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ECONOMIC, SOCIAL AND CULTURAL RIGHTS

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*

* The present report is submitted late so as to include as much up-to-date information as possible.

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Summary

Pursuant to Commission resolution 2004/27, the present report outlines some of the activities that the Special Rapporteur on the right to the enjoyment of the highest attainable standard of physical and mental health has undertaken since his second interim report to the General Assembly (A/59/422).

In his preliminary report of February 2003 to the Commission on Human Rights (E/CN.4/2003/58), the Special Rapporteur signalled his intention to give particular attention to, inter alia, discrimination and stigma, an emphasis that was endorsed by the Commission on Human Rights in resolution 2003/28.

In that context, the Special Rapporteur devotes his present report to a group that is among the most neglected, marginalized and vulnerable: persons with mental disabilities.

The human right to the enjoyment of the highest attainable standard of physical and mental health is complex and extensive. In the exercise of his mandate, the Special Rapporteur is developing a common way of approaching the right with a view to making it easier to understand.

Section I.A of the present report applies this common approach to mental disability and the right to health. It considers, for example, this subject in the context of freedoms, entitlements, non-discrimination and equality, participation, and international assistance and cooperation.

Section I.B briefly highlights three mental disability issues that demand particular attention: intellectual disability, the right to community integration, and consent to treatment.

The report closes with some brief conclusions and recommendations.
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Introduction

1. By its resolution 2002/31, the Commission on Human Rights established the mandate of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (“right to health”). Following his appointment in 2002, the Special Rapporteur presented a preliminary report to the Commission (E/CN.4/2003/58), outlining the approach that he proposes to take to his mandate, including the main themes of poverty, discrimination and the right to health.

2. In 2003, the Special Rapporteur submitted a report to the General Assembly (A/58/427) that considered, inter alia, the issue of indicators and benchmarks, as well as HIV/AIDS and the right to health. In 2004, the Special Rapporteur submitted a report to the Commission on Human Rights (E/CN.4/2004/49) that considered, inter alia, sexual and reproductive health rights, Niger’s Poverty Reduction Strategy, and neglected diseases. He also submitted a report on his mission to the World Trade Organization (E/CN.4/2004/49/Add.1). In resolution 2004/27, the Commission on Human Rights took note of the report of the Special Rapporteur, invited him to continue his analysis of the human rights dimensions of the issue of neglected diseases, and asked him to submit a report to the Commission at its sixty-first session on the activities undertaken in the course of his mandate, as well as an interim report to the General Assembly. The present report is submitted in accordance with resolution 2004/27.

Recent activities

3. In 2004, the Special Rapporteur submitted a report to the General Assembly (A/59/422) that considered, inter alia, the health-related Millennium Development Goals from the perspective of the right to health. Over the course of the year 2004, the Special Rapporteur undertook country missions to Peru (6-15 June) and Romania (23-27 August) at the invitation of those Governments. In the framework of his mandate, the Special Rapporteur attended various meetings. For example, in New York he met with representatives of the Millennium Project, the Millennium Campaign and UNICEF. He participated in a conference in Utrecht, the Netherlands, organized by the International Federation of Health and Human Rights Organizations, and a meeting in London on the right to health organized by Physicians for Human Rights-UK. He has been in regular contact with the World Health Organization (WHO) on a range of issues, including neglected diseases, and has also held discussions with UNAIDS. With the support of the WHO and the United Nations Development Programme/WHO/World Bank Special Programme for Research and Training in Tropical Diseases, the Special Rapporteur will complete in 2005 a report on neglected diseases and the right to health.

4. In October, the Special Rapporteur addressed the theme of racism and health at the Intergovernmental Working Group on the Effective Implementation of the Durban Declaration and Programme of Action. While in Washington, D.C., he addressed the American Public Health Association annual convention, the board meeting of the Health, Nutrition and Population Division of the World Bank, and a health and human rights training course organized by Physicians for Human Rights - USA. As part of his ongoing dialogue with the pharmaceutical sector, the Special Rapporteur spoke at an international symposium addressing the right to health and the role of pharmaceutical corporations, hosted by the Novartis Foundation for Sustainable Development. In New York, he gave a briefing organized by the Office of the High Commissioner for Human Rights and the NGO Committee for Human Rights,

**Individual communications**

5. Following the practice adopted by the Commission on Human Rights, information on specific cases raised by the Special Rapporteur during the period under review is published in an addendum (E/CN.4/2005/51/Add.1).

**I. MENTAL DISABILITY AND THE RIGHT TO HEALTH**

6. One in every four persons will suffer from a mental disorder at some stage in his or her life. Moreover, the incidence of such disorders is increasing. Today, about 450 million people around the world suffer from mental or neurological disorders, or from psychosocial problems. Very few of them are receiving treatment, care and support - and if they are, it is often seriously inappropriate. Mental and behavioural disorders are estimated to account for 12 per cent of the global burden of disease, yet the mental health budget of most countries is less than 1 per cent of their total health expenditure. Mental health care and support services are often not covered by health insurance. More than 40 per cent of countries have no mental health policy and over 30 per cent have no mental health programme. Over 90 per cent of countries have no mental health policy that includes children and adolescents. In short, mental health is among the most grossly neglected elements of the right to health.

7. Persons with intellectual disability are among the most neglected - the most “invisible” in our communities. Consistent with this neglect, there are no estimates for the burden of intellectual disability, but what evidence there is suggests it is substantial. Intellectual disability can place severe personal, economic and social burdens on both individuals and their families.

8. Where mental health care and support services are available, users are vulnerable to violations of their human rights within these settings. This is particularly true in segregated service systems and residential institutions, such as psychiatric hospitals, institutions for people with intellectual disabilities, nursing homes, social care facilities, orphanages, and prisons.

9. The Special Rapporteur has received numerous accounts of the long-term, inappropriate institutionalization of persons with mental disabilities in psychiatric hospitals and other institutions where they have been subjected to human rights abuses, including: rape and sexual abuse by other users or staff; forced sterilizations; being chained to soiled beds for long periods of time, and, in some cases, being held inside cages; violence and torture; the administration of treatment without informed consent; unmodified use (i.e. without anaesthesia or muscle relaxants) of electro-convulsive therapy (ECT); grossly inadequate sanitation; and a lack of food. In one European country last year, 18 patients at a psychiatric hospital died, from causes including malnutrition and hypothermia.

10. While abuse is particularly rife in large psychiatric hospitals and other residential institutions, there is also increasing information about human rights violations sustained by
persons with mental disabilities in community-based facilities. As countries move to community-based care and support, violations in this context will inevitably become more numerous unless appropriate safeguards are introduced.

11. Also alarming is the high rate of persons with mental disabilities, as well as the high rate of suicides, in prisons. In many cases, persons with severe mental disabilities who have not committed a crime, or who have committed only a minor offence, are misdirected towards prison rather than appropriate mental health care or support services. Prison conditions - such as overcrowding, lack of privacy, enforced isolation and violence - tend to exacerbate mental disabilities. However, there is often little access to even rudimentary mental health care and support services.\(^5\) Recent jurisprudence testifies to the vulnerabilities of persons with mental disabilities in detention to the violation of a range of their human rights.\(^6\)

12. Other groups also face particular vulnerabilities. For example, women with mental disabilities are especially vulnerable to forced sterilization and sexual violence, a violation of their sexual and reproductive health rights.\(^7\) Ethnic and racial minorities often face discrimination in access to, and treatment in, mental health care and support services. Indigenous populations are frequently ignored, with no specialist development of psychiatric and support services despite acute needs that are manifest in increasing suicide rates and overrepresentation in high-security mental health facilities.

13. Mental disabilities are common in all countries and may have a dramatic impact on the lives of individuals and their families. In addition to sometimes distressing limitations, stigmatization of various conditions often leads to discrimination against those affected - and this in turn may lead to their marginalization. It is this interaction between personal and societal limitations that gives rise to disability, and often denies those affected equal opportunities to enjoy a wide range of human rights and fundamental freedoms, including the rights to education, work, recognition as a person before the law, privacy, social security, adequate housing, adequate nutrition, and liberty. Where such disability-based stigma compounds discrimination on other grounds, such as gender, race and ethnicity, those affected are particularly vulnerable to violations of their human rights.

14. The World Health Organization recommends that mental health services, including support services, be based in the community and integrated as far as possible into general health services, including primary health care, in accordance with the vital principle of the least restrictive environment.\(^8\) However, in many developing countries, mental health care is not provided according to this model but is predominantly centralized and provided in large psychiatric hospitals, with little or no care and support services available in the community. Persons with mental disabilities and their families have to make difficult choices about whether to take up care far from their homes and communities, thereby depriving them of their right to live and work, as far as possible, in the community. In many countries, including developed countries, a lack of accessible community-based services and social housing leaves persons with mental disabilities homeless, deepening their marginalization.

15. As a result of increased knowledge about mental disability and new models of community-based services and support systems, many people with mental disabilities, once relegated to living in closed institutions, have demonstrated that they can live full and meaningful lives in the community. People once thought incapable of making decisions for
themselves have shattered stereotypes by showing that they are capable of living independently if provided with appropriate legal protections and supportive services. Moreover, many people once thought permanently or inherently limited by a diagnosis of major mental illness have demonstrated that full recovery is possible. Despite these significant advances, however, people with mental disabilities remain one of the most marginalized and vulnerable groups in all countries.

16. This chapter aims to clarify the right to health as it relates to persons with mental disabilities. It draws upon a range of sources, including case law, international human rights treaties and specialized non-binding international instruments, such as the recently adopted Montreal Declaration on Intellectual Disability. In his recent reports, the Special Rapporteur has been developing a common way of approaching large and complex right to health issues, with a view to making them easier to understand. This common approach looks at right to health issues in terms of freedoms, entitlements, non-discrimination and equality, participation, international assistance and cooperation, monitoring and accountability, and so forth. In this report, section I.A applies this common approach to mental disability, while section I.B selects three specific mental disability issues and looks at them in more detail.

17. In accordance with his mandate, the Special Rapporteur focuses on the right to health-related aspects of mental disability. Of course, however, persons with mental disabilities are entitled to the full range of human rights.

A note on terminology

18. When discussing mental health and mental disability, a complicating factor is the absence of agreement on the most appropriate terminology. Mental illness, mental disorder, mental incapacity, psychiatric disability, mental disability, psychosocial problems, intellectual disability, and several other terms are all used with different connotations and shades of meaning. Intellectual disability, once commonly referred to as mental retardation or handicap, is now sometimes referred to as developmental disability. Moreover, some of the terms reflect very important and sensitive debates, such as the discussion about a “medical model” or “social model” of functioning.9

19. Having taken extensive advice, the Special Rapporteur has decided to adopt the generic term “mental disability”. In this report the umbrella term “mental disability” includes major mental illness and psychiatric disorders, e.g. schizophrenia and bipolar disorder; more minor mental ill health and disorders, often called psychosocial problems, e.g. mild anxiety disorders; and intellectual disabilities, e.g. limitations caused by, among others, Down’s syndrome and other chromosomal abnormalities, brain damage before, during or after birth, and malnutrition during early childhood. “Disability” refers to a range of impairments, activity limitations, and participation restrictions, whether permanent or transitory.10

20. Accordingly, the Special Rapporteur uses the term mental disability when referring to the right-to-health entitlements and freedoms of common concern to, as well as abuses often experienced by, persons with all types of mental disability. He emphasizes, however, that the term encompasses a wide range of profoundly different conditions and notably two sets of conditions, psychiatric disabilities and intellectual disabilities, which are distinct in their causes and effects. These differences have a crucial bearing on how the right to health must be
interpreted and implemented if all persons with a mental disability are to enjoy their human rights on the basis of equality and non-discrimination. Because of space constraints, it is not possible specifically to explore all different conditions through the prism of the right to health. Instead, section I.A endeavours to provide a general guide to mental disability and the right to health, while section I.B devotes particular attention to, inter alia, persons with intellectual disabilities.

21. This chapter is also relevant to individuals who do not have a diagnosed mental illness, such as individuals who are perceived to have a mental illness and who are treated on this basis, as well as those without mental disability who are institutionalized in psychiatric hospitals for political, cultural, social, economic or other reasons.

22. Moreover, the right to mental health is not simply a concern of persons with mental disabilities, but also the population more generally. Mental health is a central element of good health and the right to mental health is a central element of the right to health for all. In some contexts, such as conflict or other humanitarian disasters, a particularly heavy burden is placed on the mental health of entire populations. The Special Rapporteur proposes to devote attention to the mental health dimensions of conflict in a forthcoming report focusing on the right to health in the context of conflict.

A. Evolving standards and obligations

23. Before considering mental disability and the right to health in the context of various international human rights treaties, the Special Rapporteur wishes to introduce some specialized non-binding international instruments that have crucial relevance to this chapter.

1. Some non-binding international instruments

24. Adopted by the General Assembly in 1991, the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (Mental Illness Principles) contain detailed minimum standards concerning the rights to, and in, health care of persons with mental illness, as well as the rights of anyone else in a mental health-care facility. The 25 Principles include a wide range of commitments relating to: standards of care and treatment, including the right to the least restrictive environment; the right to medication; consent to treatment; the treatment of minors and criminal offenders; the review of involuntary admissions; access to information; complaints, monitoring and remedies; and others. The Principles take a strong and positive position with regards to community integration, recognizing, inter alia, the right of every person with a mental illness to be treated and cared for, as far as possible, in the community in which he or she lives. While some of the Principles recognize important rights and standards, others are controversial and offer inadequate protections, notably on the issue of informed consent. (The Special Rapporteur revisits this issue in section I.B.)

25. Adopted by the General Assembly in 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) contain a broad range of commitments to ensure equal opportunities are available to persons with disabilities in all fields. The 22 detailed rules set out important principles for responsibility, action and cooperation including in relation to health care, rehabilitation, support services, awareness-raising, education,
employment, family life, policy-making and legislation. Significantly, they place emphasis on the right to participate of persons with disabilities, as well as the important role played by their representative organizations.  

26. In October 2004, State representatives, international organizations and representatives of civil society, including persons with intellectual disabilities and their families, adopted the Montreal Declaration on Intellectual Disability at an international conference organized by the Pan-American Health Organization (PAHO) and WHO. In brief, the Declaration recognizes the human rights of persons with intellectual disabilities, including the right to health, and the connections between this and other rights.


28. At the heart of these commitments is a range of cross-cutting human rights principles which underpin the realization of all human rights of persons with mental disabilities, including non-discrimination and equality, participation, autonomy, and access to procedural safeguards, accountability mechanisms and remedies.

29. While elements of these instruments are helpful and detailed, some are inadequate and need re-visiting, such as some provisions in the Mental Illness Principles. Moreover, these instruments are not binding on States. Meanwhile, the implementation of States’ binding human rights obligations in the context of mental health has been given inadequate attention. As a recent report by the Secretary-General put it, “a more detailed analysis of the implementation of State human rights obligations in the context of mental health institutions would be desirable”.

30. Many provisions contained in the Mental Illness Principles, the Standard Rules, the Montreal Declaration and other commitments relating to mental disabilities, have profound connections to the right to health. Common sense dictates that, where appropriate, these specialized instruments should be used as interpretive guides in relation to the treaty-based right to health. This is certainly the mature view taken by the Committee on Economic, Social and Cultural Rights. Equally, a range of conceptual frameworks, and other insights, arising from the treaty-based right to health provide useful guidance regarding the non-binding international instruments relating to mental disabilities. Properly understood, the generalized international human rights treaties and specialized international instruments relating to mental disabilities are mutually reinforcing, as the remainder of this chapter endeavours to illustrate.

2. Disability and the human right to the highest attainable standard of physical and mental health

31. The International Covenant on Economic, Social and Cultural Rights (ICESCR) recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. While ICESCR does not explicitly refer to disability as a prohibited ground of discrimination, general comments adopted by the Committee on Economic, Social and
Cultural Rights take the view that the Covenant prohibits discrimination on this ground. Other international treaties, such as the Convention on the Rights of the Child, regional treaties, as well as Constitutions and national legislation, enshrine both the right to the highest attainable standard of physical and mental health, and explicitly prohibit discrimination on grounds of disability.

32. The right to health is not a right to be healthy. It is a right to facilities, goods, services and conditions that are conducive to the realization of the highest attainable standard of physical and mental health. States should ensure facilities, goods, services and conditions for persons with mental disabilities so they may enjoy the highest attainable standard of health. In addition to entitlements to facilities, goods, services and conditions, the right to health includes certain freedoms.

3. Progressive realization and resource constraints

33. The international right to physical and mental health is subject to progressive realization and resource constraints. This has a number of important implications. Put simply, all States are expected to be doing better in five years time than what they are doing today (progressive realization). And what is legally required of a developed State is of a higher standard than what is legally required of a least-developed country (resource constraints).

34. It should be emphasized, however, that the international right to health also imposes some obligations of immediate effect. For example, it encompasses the right to be free from non-consensual medical treatment. The enjoyment of this freedom is subject to neither progressive realization nor resource availability. Like the requirement of non-discrimination, it has immediate application.

35. While many elements of the right to physical and mental health are subject to progressive realization and resource availability, there is a great deal that countries can do, even with very limited resources, towards the realization of the right. For example, even a country with very few resources can: include the recognition, care and treatment of mental disabilities in training curricula of all health personnel; promote public campaigns against stigma and discrimination of persons with mental disabilities; support the formation of civil society groups that are representative of mental health-care users and their families; formulate modern policies and programmes on mental disabilities; downsize psychiatric hospitals and, as far as possible, extend community care; in relation to persons with mental disabilities, actively seek assistance and cooperation from donors and international organizations; and so on.

36. This chapter includes many examples of what States - developing and developed - can do in relation to persons with mental disabilities and the right to health. Above all, however, it introduces a way of approaching, analysing and understanding mental disabilities through the prism of the right to health.

37. It is not possible in this chapter to provide a detailed analysis of the concepts of progressive realization and resource availability. For example, a State is obliged to use the maximum of its available resources towards the realization of the right to health. And progressive realization demands indicators and benchmarks to monitor progress in relation to mental disabilities and the right to health. An examination of these and other features of resource availability and progressive realization should be pursued on another occasion.
4. Freedoms

38. The right to health not only contains entitlements but also freedoms, including freedom from discrimination. Freedoms of particular relevance to the experience of individuals, especially women, with mental disabilities, include the right to control one’s health and body. Forced sterilizations, rape and other forms of sexual violence, which women with mental disabilities are vulnerable to, are inherently inconsistent with their sexual and reproductive health rights and freedoms. The Special Rapporteur notes that rape and other forms of sexual violence are psychologically, as well as physically, traumatic, and they negatively impact mental health.

39. Several international human rights instruments allow for exceptional circumstances in which persons with mental disabilities can be involuntarily admitted to a hospital or other designated institution. Clearly, such involuntary detention is an extremely serious interference with the freedom of persons with disabilities, in particular their right to liberty and security. Because of its seriousness, international and national human rights law establishes numerous procedural safeguards in relation to such involuntary admission. Moreover, these safeguards are generating a significant jurisprudence, most notably in the regional human rights commissions and courts.

40. Because of space constraints, the Special Rapporteur will not survey these procedural safeguards, but he wishes to emphasize that in many countries these protections are not respected. In some countries, for example, persons with mental disabilities are involuntarily detained without the input of a qualified mental health practitioner, or in inappropriate facilities. Also, they often do not have access to courts or tribunals to challenge their involuntary admission.

41. Crucially, the freedom element in the right to health, signalled in these paragraphs, is subject to neither progressive realization nor resource availability. Often, the involuntary admission of persons with mental disability not only is a deprivation of liberty but also involves the administration of medical treatment without their informed consent. (This issue is considered in paragraphs 87-90 below.)

5. Entitlements

42. The right to health includes an entitlement to a system of health protection, including health care and the underlying determinants of health, which provides equality of opportunity for people to enjoy the highest attainable standard of health. Crucially, care and support services - as well as medical attention - play a vital role in ensuring the health and dignity of persons with mental disabilities.

43. States should take steps to ensure a full package of community-based mental health care and support services conducive to health, dignity, and inclusion, including medication, psychotherapy, ambulatory services, hospital care for acute admissions, residential facilities, rehabilitation for persons with psychiatric disabilities, programmes to maximize the independence and skills of persons with intellectual disabilities, supported housing and employment, income support, inclusive and appropriate education for children with intellectual disabilities, and respite care for families looking after a person with a mental disability 24 hours a day. In this way, unnecessary institutionalization can be avoided.
44. Scaling up interventions to ensure equality of opportunity for the enjoyment of the right to health will require training adequate numbers of professionals, including psychiatrists, clinical psychologists, psychiatric nurses, psychiatric social workers, occupational therapists, speech therapists, behavioural therapists, as well as carers, in order to work towards the care and full integration of individuals with mental disabilities in the community. General practitioners, and other primary care providers, should be provided with essential mental health-care and disability sensitization training to enable them to provide front-line mental and physical health care to persons with mental disabilities.

45. As well as an entitlement to health care, the right to health includes an entitlement to the underlying determinants of health, including adequate sanitation, safe water and adequate food and shelter. Persons with mental disabilities are disproportionately affected by poverty, which is usually characterized by deprivations of these entitlements. Also, the conditions in psychiatric hospitals, as well as other institutions used by persons with mental disabilities, are often grossly inadequate from this point of view.

6. Available, accessible, acceptable and good quality

46. Analytical frameworks or tools can deepen our understanding of economic, social and cultural rights, including the right to health. One right-to-health framework that is especially useful in the context of policy-making is that health services, goods and facilities, including the underlying determinants of health, shall be available, accessible, acceptable and of good quality.

(a) Health-care facilities, goods and services must be available in adequate numbers throughout a State. This includes adequate numbers of mental health-related facilities and support services and adequate numbers of medical and other professionals trained to provide these services. For some persons with certain psychiatric disabilities, an adequate supply of essential medicines, including essential psychotropic medicines on WHO’s List of Essential Medicines, should also be available;

(b) Accessibility has four dimensions. First, health-care facilities, goods and services, including support services, must be accessible physically and geographically, in other words, in safe physical and geographical reach of persons with disabilities. This has especially important implications for community-based care. Second, health facilities, goods and services, including psychotropic drugs, must be economically accessible (i.e. affordable) to users. Mental health care and support services are often neither subsidized by the State, nor covered by health insurance, meaning that they can be unaffordable to most of those who need it. Third, mental and physical health-care services should also be accessible without discrimination on any of the prohibited grounds. States may need to take affirmative action to ensure equality of access for all individuals and groups, such as ethnic and racial minorities in need of care and support. States should ensure that persons with disabilities get the same level of medical care within the same system as other members of society, and do not face discrimination on the basis of
presumptions of their quality of life and potential. A fourth dimension concerns the accessibility of information. This entitlement is often denied to persons with mental disabilities because they are wrongly judged to lack the capacity to make or participate in any decisions about their own treatment and care. Information on health (and other) matters, including diagnosis and treatment, must be accessible to persons with mental disabilities, and the parents of children with mental disabilities;

(c) Health-care facilities, goods and services must be culturally acceptable and respectful of medical ethics. For example, mental health care and support services for indigenous peoples must be respectful of their cultures and traditions. According to the Mental Illness Principles: “Every patient shall have the right to treatment suited to his or her cultural background.” Also, they “shall have the right to receive such health and social care as is appropriate to [their] health needs”. Further, treatment and care “shall be based on an individually prescribed plan discussed with the patient, reviewed regularly, revised as necessary and provided by professional staff”. In some cases, for example severe intellectual disability, the discussion will involve the person’s guardian;

(d) Health-care facilities, goods and services must be of good quality, including scientifically and medically appropriate. This requires, inter alia, skilled medical and other personnel, evidence-based psychosocial interventions, scientifically approved and unexpired drugs, appropriate hospital equipment, safe and potable water, and adequate sanitation. In the context of mental disabilities this means that, for example, health professionals should be provided with adequate mental health-care training, and adequate sanitary facilities must be assured in psychiatric hospitals and other support services.

7. Respect, protect and fulfil

47. Another useful analytical framework is that States have specific obligations under international law to respect, protect and fulfil the right to health. While the framework outlined in the preceding paragraphs (availability, etc.) is especially helpful in the context of policy-making, the respect, protect and fulfil framework is especially useful as a way of sharpening legal analysis of the right to health, including in relation to mental disabilities.

48. The obligation to respect requires States to refrain from denying or limiting equal access to health-care services, as well as to underlying determinants of health, for persons with mental disabilities. They should also ensure that persons with mental disabilities in public institutions are not denied access to health care and related support services, or underlying determinants of health, including water and sanitation.

49. The obligation to protect means that States should take actions to ensure that third parties do not harm the right to health of persons with mental disabilities. For example, States should take measures to protect persons with mental disabilities, in particular women, adolescents and other especially vulnerable groups, from violence and other right to health-related abuses occurring in private health care or support services.

50. The obligation to fulfil requires States to recognize the right to health, including the right to health of persons with mental disabilities, in national political and legal systems, with a view to ensuring its implementation. States should adopt appropriate legislative, administrative,
budgetary, judicial, promotional and other measures towards this end.\textsuperscript{35} For example, States should ensure that the population’s right to the highest attainable standard of mental health, and the right to health of persons with mental disabilities, are adequately reflected in their national health strategy and plan of action, as well as other relevant policies, such as national poverty reduction strategies, and the national budget.\textsuperscript{36} The Special Rapporteur notes the importance of adopting mental health laws, policies, programmes and projects that: embody human rights and empower people with mental disabilities to make choices about their lives; give legal protections relating to the establishment of (and access to) quality mental health facilities, as well as care and support services; establish robust procedural mechanisms for the protection of those with mental disabilities; ensure the integration of persons with mental disabilities into the community; and promote mental health throughout society.\textsuperscript{37} Patients’ rights charters should encompass the human rights of persons with mental disabilities. States should also ensure that access to information about their human rights is provided to persons with mental disabilities and their guardians, as well as others who may be institutionalized in psychiatric hospitals.

\textbf{8. Non-discrimination and equality}

51. International human rights law proscribes discrimination in access to health care and the underlying determinants of health, and to the means for their procurement, on grounds including physical and mental disability, and health status.\textsuperscript{38}

52. Various forms of stigma and discrimination continue to undermine the realization of the right to health for persons with mental disabilities. For example, they often face discrimination in access to general health-care services, or stigmatizing attitudes within these services, which may dissuade them from seeking care in the first place. Stigma and discrimination within the community, schools and workplaces can also act as a barrier to persons seeking social support, diagnosis and treatment.

53. While the majority of families provide deeply caring and supportive environments for family members with mental disabilities, in some cases stigma may lead to inappropriate institutionalization of persons with mental disabilities against their will, including sometimes in institutions which have inadequate facilities for treatment and care, and where their dignity and other human rights are at risk.

54. Decisions to isolate or segregate persons with mental disabilities, including through unnecessary institutionalization, are inherently discriminatory and contrary to the right of community integration enshrined in international standards.\textsuperscript{39} Segregation and isolation in itself can also entrench stigma surrounding mental disability. The Special Rapporteur revisits the issue of community-based care in section I.B.

55. A lack of accurate information about mental disability, as well as inadequate support services, often fuels these decisions. The dissemination of information about mental disability, and the human rights of persons with disabilities, is an important strategy for combating stigma and discrimination. States have an obligation “to provide education and access to information concerning the main health problems in the community”.\textsuperscript{40} The provision of human rights and disability awareness training for health workers, as well as staff in related sectors, is also essential for ensuring equal access to care, and the respect of the human rights and dignity of persons with mental disabilities within care.
56. Under international human rights law, States not only have an obligation to prohibit discrimination, they also have a positive obligation to ensure equality of opportunity for the enjoyment of the right to health by persons with mental disabilities. For example, as well as being entitled to the same health-care services as other members of society, the right to health gives rise to an entitlement of persons with mental disabilities to have access to, and to benefit from, those medical and social services which promote their independence and autonomy, prevent further disabilities and support their social integration.\(^41\)

57. This may demand special measures for particular groups. For example, States should ensure that adolescents with mental disabilities or psychosocial problems have access to necessary services that are sensitive to their needs.\(^42\) The Committee on the Rights of the Child has stressed the particular importance of paying particular attention to, among others, the special needs relating to the sexuality of adolescents with disabilities.\(^43\)

58. Inappropriate resource allocation can lead to inadvertent discrimination.\(^44\) Crucially, the small budgetary allocations that most countries accord to mental health is a significant barrier to persons with mental disabilities enjoying their right to health on the basis of equality of opportunity.

9. Participation

59. Under international human rights law, the population is entitled to participate in health-related policy decision-making at the local, national and international levels.\(^45\) The right of persons with mental disabilities to participate in decision-making processes that affect their health and development, as well as in every aspect of service delivery, is an integral part of the right to health, and is affirmed in the Standard Rules and Montreal Declaration.\(^46\) Some persons with mental disabilities face difficulties making decisions or communicating preferences - in which case they should be supported in doing so.

60. It is essential that persons with mental disabilities, and their representative organizations, are involved at all stages of the development, implementation and monitoring of legislation, policies, programmes and services relating to mental health and social support, as well as broader policies and programmes, including poverty reduction strategies, that affect them. States should affirmatively solicit their input. As providers of care and support, family members also have an important contribution to make in legislative and policy processes, as well as decisions concerning care. Involving mental health-care users, their families and representative organizations, and encompassing their perspectives in the design and implementation of all relevant initiatives, helps to ensure that the needs of persons with mental disabilities are met.

61. While the Standard Rules and Montreal Declaration recognize that it is particularly important to engage representative organizations, such as mutual support and self-advocacy groups, mental disability organizations are not well developed in many parts of the world.\(^47\) In order to ensure compliance with these international instruments, States should support the development and strengthening of advocacy groups of persons with mental disabilities. Recent literature from the World Health Organization provides useful guidance for Ministries of Health in this respect.\(^48\)
10. International assistance and cooperation

62. In addition to obligations at the domestic level, States have a responsibility deriving from, inter alia, ICESCR article 2 (1) and CRC article 4, to take measures of international assistance and cooperation towards the realization of economic, social and cultural rights, including the right to health. This responsibility, which is particularly incumbent on developed States, also arises in the context of commitments made at recent world conferences, including the Millennium Summit and Millennium Development Goal 8, which the Special Rapporteur explores in his second report to the General Assembly.49

63. States should respect the right to health in other countries, ensure that their actions as members of international organizations take due account of the right to health, and pay particular attention to helping other States give effect to minimum essential levels of health.

64. Mental health care and support services are not a priority health area for donors. Where donors have provided financial assistance, this has sometimes supported inappropriate programmes, such as rebuilding a damaged psychiatric institution that was first constructed many years ago on the basis of conceptions of mental disability that are now discredited. By funding such a reconstruction, the donor inadvertently prolongs, for many years, seriously inappropriate approaches to mental disability. It is also unacceptable for a donor to fund a programme that moves a psychiatric institution to an isolated location, making it impossible for the users to sustain or develop their links with the community.50 If a donor wishes to assist children with intellectual disabilities, it might wish to fund community-based services to support children and their parents, enabling the children to remain at home, instead of funding new facilities in a remote institution that the parents can only afford to visit once a month, if at all.51

65. The Special Rapporteur urges donors to consider more - and better-quality - support in the area of mental disability. In accordance with their responsibility of international assistance and cooperation, donors should support a range of measures such as: supporting the development of appropriate community-based care and support services; supporting advocacy by persons with mental disabilities, their families and representative organizations; and providing policy and technical expertise. Donors should ensure that all their programmes promote equality and non-discrimination for persons with mental disabilities. Some agencies are already giving attention to these issues.52 For example, the United States Agency for International Development (USAID) now requires all applicants for funding to demonstrate how their programmes would be accessible to people with disabilities.53

66. A further aspect of international assistance and cooperation is the role played by international agencies in providing technical support. On this point, the Special Rapporteur emphasizes his support for the excellent technical support being carried out by organizations such as WHO and PAHO, as well as their publication of a range of excellent handbooks and guides on legislation and policy-making, including human rights dimensions.54

11. Monitoring and accountability

67. Human rights empower individuals and communities by granting them entitlements and placing legal obligations on others. Crucially, rights and obligations demand accountability: unless supported by a system of accountability, they can become no more than window dressing.
Accordingly, a human rights - or right to health - approach emphasizes obligations and requires that all duty-holders be held to account for their conduct. This applies in relation to the human rights of persons with mental disabilities. Indeed, because of the acute vulnerability of some persons with mental disabilities, it is especially crucial that effective, transparent and accessible monitoring and accountability arrangements be available.\textsuperscript{55}

68. One of the most urgent steps which many States need to take to facilitate the realization of the right to health of persons with mental disabilities, and other individuals who may be institutionalized in psychiatric hospitals, is to enhance monitoring and accountability at the national and international levels.

69. \textbf{At the national level:} In many countries, there is an absence of sustained and independent monitoring of mental health care. All too frequent abuses of the right to health, and other human rights, go unnoticed. This is the case not only in large psychiatric hospitals, but also in community-based settings. The Mental Illness Principles emphasize that: “States shall ensure that appropriate mechanisms are in force to promote compliance with these Principles, for the inspection of mental health facilities, for the submission, investigation and resolution of complaints and for the institution of appropriate disciplinary or judicial proceedings for professional misconduct or violation of the rights of a patient.”\textsuperscript{56}

70. This lack of surveillance is doubly problematic because persons with mental disabilities, especially those who are institutionalized, but also those living in the community, are often unable to access independent and effective accountability mechanisms when their human rights have been violated. This may arise for various reasons, including: where the severity of their condition renders them unable to independently protect their interests through legal proceedings; the absence of effective procedural safeguards, such as the right of persons who are deemed to lack legal capacity to have a personal representative; a lack of access to legal aid; and a lack of awareness of their human rights and other entitlements. In some cases, there is no independent accountability mechanism in the first place.

71. In addition to the crucial importance of effective monitoring arrangements, the Special Rapporteur emphasizes the vital role of accountability procedures and remedies in relation to mental disability, including for access to care and support services, discrimination and participation. An independent review body must be made accessible to persons with mental disabilities, or other appropriate persons, to periodically review cases of involuntary admission and treatment.\textsuperscript{57} It is imperative that the independent review body has the ability to overturn the involuntary admission if it finds continued confinement to be inappropriate or unnecessary. Persons with mental disabilities must be assured all the procedural safeguards spelled out in the Mental Illness Principles and elsewhere.\textsuperscript{58} A review body should also be empowered to consider cases where admission has been sought, but denied.

72. Unless such an arrangement already exists, the Special Rapporteur urges States to give urgent consideration to establishing an independent national human rights institution with a mandate that includes the promotion and protection of the human rights of persons with mental disabilities. The institution should have wide powers to carry out investigations, conduct public enquiries and determine complaints. Properly resourced, it should conform to the Paris Principles and report annually to Parliament. In appropriate cases, a State may wish to approach the OHCHR Technical Cooperation Programme for assistance in establishing such an institution.
73. **At the international level:** Clearly, there is a range of detailed international standards concerning the human rights of persons with mental disabilities. However, a significant problem remains their lack of implementation. While the identification of international standards is important, the real goal remains effective implementation. Although international monitoring of the Standard Rules is entrusted to the Special Rapporteur of the Commission for Social Development on the monitoring and implementation of the Standard Rules, the Mental Illness Principles do not establish a monitoring or accountability mechanism.

74. However, international human rights treaties, including ICESCR, CRC, CEDAW and CERD and ICCPR, extend protections to persons with mental disabilities. The Special Rapporteur encourages States to give greater attention to the right to health of persons with mental disabilities in their State party reports. The human rights treaty bodies should, in turn, be encouraged to give a greater focus to these issues in their discussions with States parties, concluding observations, and general comments or recommendations. Relevant civil society organizations, including representatives of persons with mental disabilities, should also be encouraged to engage with the treaty bodies, as well as the special procedures of the Commission on Human Rights.

75. In 2001, the General Assembly adopted a resolution in which it decided to establish an Ad Hoc Committee to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities. The Special Rapporteur warmly welcomes this development, as well as the active participation of organizations of persons with mental disabilities in this process. He emphasizes how important it is that the convention strengthens - and does not water down - the existing standards relating to the right to health of persons with mental disabilities and that it provides for a strong monitoring and accountability procedure.59

### B. Selected issues

76. While section I.A considers, in general terms, mental disability through the prism of the right to health, section I.B looks at three specific mental disability issues: intellectual disability; consent to treatment; and the right to community integration. Of course, there are many other specific mental disability issues that demand close examination. Also, the three selected issues deserve a much deeper treatment than they enjoy here. The purpose of the following paragraphs is very modest: to highlight briefly three crucial issues from the perspective of mental disability and the right to health.

#### 1. Intellectual disability

77. For years, the human rights community tended to neglect persons with disabilities. Within that group, persons with mental disabilities were often especially marginalized. Among persons with mental disabilities, among the most neglected were those with intellectual disabilities.60 In other words, for many years persons with intellectual disabilities were placed at the edges of the margins. More recently, some progress has been made to reverse this unacceptable situation. Nonetheless, in the course of researching this report, the Special Rapporteur has gained the impression that persons with intellectual disabilities remain among the most neglected - the most “invisible” - members of our communities. Their neglect is reflected in society at large, among the health professions, and in the human rights community.
78. Intellectual disability “is a condition of arrested or incomplete development of the mind characterized by impairment of skills and overall intelligence in areas such as cognition, language, and motor or social abilities”\(^6^1\). In short, the characteristic feature of this disability is a reduced level of intellectual functioning.\(^6^2\) There are many differences among persons with intellectual disabilities in terms of understanding, communication skills, concerns, discomforts and functioning, and this makes generalized prescriptions especially hazardous. Intellectual disability is distinct from psychiatric disability in causes, effects and needs. While it is misguided to conceive of intellectual disability as an illness, the Special Rapporteur’s preoccupation is the relationship between persons with intellectual disabilities and their right to health.

79. Despite differences, persons with all sorts of mental disabilities - intellectual or psychiatric - are vulnerable to many similar human rights abuses although, because of their varying ability to protect their own interests without assistance, persons with intellectual disabilities are often especially vulnerable. They can also be vulnerable in different contexts. For example, intellectual disability has been used as a ground to deny access to medical procedures such as organ transplants and life-saving treatments for newborn babies.\(^6^3\) Such reasoning is inherently discriminatory, with significant implications for the rights to health and life. Guardianship has been overused and abused in the medical, as well as other, contexts, including at the most extreme level to place persons with intellectual disabilities in psychiatric institutions.\(^6^4\) This is inappropriate medically and socially, and is inconsistent with the rights of persons with intellectual disabilities to health, autonomy, participation, non-discrimination and social inclusion.

80. Persons, and in particular children, with intellectual disabilities are vulnerable to a range of health complications particularly associated with their condition. In some cases, they may lack the capacity to learn healthy behaviours. For this reason, it can be especially difficult to distinguish their health, educational, developmental and other needs and rights. For children with intellectual disabilities, the goal is what the Convention on the Rights of the Child calls the child’s “fullest possible social integration and individual development”.\(^6^5\)

81. The support and care needs of persons with intellectual disabilities, and their families, are unmet in most - perhaps all - countries around the world. Persons with intellectual disabilities often require specialized support services which are tailored to their individual needs. This might include habilitation, speech pathology, occupational therapy, physiotherapy, and behavioural therapy. Along with other determinants of health, such as adequate housing, nutrition, and education, the accessibility of such services plays an important role in ensuring equality of opportunity for the right to health (and other human rights) of persons with intellectual disabilities. Support is also essential for the families of persons with severe intellectual disabilities, given the acute demands that care and support can place on them. For some individuals with intellectual disabilities and their families, a good environment may include access to a small, open community house with a stable staff and specialized support services.

82. The Montreal Declaration on Intellectual Disability, adopted in 2004, recognizes human rights standards pertaining to intellectual disability, including the right to health. According to the Declaration: “For persons with intellectual disabilities, as for other persons, the exercise of the right to health requires full social inclusion, an adequate standard of living, access to
inclusive education, access to work justly compensated and access to community services.”

The Declaration also contains other important standards, such as those on supported decision-making. In summary, the Declaration is an important first step in redressing the marginalization of persons with intellectual disabilities in relation to the right to health, as well as their other human rights.

2. The right to community integration

83. As has been emphasized elsewhere in this report, treatment and care are often provided far from the homes and places of work of persons with mental disabilities, while there is also a lack of community-based support services. This denies them their rights to live, work, and be treated and fully supported, as far as possible, in their communities.

84. The importance of community-based treatment, care and support is given significant emphasis in all modern standards concerning mental disability and can be seen as related to the movement to treat mental disability health services as part of primary health care. The Declaration of Caracas (1990), for example, promotes as its central message community-based service models integrated into social and health-care networks. One of the twin objectives of the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities, adopted in 1999, is to promote the full integration of persons with disabilities into society. The Mental Illness Principles explicitly refer to “the right to live and work, as far as possible, in the community” (Principle 3), “the right to be treated and cared for, as far as possible, in the community” (Principle 7 (1)), and “the right to return to the community as soon as possible” where treatment and care is otherwise unavailable (Principle 7 (2)).

85. 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 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.

86. Accordingly, the segregation and isolation of persons with mental disabilities from society is inconsistent with the right to health, as well as the derivative right to community integration, unless justified by objective and reasonable considerations, grounded in law and subject to independent scrutiny and determination.

3. Consent to treatment

87. Consent to treatment is one of the most important human rights issues relating to mental disability. While the issue is often considered in relation to the right to liberty and security of the person, as well as the prohibition against inhuman and degrading treatment, it is less frequently considered in the context of the right to health. However, consent to treatment is intimately connected with a vital element of the right to health: the freedom to control one’s health and body.
88. The Mental Illness Principles recognize that no treatment shall be given without informed consent. This is consistent with fundamental tenets of international human rights law, such as the autonomy of the individual. But this core provision in the Principles is subject to extensive exceptions and qualifications. While it is not possible here to analyse these complex exceptions and qualifications, in practice their combined effect tends to render the right of informed consent almost meaningless.

89. In the Special Rapporteur’s experience, decisions to administer treatment without consent are often driven by inappropriate considerations. For example, they sometimes occur in the context of ignorance or stigma surrounding mental disabilities, and expediency or indifference on the part of staff. This is inherently incompatible with the right to health, the prohibition of discrimination on the ground of disability, and other provisions in the Mental Illness Principles.

90. In these circumstances, it is especially important that the procedural safeguards protecting the right to informed consent are both watertight and strictly applied. Because this is presently not the case, the Special Rapporteur recommends that this important right to health issue is given urgent reconsideration with a view to better protecting, at the international and national levels, the right to informed consent.

II. CONCLUSIONS AND RECOMMENDATIONS

91. Mental disability has been neglected on many fronts. Many States have devoted inadequate budgetary resources to mental health and support services, and failed to develop adequate policies, programmes and laws. Some are responsible for systems of care within which the human rights of persons with mental disabilities are more likely to be violated than progressively realized. International organizations have traditionally given little focus to mental health, although WHO and PAHO are both making important strides towards redressing this imbalance. Donors have rarely supported persons with mental disabilities in their policies or assessed policies for their impact on persons with disabilities, although there are some signs that this, too, is beginning to change. Civil society organizations, including associations of persons presently or formerly affected by mental disabilities, have made remarkable progress in advancing debates on issues of mental disabilities and human rights, in the face of widespread discrimination and stigmatization.

92. Moreover, significant progress is being made in understanding the issues, as well as the development of appropriate support for persons with disabilities. This leads to greater opportunities for persons with mental disabilities to live a life of dignity, and to ensure, to the maximum extent, their autonomy, participation and integration into society. Increased attention to mental disability by policy and lawmakers is vital if these developments are to be used to support the realization of the human rights of persons with mental disabilities, including their right to health.

93. The Special Rapporteur recommends that States enhance and amplify policy and legal initiatives in the field of mental disability with the objective of ensuring the right to health, and other human rights, of persons with mental disabilities. In appropriate cases, they should request technical cooperation from WHO or PAHO, and financial support from donors. They should devote a much more significant part of their health budgets to mental health, and use this to develop prevention, as well as community-based treatment
and care. Monitoring of mental health care and support services, as well as strong accountability mechanisms that provide proper opportunities for persons with mental disabilities to seek redress, must also be given greater attention. A human rights approach, including participation, autonomy, dignity, and inclusion, should guide all these and other relevant actions.

Notes

1 World Health Report 2001, p. 3.

2 Ibid., p. 35.

3 The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment (CPT) has taken a strong stance against unmodified ECT; see CPT Standards: “Substantive” sections of the CPT’s General Reports, CPT/Inf/E (2002) 1 - Rev.2003.

4 See Mental Disability Rights International (MDRI)/Asociación Pro Derechos Humanos, Human Rights and Mental Health in Peru (2004); Mental Disability Advocacy Centre, Cage Beds: Inhumane and Degrading Treatment in Four EU Accession Countries (2003); Amnesty International, Romania: Memorandum to the Government Concerning Inpatient Psychiatric Treatment (2003).


7 See K. Raye, Violence, Women and Mental Disability (MDRI, 1999).


9 See WHO, International Classification of Functioning, Disability and Health (ICF), 2000.

10 WHO, ICF.

11 Also see G. Quinn, T. Degener, Human Rights and Disability, the Current Use and Future Potential of Human Rights Instruments in the Context of Disability (HR/PUB/02/1, United Nations, 2002).


13 See Standard Rule 14 (2).
Adopted respectively by: General Assembly resolution 37/52; the Regional Conference on the Restructuring of Psychiatric Care in Latin America, convened by PAHO/WHO; and the Parliamentary Assembly of the Council of Europe.

A/58/181, para. 43.

CESCR, general comment No. 5, paras. 7 (b) and 34.

CESCR, general comment No. 5, para. 5; CESCR, general comment No. 14, paras. 18 and 26.

ICESCR, art. 2 (1).


For the Special Rapporteur’s latest contribution about right-to-health approaches to indicators and benchmarks, see A/59/422.

See European Convention on Human Rights, art. 5 (1) (e) and Mental Illness Principle 16.


Standard Rules 2-4.

CESCR general comment No. 14, para. 4.

CESCR, general comment No. 14, para. 12.


Mental Illness Principle 7 (3).

Mental Illness Principle 8 (1).

Mental Illness Principle 9 (2).
33 CESCR, general comment No. 14, para. 33.


35 ICESCR, art. 2.1, general comment No. 14, para. 36.


38 See para. 31 above.

39 CESCR, general comment No. 5, para. 15.

40 CESCR, general comment No. 14, para. 44 (d).

41 CESCR, general comment No. 5, para. 34.

42 CRC, general comment No. 4, para. 22.

43 CRC, general comment No. 4, para. 35; UN Standard Rule 9 (2).

44 CESCR, general comment No. 14, para. 19.

45 CESCR, general comment No. 14, para. 11.

46 Standard Rules 14 and 18; Montreal Declaration, para. 6.

47 Standard Rules 14 (2) and 18; Montreal Declaration, para. 9 (d).


49 See A/59/422; Standard Rules 21 and 22 on International Cooperation.

50 See, for example, MDRI, *Not on the Agenda: Human Rights of People With Mental Disabilities in Kosovo* (2002).


53 See Consolidated Appropriations Act, 2005, Part D (Foreign Operations), Sec. 579.

Health Legislation (WHO: 2004); Modules included in the WHO Mental Health Policy and Service Guidance Package (www.who.int).

55 For some comments on accountability see the Special Rapporteur’s second report to the General Assembly, paras. 36-46, A/59/422, 2004.

56 Mental Illness Principle 22.

57 Mental Illness Principle 17.

58 Mental Illness Principles 11 and 18.

59 For information on the draft Convention and the drafting process, see www.un.org/esa/socdev/enable/.

60 E.g., the Mental Illness Principles focus on psychiatric disability. There is a more extensive body of case law on psychiatric disability. However, two important regional cases concerning intellectual disability are ECHR, HL v. UK (2004), and European Committee of Social Rights, Autism-Europe v. France (2002).

61 World Health Report 2001, p. 35. Also see WHO, ICD-10 Classification of Mental and Behavioural Disorders (1992).

62 Although a diagnosis is made only if also associated with a diminished ability to adapt to the daily demands of the normal social environment, see World Health Report 2001, p. 35.


64 S. Herr, Alternatives to Guardianship, in Herr et al. (2003).

65 Art. 23 (3).

66 Para. 4.

67 Principle 11. See also A/58/181.

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