **United States** Supreme Court held in Olmsted v. LC (1999) that the unjustified institutional isolation of people with disabilities amounted to unlawful discrimination. This was evidenced not only by restrictions placed on the rights of those confined in the institutions, but also "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in life."

Table 9: Mental disability and the right to independent living

Examples of Human Rights Violations	
• A child is placed in an institution because she is diagnosed as having Down Syndrome and her parents are told that there is no support available to help them take care of her at home. • A young man with intellectual disabilities is admitted to a social care home far from his home because his mother has become ill and can no longer look after him without some help. • Residents of an institution cannot live in the community because funding is only available for institutional care.	
Human Rights Standards	**Precedents and Interpretations**
CRPD 19 Living independently and being included in the community: States Parties . . . recognize the equal right of all persons with disabilities to live in the community, with choices equal to others and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community. **CRPD 26** Habilitation and rehabilitation: State Parties shall take . . . measures . . . to enable persons with disabilities to attain and maintain maximum independence, full physical, mental social and vocational ability, and full inclusion and participation in all aspects of life. **CRC 23(1)** States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. **(2)** States Parties recognize the right of the disabled child to special care and . . . [assistance] shall be provided free of charge . . and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.	**CRC Committee:** requiring the implementation of alternative measures to the institutionalization of children with disabilities, encouraging the inclusion and integration of disabled children in the educational system and into society, and calling for adequate monitoring of private institutions of children with disabilities in **Malta**. [CRC/C/15/ADD.129 (CRC, 2000), para. 38]. **CRC Committee:** calling for the implementation of measures to provide alternatives to the institutionalization of disabled and for the strengthening of community-based programmes to enable them to stay at home with their families in the **Czech Republic**. [CRC/C/15/ADD.201 (CRC, 2003), para. 49]. **CRC Committee:** calling for community-based rehabilitation programmes, including parent support groups, in **Hungary** to avoid the marginalization and exclusion of disabled children and children with disabled parents. [CRC/C/HUN/CO/2 (CRC, 2006), para. 40]. **CRC Committee:** recommending support to community-based services to move children from institutions to a family environment in Kazakhstan. [CRC/C/15/ADD.213 (CRC, 2003), para. 55].

Table 9: Mental disability and the right to independent living, **continued**

Human Rights Standards	Precedents and Interpretations
ACHPR 18(4) The aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs. **ESC 15** The right of persons with disabilities to independence, social integration and participation in the life of the community: With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community . . .	**CESCR:** "Institutionalization of persons with disabilities, unless rendered necessary for other reasons, cannot be regarded as an adequate substitute for the social security and income-support rights of such persons." [GC 5, para. 29]. **CESCR:** "[E]verything possible should be done to enable . . persons [with disabilities], when they so wish, to live with their families." [GC 5, para. 30]. **CESCR:** "[I]t is necessary to ensure that support services . . . are available for persons with disabilities to assist them to increase their level of independence in their daily living and to exercise their rights." "[S]unch persons should be provided with rehabilitation services which would enable them to reach and sustain their optimum level of independence and functioning." [GC 5, paras 33, 34]. ***See also:*** • The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993: "Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of health, employment and social services." • The UN Principles for the Protection of Persons with Mental Illness, 1991 state that people with mental illness have the right to live and work in the community (Principle 3) and be treated and cared for in the community in which they live so far as possible (Principle 7). • Recommendation (Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015: "People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community. Enhancing community living… requires strategic policies which support the move from institutional care to community-based settings…"

Table 10: Mental disability and the right to education

Examples of Human Rights Violations	
• No education is provided to children in an institution. • Parents of a child with intellectual disabilities are told that their daughter cannot go to school because she is 'uneducable.'	
Human Rights Standards	**Precedents and Interpretations**
ICESCR 13 States Parties...recognize the right of everyone to education ... **CRPD 24(1)** States Parties recognize the right of persons with disabilities to education... **(2)** In realizing this right, States Parties shall ensure that: (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory education, of from secondary education, on the basis of disability. **CRC 28** States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular: a. Make primary education compulsory and available free to all; b. Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child and take appropriate measures such as the introduction of free education and offering financial assistance in case of need... **ACHR 17(1)** Every individual shall have the right to education. **ECHR Protocol No.1**, 2 No person shall be denied the right to education...	**CESCR:** Recognizing that "persons with disabilities can best be educated within the general education system." "States should ensure that teachers are trained to educate children with disabilities within regular schools and that the necessary equipment and support are available to bring persons with disabilities up to the same level of education as their non-disabled peers." [GC 5, para. 35]. **CRC Committee:** Condemning the practice of institutionalizing children with disabilities, lack of support to families, and the limited inclusion of children with disabilities in the educational system in **Kazakhstan** and **Ukraine**. [CRC/C/15/ADD.213 (CRC, 2003), para. 54; CRC/C/15/ADD.191 (CRC, 2002), para. 53]. **CRC Committee:** Criticizing the limited number of trained teachers to work with children with disabilities, insufficient efforts made to facilitate the children's inclusion into the educational system, and inadequate resources allocated to special education in **India**, **Rwanda**, and **Zambia**. [CRC/C/15/ADD.228 (CRC, 2004), para. 56; CRC/C/15/ADD.234 (CRC, 2004), para. 46; CRC/C/15/ADD.206 (CRC, 2003), para. 52]. **CRC Committee:** Calling for the integration of children with disabilities into the regular educational system and for increased resources for special education in **Kyrgyzstan**. [CRC/C/15/Add.244 (CRC, 2004), para. 48]. ***See also:*** • States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system. [Standard Rules, 6].

Table 10: Mental disability and the right to education, **continued**

Human Rights Standards	Precedents and Interpretations
See also: • CRC 23(3): "States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas." • African Charter on the Rights and Welfare of the Child, art. 11(1): "Every child shall have the right to an education. (2) The education of the child shall be directed to: (a) the promotion and development of the child's personality, talents and mental and physical abilities to their fullest potential" • European Charter on Fundamental Rights, art. 14: "Everyone has the right to education and to have access to vocational and continuing training"	

Table 11: Mental disability and the right to employment

Examples of Human Rights Violations
• People in a social care home are told that they are not capable of getting a job. • A person with intellectual disabilities is placed under guardianship, and the guardian does not allow him to continue to be employed. • An employer refuses to hire a woman even though she is the best applicant for the job because she has suffered from depression in the past. • People with intellectual disabilities are 'employed' in a workshop where they are given menial tasks to do all day for which they receive 'pocket money' at the end of the week.

Human Rights Standards	Precedents and Interpretations
ICESCR 6 (1) The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right. (2) The steps to be taken by a State Party . . . shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual. **CRPD 27(1)** States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities... **ACHR 15** Every individual shall have the right to work under equitable and satisfactory conditions. **ESC 1** – The right to work ***See also:*** • European Union Charter, art. 15: "Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation." • European Directive on Equal Treatment in Employment, Council Directive 2000/78/EC	**CESCR:** "The 'right of everyone to the opportunity to gain his living by work which he freely chooses or accepts' (Art 6(1)) is not realized where the only real opportunity open to disabled workers is to work in so-called 'sheltered' facilities under substandard conditions. Arrangements whereby persons with a certain category of disability are effectively confined to certain occupations or the production of certain good may violate this right." [GC 5, para 21]. ***See also:*** • States should actively support the integration of persons with disabilities into open employment. This active support should occur through a variety of measures such as vocational training, incentive-oriented quota schemes...financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities. [Standard Rules, Rule 7]. • Council of the European Resolution – asking Member States to 'continue efforts to remove barriers to the integration and participation of people with disabilities in the labour market, by enforcing equal treatment measures and improving integration and participation at all levels of the education and training system' [2003/C175/01].

What are some examples of effective human rights programming in the area of mental disability?

Introduction

In this section, you are presented with four **examples** of effective advocacy strategies in mental disability and human rights. These are:

1. Litigating to protect the rights of people who lack legal capacity and are at risk of being placed in an institution
2. Advocating for the Implementation of the UN Convention on the Rights of Persons with Disabilities in **Croatia**
3. Advocating across Europe for Independent Living for People with Disabilities
4. Establishing Community-Based Supported Housing in **Serbia**.

Rights-based programming

As you review each activity, ask yourself whether it incorporates the **five elements** of "rights-based" programming:

- **Participation**
  Does the activity include the active and meaningful participation by the affected people and communities, civil society, and other relevant stakeholders?

- **Accountability**
  Does the activity identify both the *entitlements of claim-holders* and the *obligations of duty-holders*? Does it create mechanisms of accountability for violations of rights?

- **Non-discrimination**
  Does the activity identify who is most vulnerable, and how? Does it pay particular attention to the specific needs of people with mental disabilities?

- **Empowerment**
  Does the activity give its beneficiaries the power, capability, capacity, and access to bring about change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?

- **Linkage to rights**
  Does the activity define its objectives in terms of legally enforceable rights (civil, political, economic, social, and cultural rights), with clear links to international, regional, and national laws?

Finally, ask yourself whether and how the activity might be created or replicated in your country:

- Does such a project **already exist** in your country? If so, does it need to be **expanded** or **adapted**?

- If not, should it be **created**? What **steps** need to be taken to replicate it? What **barriers** need to be overcome to ensure successful replication?

Example 1: Litigation to protect the rights of people who lack legal capacity and are at risk of being placed in an institution

Litigation against the United Kingdom in the European Court of Human Rights led to additional safeguards against involuntary hospital admission for people lacking legal capacity.

Project type
Strategic litigation

Health and human rights issue
Under the *Mental Health Act* of 1983 (England and Wales), patients who are detained in psychiatric hospitals have the right to independent review of their detention. However, patients who are hospitalized "informally" or fall outside the jurisdiction of the Act are denied these protections. A 48-year-old man with autism, Mr. L., was admitted to a psychiatric hospital after becoming agitated at the day-care center he attended regularly. Because he was "quite compliant" and had "not attempted to run away", his psychiatrist did not formally detain him under the Act, thus denying him the right to independent review.

Actions taken
Mr. L.'s carers took legal action against the National Health Service Trust which managed the hospital, claiming he had been unlawfully detained. The UK House of Lords held that patients such as Mr. L. who lack capacity but do not object to their admission can be admitted to hospital informally. Mr. L.'s carers appealed to the European Court of Human Rights.

Results
- The European Court held that Mr. L.'s right to liberty under Article 5 of the European Convention on the Protection of Human Rights and Fundamental Freedoms had been violated. Mr. L. had been "deprived of his liberty" within the meaning of Article 5(1) and his detention had been unlawful, the Court ruled, because his admission was not "in accordance with a procedure prescribed by law". The Court also found that the legal proceedings available to Mr. L. had not met the standards required by Article 5(4) for "the lawfulness of his detention" to be "decided speedily by a court."

- The UK government took action to address the violations identified by the Court by providing additional safeguards for people who lack capacity and are deprived of their liberty. The safeguards were inserted into the Mental Capacity Act 2005, which provides a framework for decision making on behalf of those who lack capacity to make decisions for themselves. They are likely to come into force in October 2009.

Lessons learned
The case highlights the use of legal mechanisms to protect and promote the rights of people who lack capacity to make decisions for themselves. While there remains concern that the procedures proposed by the government are complex and bureaucratic, the procedures nevertheless provide an important means of preventing abuse against people who are unable to make decisions about their care and treatment because they lack legal capacity.

Contact
Scott-Moncrieff, Harbour & Sinclair
Tel: +44 (20) 7485 5588
Email: scomo@scomo.com

Case of HL v. The United Kingdom, Application No. 45508/99 (5 October 2004), available at www.echr.coe.int/ECHR/EN/Header/Case-Law/HUDOC/HUDOC+database/

Example 2: Advocating for the Implementation of the UN Convention on the Rights of Persons with Disabilities in Croatia

The new UN Convention on the Rights of Persons with Disabilities has the potential to introduce significant improvements in the lives of people with intellectual disabilities. The Association for Self-Advocacy (ASA) in Croatia has undertaken a number of activities to ensure its government's compliance with the Convention.

Project type

Human rights training and capacity-building; integrating human rights approaches in health services delivery

Health and human rights issue

Croatia was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities (the Convention), yet people with intellectual disabilities remain among the most marginalized in society. Many people with intellectual disabilities in Croatia are deprived of their legal capacity and thus denied the right to make any decisions regarding their lives. Many cannot realize their right to education, employment, marriage, ownership of property, voting, and other basic rights. With a lack of community based services, one in three children and adults with severe intellectual disabilities remains institutionalized.

Actions taken

The Association for Self Advocacy (ASA), established in 2003 is the first and only NGO in Croatia run by and for people with intellectual disabilities. ASA undertakes a variety of activities aimed at promoting the implementation of various provisions of the Convention:

- Consistent with the Convention's guarantee of full and effective participation and inclusion in society, ASA advocates for the development of community-based services as alternatives to institutionalization.
- Consistent with the Convention's provisions on raising public awareness, ASA trains people with intellectual disabilities about human rights and self-advocacy, and organizes public awareness campaigns about the human rights of people with intellectual disabilities.
- Consistent with the Convention's guarantee of accessibility, ASA prepares and distributes easy-to-read materials on the rights of people with intellectual disabilities.

Results and lessons learned

- ASA has become an established NGO, led by people with intellectual disabilities and recognized for its expertise in human rights and advocacy.
- People with intellectual disabilities in Croatia, Slovenia and Bosnia and Herzegovina who have participated in ASA's self-determination and self-advocacy training are able to advocate for their human and civil rights in their own countries.
- ASA works with other self advocacy groups, human rights organizations and NGOs providing community based services for people with intellectual disabilities to promote implementation of the Convention.

Contact
Association for Self-Advocacy (ASA),
Bleiweissova 15, 10 000 Zagreb, Croatia
Tel: +385 1 375 1698
Email: samozastupanje@zg.t-com.hr

Example 3: Advocating across Europe for Independent Living for People with Disabilities

To advocate for community-based living for people with disabilities, a group of advocacy organizations formed a coalition, the European Network for Community Living, that advocates at the European level and supports member organizations in their national level advocacy.

Project type
Strategic networking

Health and human rights issue
Over a million people with disabilities are confined to long-stay institutions across Europe, often for life. Despite recognition that people with disabilities have the right to live in the community as equal citizens, the legal, financial and other reforms necessary for community living have not been made. The development of a wide range of quality community-based alternatives to institutionalization is crucial to this reform.

Actions taken
In 2005, a group of advocacy organisations established the European Coalition for Community Living (ECCL) to advocate for the development of comprehensive, quality community-based services as an alternative to institutionalization. A Europe wide cross-disability initiative, ECCL is led by the European Network on Independent Living, the European umbrella organisation run by people with disabilities. ECCL's activities include:

- Publishing position papers and briefings and making recommendations on the right of people with disabilities to live in the community.
- Advocating before European institutions for polices that support community-based services, and highlighting the crucial importance of involving people with disabilities as equal partners in this work.
- Supporting ECCL members in their national advocacy activities.
- Facilitating exchange of information and the promotion of best practice in the development of community based services, through seminars and newsletters for ECCL members and other interested organizations.
- Launching a campaign calling for recognition of the right of all people with disabilities to live in the community and for a shift in government funding from long stay institutions to community-based services. A commitment to the campaign can be signed at www.community-living.info.

Results and lessons learned
- ECCL has provided organizations with information and contacts in planning, providing or advocating for community-based services.
- ECCL has established cooperation with policy and decision makers at the European level and is considered to be an expert on community living and deinstitutionalization by various European disability organizations.
- By insisting on the central role of people with disabilities in the planning and delivery of services, ECCL has gained the trust of user-led organizations and is considered a legitimate representative of their interests.

Contact
European Coalition for Community Living
Tel: +385 1 375 1698
Email: coordinator@community-living.info
Web: www.community-living.info

Example 4: Establishing Community-Based Supported Housing in Serbia

Through a combination of pilot programs, research, and development of minimum standards, a non-governmental organization had a major influence on the establishment of community-based supported housing for people with intellectual disabilities in Serbia.

Project type
Law reform; Integrating human rights approaches in health services delivery

Health and human rights issue
In Serbia, as in many Central and Eastern European countries, most people with intellectual disabilities are placed in long-stay institutions with little or no contact with their families and communities. A major reason for this is the lack of alternative services and support at the community level.

Actions taken
The Serbian Association for Promotion of Inclusion (SAPI), a non-governmental organization that promotes the human rights and social inclusion of people with intellectual disabilities, has worked effectively with the Ministry of Social and Labor Policy to establish community-based supported housing as an alternative to institutionalization. SAPI's work includes:

- Developing pilot community-based alternatives to institutions, focusing on supported housing.
- From 2003 to 2007, in partnership with OSMHI and the Ministry for Labor and Social Policy, developing a project study entitled the *Community for All Initiative Serbia* that detailed how to implement national level reform.
- Participating in developing the proposal for "Minimum standards and specifications of supported housing services" as a member of the Ministry's Working Group for developing standards for social welfare services.

Results and lessons learned
- SAPI's work has shown that it is possible for non-governmental organisations to develop good quality community based services and to have a significant influence on policy and service development.
- SAPI's pilot community-based alternatives have been recognized by the Ministry for their quality, and have helped to make community-based supported housing a Ministry priority, with SAPI a key Ministry partner.
- The legislative proposals in the Community for All study were included in a draft law expected to be adopted by Parliament and implemented by the end of 2008. The key component of the proposed amendments is that community-based supported housing will now be legally recognized as a viable alternative to institutional placement.
- For the evaluation of the minimum standards for community-based services, SAPI was selected by the Ministry as a Model Service Provider. At the Ministry's request, SAPI developed financial regulations for supported housing.

Contact
Dragan Lukic, Director of SAPI
Email: sapi@nadlanu.com

Where can I find additional resources on mental disability and human rights?

Resources

To further your understanding on the topic of human rights in patient care, a list of commonly used resources has been compiled and organized into the following categories:

- Declarations, resolutions, and conventions: UN
- Declarations, resolutions, and conventions: non-UN
- Books
- Reports, key articles, and other documents
- Periodicals
- Websites

Declarations, resolutions, and conventions: UN

- United Nations Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, 1991.
  Source: www.unhchr.ch/html/menu3/b/68.htm
- United Nations Standard Rules for the Equalization of Opportunities for Persons with Disabilities, 1993.
- United Nations Convention on the Rights of Persons with Disabilities, 2006.
- ICESCR GC 5 – International Covenant on Economic, Social and Cultural Rights, (1994), General Comment 5, Persons with Disabilities.
- ICESCR GC 14 – International Covenant on Economic, Social and Cultural Rights, (2000) General Comment 14, The Right to the highest attainable standard of health (art.12).

Declarations, resolutions, and conventions: non-UN

- Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Council of Europe 1997). Source: conventions.coe.int/Treaty/EN/Treaties/Html/164.htm

- Recommendation 1592 (2003) Towards full social inclusion of people with disabilities, Parliamentary Assembly, Council of Europe Council of Europe, 2004.

- Recommendation No REC (2004)10 of the Committee of Ministers concerning the protection of the human rights and dignity of persons with and its Explanatory Memorandum.

- CPT Standards – European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), "Substantive" Sections of the CPT's General Reports, Council of Europe, Strasbourg, CPT/Inf/E(2002)1 – Rev 2004.

- World Health Organization, (2005) Mental Health Declaration for Europe – Facing Challenges, Building Solutions, January 2005.

Books

- Clements L, Read J. Disabled People and European Human Rights, A review of the implications of the 1998 Human Rights Act for disabled children and adults in the UK, The Policy Press, Bristol, 2003.

- Jenkins R, McCulloch A, Friedli L and Parker C. Developing a National Mental Health Policy, Psychology Press Ltd, Hove, 2002.

- Knapp M, McDaid D, Mossialos E and Thornicroft G (eds). *Mental Health Policy and Practice across Europe,* Buckingham, Open University Press, 2007.

- Kozma A, Bulic I. Creating Successful Campaigns for Community Living, An advocacy manual for disability organisations and service providers, European Coalition for Community Living, 2008. Source: http://www.community-living.info/?page=292

- Lasik JL (ed.). Pain and Survival: Human Rights Violations and Mental Health, 1994.

- Sayce L. From Psychiatric Patient to Citizen – Overcoming Discrimination and Social Exclusion, Palgrave, 2000.

Reports, key articles, and other documents

- Amnesty International. *Bulgaria, Far from the eyes of society: Systematic discrimination against people with mental disabilities.* Amnesty International, 2003.
- Applebaum, Paul S. *Present at the Creation: Mental Health Law in Eastern Europe and the Former Soviet Union*, Psychiatric Services Vol. 49, No. 10, 1998.
- Davidson G, McCallion M. and Potter M. Connecting Mental Health and Human Rights, Northern Irish Human Rights Commission, Belfast, 2003.
- European Coalition for Community Living. Focus on the rights of Children with Disabilities to Live in the Community, 2006.
  Source: www.community-living.info/documents/ECCL-AR-2006-FINAL.pdf
- Freyhoff G, Parker C, Coué M and Grieg N. Included in Society – Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People, (Supported by the European Commission) 2004.
- Gostin, Lawrence O. *International Human Rights Law and Mental Disability*, Hastings Center Report, March-April 2004: 11-12.
- *Human Rights in Action---A Framework for Local Action* (designed by Department of Health, British Institute of Human Rights, and 5 NHS Trusts), Equality and Human Rights Group, 2007.
- Latvian Center for Human Rights. *Human rights in Mental Health Care in Baltic Countries*, Policy Paper, 2006.
- Mansell J, Knapp M, Beadle-Brown J and Beecham J. Deinstitutionalisation and Community Living – outcomes and costs: report of a European Study, Volume 2, Main Report. Canterbury: Tizard Centre, University of Kent, 2007.
  Source:
  www.kent.ac.uk/tizard/research/DECL%20network/Project%20reports.html
- Mencap, Death by Indifference.
  Source:
  www.mencap.org.uk/html/campaigns/deathbyindifference/DBIreport.pdf
- MDAC - Mental Disability Advocacy Center (2003) Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries, MDAC Budapest, 2003.

- Mental Disability Rights International, Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities, 2006.

- Mind, Another Assault, Mind's campaign for equal access to justice for people with mental health problems, Mind 2007.
  Source: www.mind.org.uk/anotherassault

- Open Society Mental Health Initiative, Access to Education and Employment for People with Intellectual Disabilities: An Overview of the Situation in Central and Eastern Europe.
  Source: www.osmhi.org/contentpics/202/MHIReportEdEmp3Oct.pdf

- Open Society Mental Health Initiative, Memorandum in 'Improving the mental health of the population': can the European Union help? Volume II: Evidence.
  Source:
  www.publications.parliament.uk/pa/ld200607/ldselect/ldeucom/73/73ii.pdf

- Open Society Mental Health Initiative, A Community for All: The Open Society Mental Health Initiative and its Work to Promote Social Inclusion for People with Mental Disabilities, 2006.

- Parker C, Goedhart F, and Gomez G. Partners for Better Policies: A Manual for Mainstreaming, Inclusion Europe, Open Society Mental Health Initiative and Global Initiative on Psychiatry, 2006.
  Source: www.osmhi.org/contentpics/202/EN_Manual.pdf

- Quinn G and Degener T with Bruce A, Burke C, Castellino J, Kenna P, Kilkelly U and Quinlivan S. (2002) Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability.
  Source: www.unhchr.ch/disability/hrstudy.htm

- Rosenthal E and Sundram CJ. International Human Rights and Mental Health Legislation, World Health Organization, 2003.

- Salize H, Drefsing H and Peitz M. Compulsory Admission and Involuntary Treatment of Mentally Ill Patients – Legislation and Practice in EU Member States, European Commission, 2002.

- World Health Organization The World Health Report - Mental Health: New Understanding, New Hope, World Health Organisation, Geneva, 2001.

- World Health Organization, Mental Health Policy and Service Guidance Package, Mental Health Legislation and Human Rights, World Health Organisation, Geneva, 2003.

- World Health Organization, Mental Health Action Plan for Europe - Facing Challenges, Building Solutions, January 2005.
- World Health Organization, Resource Book on Mental Health, Human Rights and Legislation stop exclusion, dare to care, 2005.

Periodicals

- Journal of Intellectual & Developmental Disability.

Websites

- British Medical association Human Rights Publications
  www.bma.org.uk/ap.nsf/Content/HRpublications
- European Coalition for Community Living
  www.community-living.info/
- European Court of Human Rights- Mental Disability Cases
  www.mdac.info/resources/echr_cases.htm
- Global Initiative on Psychiatry
  gip-global.org/
- Inclusion Europe
  www.inclusion-europe.org/
- Open Society Mental Health Initiative
  www.osmhi.org/
- Mental Disability Advocacy Center
  http://www.mdac.info/resources/echr_cases.htm
- Mental Health Improvements for Nations Development: The WHO MIND Project
  www.who.int/mental_health/policy/en/

What are key terms related to mental disability and human rights?

Glossary

A variety of terms is used in human rights and patient care work. Where noted, these definitions come from the World Health Organization (WHO).

A

Acceptability
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Acceptability: means that all health facilities, goods and services must be respectful of medical ethics, culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned (General Comment 14). *See also* "Adequacy," "Availability," and "Quality."

Accessibility
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health health. Accessibility: means that health facilities, goods and services have to be accessible to everyone without discrimination. Accessibility has four overlapping dimensions: non-discrimination, physical accessibility, economic accessibility (affordability), and information accessibility (General Comment 14). *See also* "Acceptability," "Adequacy," and "Quality."

Availability
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Availability: means that functioning public health and health care facilities, goods, and services, as well as programmes, have to be available in sufficient quantity. This should include the underlying determinants of health, such as safe drinking water, adequate sanitation facilities, clinics and health-related buildings, trained medical personnel, and essential drugs (General Comment 14). *See also* "Acceptability," "Accessibility," and "Quality."

B

Basic needs
Used largely in the development community to refer to basic health services, education, housing, and other goods necessary for a person to live.

C

Community-based services
These are the range of services and support that help people with disabilities, including people with mental disabilities, live with their families or friends and engage in community life (such as go to school or work and enjoy leisure activities). Work with small children (early intervention), day services, the provision of independent living skills (such as being taught how to cook and manage personal finances), and supported employment and housing are examples of community-based services. Through the provision of such services the unnecessary institutionalization can be avoided.

Consumers
This term is sometimes used in relation to people with mental health problems who are receiving mental health services. (See also "service user" below.)

Consumer Involvement
This describes the practice of involving people with mental health problems in the planning and delivery of mental health services, as well as enabling people with mental health problems to make decisions about their treatment and their lives. Consumers and providers of mental health services are realizing that involvement in decisions relevant to the course of their lives is an integral component of effective and long-term recovery from mental health problems. Many service providers are moving towards a person-centered model that encourages partnership between consumer, service provider, and other relevant parties (family, careers).

D

Developmental disabilities
See "intellectual disabilities" below.

Deinstitutionalization
This term is used to describe the process to achieve the closure of institutions and the development of a range of community based services, as alternatives to institutional care, appropriate to the individual needs of people with disabilities. As former residents of institutions move to family-scale housing in the community, service providers must ensure that appropriate supports are in place so that people have meaningful opportunities to participate in society. Therefore, simultaneous with the closure of institutions, sustainable community support services that address the individual needs of people with mental disabilities must be developed.

Disability
The Disability Convention states "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Article 1).

E

Early Intervention
This describes a wide range of multi-disciplinary services offered to children with intellectual disabilities between birth and school age. Such services seek to prevent the development of disabilities, assist children with intellectual disabilities in areas such as physical, cognitive, linguistic, social, and emotional development, and support families in maximising their children's development. These services also facilitate the inclusion of children with intellectual disabilities in mainstream education.

G

Guardian
A person appointed by a court to act on behalf of another person who is considered to lack the capacity to make decisions for him or herself. See "guardianship" below.

Guardianship
This term refers to the legal arrangements for decision-making on behalf of adults (usually 18 or over) who are deemed by a court to lack the capacity to make decisions themselves. There are two types of guardianship, "plenary" or "full" guardianship and "partial" guardianship. Under "plenary" guardianship the person loses his or her legal capacity to act and is no longer recognized before the law and the guardian is given extensive decision-making powers. Under "partial" guardianship the guardian is appointed to make decisions in connection with specific issues about which the individual is considered to lack decision-making capacity.

H

Health
A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO).

Health care or patient care (see also Patient care)
1. The prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by the medical, nursing, and allied health professions. This definition and similar ones sometimes are given for "*patient care*" as well. The World Health Organization states that this embraces all the goods and services designed to promote health, including preventive, curative, and palliative interventions, whether directed to individuals or populations.
2. "Any type of services provided by professionals or paraprofessionals with an impact on health status" (European Observatory on Health Systems and Policy online glossary).
3. "Medical, nursing or allied services dispensed by health care providers and health care establishments" (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Health care establishment
Any health care facility such as a hospital, nursing home, or establishment for disabled persons (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam, 1994).

Health care providers
Physicians, nurses, dentists, or other health professionals (Declaration on Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Health care system
The organized provision of health care services.

I

Independent Living
Living in the community, with appropriate supports, so that a person with a disability may live with dignity, make personal life decisions to the best of her/his ability, and participate in the everyday activities that people without disabilities take for granted. Support for the right of all people to live as independently as possible is integral to the process of deinstitutionalization of people with mental disabilities.

Informed consent
A legal condition in which a person can be said to agree to a course of action based upon an appreciation and understanding of the facts and implications. The individual needs to be in possession of relevant facts and the ability to reason.

Informed consent in the health care context
A process by which a patient participates in health care choices. A patient must be provided with adequate and understandable information on matters such as the treatment's purpose, alternative treatments, risks, and side-effects.

In-patient
A patient whose care requires a stay in hospital or hospice facility for at least one night.

Institutionalization
The practice of placing people with disabilities in long-stay institutions, such as psychiatric hospitals, social care homes, and orphanages.

Intellectual disabilities
This term refers to a lifelong condition, usually present from birth or that develops before the age of 18. It is characterised by much lower than average intellectual ability and results in significant limitations in learning and understanding. (This condition is also described as "learning disabilities", "developmental disabilities", or "mental retardation".)

L

Learning disabilities
See "intellectual disabilities" above

M

Medical intervention
Any examination, treatment, or other act having preventive, diagnostic therapeutic or rehabilitative aims and which is carried out by a physician or other health care provider (Declaration on the Promotion of Rights of Patients in Europe, WHO, Amsterdam 1994).

Mental disabilities
This is a generic term which covers both mental health problems (see below) and intellectual disabilities (see above).

Mental Health
"Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community." (WHO)

Mental health problems
This term refers to a broad range of mental and emotional conditions and diagnoses, such as anxiety, depression, and schizophrenia, that affect the way a person feels or behaves. Individuals who experience severe and/or enduring mental health problems they may be described as suffering from a "mental illness" and may be referred to as being "mentally ill." However, many people find these terms offensive and stigmatising.

Mental illness
See "mental health problems" above.

Mental retardation
See "intellectual disabilities" above.

O

Out-patient
Patient receiving treatment without spending any nights at a health care institution.

P

Patient
A user of health care services, whether healthy or sick (Declaration on the Promotion of Patients' Rights in Europe, WHO, Amsterdam 1994).

Patient autonomy
The right of patients to make decisions about their medical care. Providers can educate and inform patients, but cannot make decisions for them.

Patient care (see also Health care)
The services rendered by members of the health professions or non-professionals

under their supervision for the benefit of the patient. Similar definitions often are provided for the term "health care."

Patient-centered care
Doctrine recognizing the provision of health services as a partnership among health care providers and patients and their families. Decisions about medical treatments must respect patients' wants, needs, preferences, and values.

Patient confidentiality
Doctrine that holds that the physician has the duty to maintain patient confidences. This is to allow patients to make full and frank disclosure to their physician, enabling appropriate treatment and diagnosis.

Person-centred planning
A model of community-based service that holds the client at the center of the life planning process. Person-centered planning is a broad model that offers multiple approaches to life planning so that the process can be tailored to the needs and wishes of the person with a disability. Rather than focusing solely on a mental disability label, person-centered planning recognizes the abilities, desires and humanity of each individual.

Primary health care
General health services available in the community near places where people live and work; the first level of contact individuals and families have with the health system.

R

Reasonable accommodation
This is defined in the Disability Convention as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms." (Article 2 (definitions)).

Respite Care
Respite care, or 'short breaks' as it is referred to in the UK, is short-term, temporary care provided for people with disabilities and their caregivers. Respite care may be planned or emergency short-term relief. It aims to provide caregivers with a break from their responsibilities, while providing a positive experience for the person with a disability. Respite care is an important part of the range of services supporting families that have a member with disabilities. Short breaks also help to combat the isolation, which children and adults with disabilities may feel, and enables them to meet new people, widen their social life and gain new experiences. Respite care is crucial in helping to reduce family stress, preserve the family unit, and provide stability. Respite care can also play a very important role in the prevention of institutionalization.

Right to health
Right to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realization of the highest attainable standard of health.

Q

Quality
One of four criteria set out by Committee on Economic, Social, and Cultural Rights by which to evaluate the right to the highest attainable standard of health. Quality: means that health facilities, goods, and services must be scientifically and medically appropriate and of good quality. This requires skilled medical personnel, scientifically approved and unexpired drugs, and hospital equipment (General Comment 14). See also "Acceptability," Accessibility," and "Availability."

S

Secondary health care
General health services available in hospitals.

Self-advocacy
Self advocacy works at both the individual and group levels. At the individual level, self advocacy assumes that each person has the right to stand up for herself or himself and that people can be empowered to do so. At the group level, self advocacy is part of a larger civil rights movement that aims to represent people who, as a group, have historically and systematically been discriminated against and barred from full inclusion in society. While self advocacy is part of the larger disability rights movement in many parts of the world, it is primarily focused on issues of concern for people with intellectual disabilities.

Self-determination
Self-determination is founded on the principle that people with mental disabilities have the right to make informed decisions about their lives and the ability to live as responsible citizens in the community. Efforts for deinstitutionalization and the prevention of institutionalization must incorporate self determination in community-based services so that people with mental disabilities are enabled to live independent lives to the greatest degree possible. Services that utilize a self determination philosophy empower and support clients to make informed decisions about their lives. Self determination also recognizes that equality of opportunity and freedom of choice are balanced with the duty to live as a responsible citizen. Therefore, services oriented for self determination provide the information and support necessary for clients to realize their responsibilities as members of society.

Service provider
An organisation that provides services and support to people with disabilities.

Service user
A person receiving community based services or support.

Supported decision-making
In contrast to guardianship (see above), supported decision-making (SDM) is based on the principle that all individuals have a right to self-determination and respect for their autonomy, irrespective of disability. This means all individuals have a will which provides the basis for decision making. This also means that

people with disabilities are entitled to necessary supports for exercising their decision-making capacity; for example, decisions made interdependently with family and trusted others should be legally recognized. In other words, SDM envisions that accommodations will be made in the legal system to enable people with intellectual disabilities and mental health problems to exercise their right to self-determination.

Supported employment

A service that facilitates employment on the open market for individuals with mental disabilities who have traditionally been denied employment and who need ongoing support to perform their work. The services include assistance in job seeking and individually tailored support and supervision for people with mental disabilities as well as ongoing support and consultation to employers and co-workers.

T

Tertiary health care

Specialized health services available in hospitals.

OPEN SOCIETY INSTITUTE

equitas
Centre international d'éducation aux droits humains
International Centre for Human Rights Education

Appendix
Links to Thirteen Health and Human Rights Documents

Links

Thirteen Health and Human Rights Documents

- International Covenant on Civil and Political Rights (ICCPR)
  www.equalpartners.info/Appendix/App_01iccpr.html
- Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights (Siracusa Principles)
  www.equalpartners.info/Appendix/App_02siracusa.html
- International Covenant on Economic, Social and Cultural Rights (ICESCR)
  www.equalpartners.info/Appendix/App_03icescr.html
- Committee on Economic, Social and Cultural Rights, General Comment 14, The right to the highest attainable standard of health
  www.equalpartners.info/Appendix/App_04EcSocCult.html
- The Maastricht Guidelines on Violations of Economic, Social and Cultural Rights (Maastricht Guidelines)
  www.equalpartners.info/Appendix/App_05Maastricht.html
- International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)
  www.equalpartners.info/Appendix/App_06icerd.html
- Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
  www.equalpartners.info/Appendix/App_07cedaw.html
- Committee on the Elimination of Discrimination against Women, General Recommendation 24, Women and Health
  www.equalpartners.info/Appendix/App_08ElDisWo.html
- African [Banjul] Charter on Human and Peoples' Rights (ACHPR)
  www.equalpartners.info/Appendix/App_09achpr.html
- Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Women's Protocol to the African Charter)
  www.equalpartners.info/Appendix/App_10WoProtocol.html
- [European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)
  www.equalpartners.info/Appendix/App_11echr.html
- European Social Charter (ESC)
  www.equalpartners.info/Appendix/App_12esc.html
- Appendix to the European Social Charter
  www.equalpartners.info/Appendix/App_13escapp.html
- European Charter of Patients' Rights
  www.equalpartners.info/Appendix/App_14ecpr.html

Health and Human Rights

A Resource Guide

Edited by Jonathan Cohen, Tamar Ezer, Paul McAdams, and Minda Miloff
With a Preface by Aryeh Neier

The field of health and human rights brings together two important movements. For public health advocates, human rights provide an essential tool for promoting accountability and addressing the non-medical roots of poor health. For human rights advocates, the protection of public health is a mark of democracy, good governance, and open society. As governments respond to urgent health threats in the 21st century, it is more important than ever for human rights groups to partner with health experts in advocating against abuses and generating pragmatic, rights-based solutions.

This Resource Guide provides a practical tool for all staff working at the intersection of health and human rights. It includes fact sheets, program descriptions, jurisprudence, case studies, and glossary definitions on seven priority areas of health and human rights: patient care; HIV/AIDS; harm reduction; palliative care; sexual health; minority health; and mental health. It also contains links to thirteen foundational human rights documents containing health-related provisions.

Prepared by OSI and Equitas staff together with leading experts in the field, this guide is designed to support health and human rights advocacy, training, education, programming, and grantmaking worldwide.

www.soros.org
www.equitas.org

OPEN SOCIETY INSTITUTE

equitas Centre international d'éducation aux droits humains
International Centre for Human Rights Education