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Human rights questions: human rights questions, including
alternative approaches for improving the effective enjoyment
of human rights and fundamental freedoms

Progress of efforts to ensure the full recognition and
enjoyment of the human rights of persons with disabilities

Report of the Secretary-General

Summary

In its resolution 2002/61, the Commission on Human Rights requested the Secretary-General to report annually to the General Assembly on the progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities. The Commission’s resolution was endorsed by the Economic and Social Council in its decision 2002/265 of 25 April 2002.

The present report focuses on the issue of procedural safeguards for persons with mental disabilities. It analyses briefly the key international human rights instruments relating to persons with mental disabilities, with a view to identifying the main substantive standards and procedural guarantees applicable with regard to persons with intellectual and psychiatric disabilities. In particular, the report considers such issues as legal capacity, involuntary institutionalization and involuntary or forced treatment, and reviews the way in which these international standards are transposed into domestic legislation.
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I. Introduction

A. Mandate contained in Commission on Human Rights resolution 2002/61

1. The present report is submitted in accordance with Commission on Human Rights resolution 2002/61 of 25 April 2002, in which the Commission requested the Secretary-General to report annually to the General Assembly on the progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities.

2. Several reports are submitted every year to different organs (General Assembly, Economic and Social Council) and subsidiary bodies (Commission on Human Rights, Commission for Social Development) of the United Nations on the issue of disability. In order to avoid duplication, the present report focuses on the protection afforded by international human rights law to persons with mental disabilities. The need to fill this information gap has been highlighted by the Special Rapporteur on Disability of the Commission for Social Development (E/CN.5/2002/4).

3. In its resolution 56/168 of 19 December 2001, the General Assembly established 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. Following the first session of the Ad Hoc Committee, the General Assembly, in its resolution 57/229 of 18 December 2002, requested the Secretary-General to seek the views of relevant bodies and organizations of the United Nations system on proposals for a convention including, inter alia, questions relating to its nature and structure and the elements to be considered. By focusing on a particular issue not fully considered in the past, the present report also aims at contributing to the discussions concerning the proposed new convention on the human rights of persons with disabilities.

B. Structure of the report

4. The present report focuses on the issue of procedural safeguards for persons with mental disabilities and aims at clarifying the protection afforded to them under international human rights law. In particular, the report analyses such issues as (a) legal capacity and arrangements for guardianship; (b) involuntary institutionalization; and (c) involuntary or forced treatment. In the report, the term “mental disability” (or “mental illness”) is used in its broadest possible sense, so as to include persons with intellectual and psychiatric disabilities. The term “mental disability” is also used to refer to individuals with no disability, who are nevertheless subject to discrimination on the perception that they have a mental illness, and individuals with a background of past treatment or hospitalization as patients with a mental disability.

5. The report does not aim to be an exhaustive analysis of human rights law as it relates to persons with mental disabilities. Therefore, such issues as protection from inhuman and degrading treatment (including protection from harm, unjustified medication and abuse of physical restraint and involuntary seclusion, the right to be treated in the least restrictive environment, the use of psychosurgery and other
intrusive and irreversible treatment for mental illness without obtaining informed consent), sexual exploitation, sterilization, access to mental health care and rehabilitation, and non-discrimination — although of extreme importance for ensuring the equal effective enjoyment of all human rights by persons with mental disabilities and closely linked with the need for procedural safeguards — are not considered on this occasion.

6. In order to solicit information on national legislation and practice relating to persons with mental disabilities, the Secretary-General distributed a questionnaire to States, relevant bodies and organizations of the United Nations system and national human rights institutions. Replies were received from the following States: Argentina, Armenia, Belize, Costa Rica, Croatia, Guatemala, Lebanon, Mexico, Morocco, Netherlands, Norway, Panama, Serbia and Montenegro, Spain, Sweden and United Kingdom of Great Britain and Northern Ireland. The United Nations Economic and Social Commission for Asia and the Pacific, the Economic and Social Commission for Western Asia and the World Health Organization submitted a contribution. The following national human rights institutions and commissions also provided information: the Human Rights Commission of Fiji; the National Commission for Human Rights of the Hellenic Republic; the Hong Kong Equal Opportunities Commission; the Islamic Human Rights Commission of the Islamic Republic of Iran; the National Human Rights Commission of Mauritius; the National Human Rights Commission of Mexico; the National Human Rights Commission of Mongolia; the National Human Rights Commission of Rwanda; the Disability Ombudsman of Sweden; and the Defensoría del Pueblo of Venezuela.

7. Section II of the report reviews briefly the key international human rights instruments, with a view to identifying the main substantive standards and procedural guarantees relating to persons with intellectual and psychiatric disabilities. Section III considers the issue of legal capacity and analyses the procedural safeguards existing under international law to protect individuals against possible improper uses of guardianship. Section IV deals with the issue of involuntary or forced institutionalization and highlights the principles of international human rights law which should govern admission to mental health facilities. Section V considers the substantive and procedural standards applicable in the context of treatment, with a particular emphasis on the human rights requirements for informed consent. Finally, section VI contains some concluding remarks and recommendations.

II. Human rights and disability: overview of the main international human rights instruments applicable for persons with mental disabilities

8. Despite the lack of United Nations human rights treaties specifically addressing the special concerns of individuals with mental disabilities, it is clear that this group of individuals is entitled to the same protection that human rights law affords in general to all persons. The Universal Declaration of Human Rights, in articles 1 and 2, states that all human beings are born free and equal in dignity and rights and are entitled to all the rights and freedoms set forth in the Declaration, 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.
Although disability is not explicitly mentioned among the prohibited grounds for discrimination, it is included in the concept of “other status” and is therefore one of the prohibited grounds of distinction.

9. Like the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (article 2 (1)) and the International Covenant on Economic, Social and Cultural Rights (article 2 (2)) include specific provisions relating to non-discrimination, and provide persons with mental disabilities with the right to liberty and security of person, to fair trial and to recognition everywhere as a person before the law, and the right to the highest attainable standard of physical and mental health, to education and to work, respectively. The Committee on Economic, Social and Cultural Rights adopted General Comment No. 5 (1994) on persons with disabilities, which spells out the relevance of economic, social and cultural rights in the context of disability. In addition to the two Covenants, which, along with the Universal Declaration, form the International Bill of Rights, other core United Nations human rights treaties are of relevance in promoting and protecting the rights of persons with mental disabilities.3

10. While most United Nations human rights treaties do not refer explicitly to persons with disabilities, other human rights instruments, such as declarations and resolutions adopted by international bodies, have set out agreed standards protecting this group of individuals.4 In particular, the General Assembly adopted two instruments specifically aimed at protecting and promoting the human rights of persons with mental disabilities, namely the Declaration on the Rights of Mentally Retarded Persons (resolution 2856 (XXVI) of 20 December 1971) and the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (resolution 46/119, annex, of 17 December 1991).

11. As its inappropriate terminology shows, the Declaration is in many ways outdated. It reflects an approach to disability commonly referred to as the “medical model”, in which persons with disabilities are primarily seen as individuals with medical problems, dependent on social security and welfare and in need of separate services and institutions. Nevertheless, the Declaration shows the first signs of a shift from a “caring” to a “rights-based” approach and contains some important principles for the protection and promotion of the human rights of persons with intellectual disabilities. Significantly, the Declaration begins by stating that such persons enjoy the same human rights as other human beings (para. 1). It then includes a list of rights which are of particular relevance, including the right to proper medical care and education.

12. The Principles set forth minimum human rights standards for persons with mental disabilities, and provide valuable guidance for the implementation of State obligations in the context of mental health facilities. They apply to all persons with an actual or perceived mental illness, whether or not they are admitted to a mental health facility. The Principles state that all persons with a mental disability — or who are being treated as such — shall be protected from discrimination on the grounds of mental illness and are entitled to enjoy the full range of civil, cultural, economic, political and social rights set forth in international human rights instruments. The Principles establish substantive standards and procedural guarantees for involuntary or forced commitment and treatment in psychiatric institutions. They also provide protection against the most serious human rights abuses which may occur in such institutions, such as misuse or inappropriate use of
physical restraint or involuntary seclusion, administration of improper medication as a punishment, sterilization, the use of psychosurgery and other intrusive and irreversible treatment for mental illness without obtaining informed consent.

13. The Principles have served as a model for drafting mental health legislation in several countries, and represent an important instrument for clarifying the content of general human rights law with regard to the particular circumstances and needs of persons with mental illnesses. However, it follows from their very legal nature that they cannot impose the same level of legal obligation upon States as binding and voluntarily accepted treaty obligations. Furthermore, they offer in some cases a lesser degree of protection than that offered by existing human rights treaties, for example with regard to the requirement for prior informed consent to treatment. In this regard, some organizations of persons with disabilities, including the World Network of Users and Survivors of Psychiatry, have called into question the protection afforded by the Principles (and in particular, principles 11 and 16) and their consistency with existing human rights standards in the context of involuntary treatment and detention. The Principles also lack specific provisions requiring the competent judicial authority to adapt guardianship arrangements to the actual capacities of the individual. The sections below provide information on the actual implementation of the relevant international standards at the national level, with a view to identifying those aspects which may be strengthened in the new proposed convention on the human rights of persons with disabilities.

III. Legal capacity

14. Under international human rights law, individuals have the right to be recognized as persons before the law. This right finds its corollary in the principle of autonomy or self-determination, according to which each individual is presumed to be able to make life choices and act independently on the basis of his or her conscience. Individuals with a mental illness may in some circumstances be unable, because of the severity of their condition, to protect their own interests. In those cases, the person may be “incapacitated” and placed under legal guardianship. The function of guardianship is to protect the individual from any danger which his or her mental conditions may cause. International human rights law requires the adoption of substantial and procedural guarantees to prevent improper recourse to, and use of, guardianship arrangements.

15. The right to recognition as a person before the law is often neglected in the context of mental health. The concept of guardianship is frequently used improperly to deprive individuals with an intellectual or psychiatric disability of their legal capacity without any form of procedural safeguards. Thus, persons are deprived of their right to make some of the most important and basic decisions about their life on account of an actual or perceived disability without a fair hearing and/or periodical review by competent judicial authorities. The lack of due process guarantees may expose the individual whose capacity is at stake to several possible forms of abuse. An individual with a limited disability may be considered completely unable to make life choices independently and placed under “plenary guardianship”. Furthermore, guardianship may be improperly used to circumvent laws governing admission in mental health institutions, and the lack of a procedure for appealing or automatically reviewing decisions concerning legal incapacity
could then determine the commitment of a person to an institution for life on the basis of an actual or perceived disability.

16. The Principles on mental illness establish substantive standards and procedural guarantees against the improper use of guardianship. Principle 4 states that a determination of mental illness must be made in accordance with internationally accepted medical standards. Principle 1 (6) provides that any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue is entitled to be represented by a counsel. In order to avoid possible conflicts of interest, principle 1 (6) also provides that the counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue. The decision concerning capacity and the need for a personal representative must be reviewed at reasonable intervals prescribed by domestic law and the person whose capacity is at issue, his or her personal representative, if any, and any other interested person have the right to appeal this decision to a higher court.

17. According to principle 1 (7), a person can be deprived of his or her legal capacity only where a court or other competent tribunal finds that a person is unable, due to his or her mental conditions, to manage his or her own affairs. In that case, measures shall be taken, so far as is necessary and appropriate to that person’s condition, to ensure the protection of his or her interests. The Principles do not provide any element to evaluate whether the measures concerning the denial or restriction of legal capacity adopted by the tribunal are “necessary” and “appropriate”. However, the right to be recognized as a person before the law and the principle of proportionality seem to suggest that any restriction on a person’s right must be based on a specific finding that the individual lacks the capacity to make decisions by himself or herself with regard to that specific activity. Consequently, the court’s decision should ascertain that the limitation of the individual’s capacity is strictly necessary to protect the rights of the person whose capacity is at issue and specify exactly what powers the guardian has and what legal capacity the person retains. Outside those cases, the placement of persons with mental illness under plenary guardianship could constitute a violation of the right to be recognized as a person before the law and, insofar as it denies people with mental disabilities the ability to exercise the same rights as all other persons, also constitutes illegal discrimination under article 26 of the International Covenant on Civil and Political Rights (equality before the law).

18. From the submissions received, it appears that, in general, a person can be deprived of his or her legal capacity when she or he is totally or partially unable to take care of his or her affairs on his or her own, owing to a psychiatric or mental disorder. In some countries, persons with a sensorial impairment who have not received a proper education are deemed incapable of taking decisions concerning themselves. The application is usually submitted by a spouse, next of kin or the public prosecutor.

19. In most of the responding countries, the decision on legal capacity is taken by the competent civil court, usually on the basis of the views of a mental health practitioner. An exception is represented by the Netherlands, where the decision on
capacity is taken by a care provider in consultation with the members of his or her team, and usually after having heard the opinion of an independent physician. In Hong Kong SAR, the appointment of a guardian is decided by the Guardianship Board, which is composed of experts in different disciplines. While the case is being heard, the judge can, in some cases, adopt interim measures, including the appointment of a provisional guardian, to protect on a temporary basis the interests of the person concerned. The person whose capacity is at stake is represented by his or her legal representative or provisional guardian; in some cases, she or he can participate and be heard at the capacity hearing. In Venezuela, such participation is required for the validity of the proceedings.

20. Courts can usually choose among different guardianship arrangements. In most countries, the legislation provides two kinds of guardianship arrangements: “full guardianship”, an arrangement for those situations in which the person concerned is deemed completely unable to act independently, and partial guardianship”, a less restrictive arrangement, in which the judge must specify the acts that the person concerned may carry out independently and those for which the assistance of a guardian is required. In some Spanish-speaking countries, for example, the legislation distinguishes between tutela (full guardianship) and curatela (partial guardianship). In a few countries, the courts may choose among a wider list of options. Under article 1679 of the Greek Civil Code, for example, the judge may adapt the two existing forms of guardianship (“privative judicial support”, which corresponds to full guardianship, “auxiliary judicial support”) to the particular circumstances of the case (so-called “combined judicial support”), and indicate the legal acts that the persons may carry out on his or her own and those for which she or he requires the guardian’s approval. In the Netherlands, the court may choose among the appointment of a guardian (the most far-reaching protective measure), an administrator or a tutor.

21. In most countries, the consequences of the determination of legal incapacity depend on the form of representation chosen by the court. In general terms, persons subject to full guardianship cannot perform any legal act by themselves and must be assisted at all times by their guardians (although they may retain the capacity to carry out independently some legal acts belonging to the sphere of family law, such as the testamentary capacity or the capacity to get married), whereas persons subject to partial guardianship retain their legal capacity for those acts which have not expressly been attributed to the guardian. In Sweden, a person for whom a guardian is appointed loses the right to decide only on the matter(s) covered by the guardianship decision, but in all other respects retains his or her legal competence; a person for whom a conservator is appointed retains instead full legal competence. In the United Kingdom, there are different approaches to testing capacity and different definitions of capacity, most of which are set out in case law rather than in statute. A new single definition of capacity, called “functional test”, is currently under discussion. It would allow for cases in which the individual is able to make some decisions, but is unable to understand the implications of others, thus ensuring that they are not excluded from making decisions that they are capable of making.

22. The submissions received indicate that, in the countries concerned, the decisions concerning capacity may usually be appealed to a higher court. In some countries, an appeal may also be lodged with other authorities. In the Netherlands, for instance, the decision on capacity may ultimately be reviewed by a complaints committee, the Medical Disciplinary Board or the ordinary courts. In Sweden, an
IV. Involuntary and forced institutionalization

23. Article 9 (1) of the International Covenant on Civil and Political Rights provides that 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. This provision is of extreme importance in the context of civil commitment of persons with intellectual or psychiatric disabilities, as it requires that the institutionalization of persons with disabilities in mental health facilities be carried out in accordance with the substantive standards and the procedural guarantees established by national law. In its General Comment No. 8 (1982) on liberty and security of person, the Human Rights Committee pointed out (para. 1) that the protection afforded by article 9 (1) was applicable to all deprivations of liberty, whether in criminal cases or in other cases such as, for example, mental illness. In particular, the Committee recognized that the right to control by a court of the legality of the detention applied to all persons deprived of their liberty, and that States parties had to ensure that an effective remedy was provided in other cases in which an individual claims to be deprived of his liberty in violation of the Covenant.

24. The general protection afforded under article 9 of the Covenant is supplemented by the Principles on mental illness, which set forth substantive criteria and due process protections against improper detention in mental health facilities.

25. With regard to the substantive criteria, the Principles limit involuntary admission to a mental health facility to people who have been diagnosed with a mental illness by a qualified mental health practitioner in accordance with internationally accepted medical standards. A determination of mental illness is a necessary but not sufficient ground for involuntary commitment. Principle 9 provides, in fact, that "every patient shall have the right to be treated in the least restrictive environment" and principle 15 (1) stipulates that where a person needs treatment in a mental health facility, every effort shall be made to avoid involuntary admission. Therefore, a person with a mental illness may be admitted to a psychiatric institution only if one of the two additional criteria referred to in principle 16 (1) are met. According to the first criterion, the person must present a "serious likelihood of immediate or imminent harm" to him or herself or to other persons (principle 16 (1) (a)). Alternatively, a person whose mental illness is severe and whose judgement is impaired may be committed to a psychiatric facility if failure to admit or retain that person is likely to lead to a serious deterioration in his or her condition or will prevent the giving of appropriate treatment that can only be given by admission to a mental health facility in accordance with the principle of the least restrictive alternative (principle 16 (1) (b)).
26. It has been noted that “this second criterion for commitment is much broader than the first, and it creates a risk of opening up psychiatric commitment to anyone who is determined to ‘need treatment’.” However, the reference to the principle of the least restrictive alternative greatly limits the discretionality of the mental health practitioner, and permits institutionalization only as an *extrema ratio*, that is, only when the person cannot be adequately treated and cared for in the community in which he or she lives (principle 7 (1)). Principle 16 (1) also provides that in the case referred to in subparagraph (b), a second such mental health practitioner, independent of the first, should be consulted, and that if such consultation takes place, the involuntary admission or retention may not take place unless the second mental health practitioner concurs.

27. With regard to procedural guarantees, principle 16 (2) establishes that involuntary admission or retention shall initially be for a short period as specified by domestic law for observation and preliminary treatment pending review of the admission or retention by the review body. The grounds and the fact of the admission must be communicated to the person “without delay”, and also communicated “promptly and in detail” to the review body, to the person’s personal representative, if any, and, unless the person objects, to his or her family. The review body is a judicial or other independent and impartial body established by domestic law and functioning in accordance with procedures laid down by domestic law. Its function is to review whether the decision to admit or retain a person as an involuntary patient has been taken in accordance with the substantive criteria set forth in principle 16 (1) (principle 17 (1)). In formulating its decision, the review body is assisted by one or more qualified and independent mental health practitioners, who must be independent from the institution seeking the involuntary commitment.

28. The person, his or her personal representative and any interested person have the right to appeal to a higher court against a decision that the person be admitted to, or be retained in, a mental health facility (principle 17 (7)). An involuntary patient may also apply to the review body for release or voluntary status, at reasonable intervals as specified by domestic law (principle 17 (4)). At each review, the review body considers whether the criteria for involuntary admission set out in principle 16 (1) are still satisfied and, if not, the person has to be released. The review body also have the task to review decisions concerning involuntary commitment ex officio, at reasonable intervals as specified by domestic law (principle 17 (3)). Principle 18 contains detailed provisions to ensure that the right of the person subject to civil commitment to a fair process is effective. The person has the right to choose and appoint a counsel to represent him or her in any complaint procedure or appeal. She or he and his or her counsel are entitled to attend, participate and be heard personally in any hearing, and to request and produce independent mental health reports as well as oral, written and other evidence that are relevant and admissible. They also have a right to access to the patient’s records.

29. Some of the submissions received provided information on the procedure to be followed in case of involuntary admission of a person with a mental illness in a mental health facility. In general terms, decisions concerning institutionalization can only be adopted by the judicial authority, on the basis of a previous diagnosis of mental illness. In some countries, where commitment to a mental health facility is carried out without the previous intervention of the judicial authority (i.e. in emergency situations, where there is a concrete and imminent threat for the health of
the person or the safety of others), mental health authorities must promptly request a review of this decision by the competent judge. In other countries, however, decisions on compulsory care are taken by medical officers, and only at a later stage subject to the scrutiny of the judicial authority. In Sweden, for example, the decision on compulsory care is taken by the chief medical officer at the department of psychiatric care without the intervention of the court, which is needed only if treatment must be provided for more than four weeks from the decision on admittance.

30. In most of the countries concerned, institutionalization can be requested only when the person presents a danger for him or herself or other persons. In others, civil commitment in a psychiatric institution may also be ordered when the person is in need of treatment. In the latter case, national legislation often provides procedural safeguards, such as the appointment of a special representative for the person (defensor especial), aimed at ensuring that admission to psychiatric facilities is not prolonged for more than is necessary for reasons of treatment. In Sweden, compulsory care can only be provided if a person suffers from a serious mental disorder and due to his or her mental condition and personal circumstances has an unavoidable need of psychiatric care, which cannot be provided in any other way than the patient being admitted to a medical institution. In a few cases (Costa Rica, Mexico), a person can be involuntarily admitted as a patient without a previous diagnosis of mental illness, on the sole basis of a certificate issued by a qualified medical doctor stating that treatment is necessary for the patient.

31. The application for involuntary institutionalization is usually lodged by a medical practitioner, the guardian or tutor or the closest relatives of the mentally ill person. In some countries, the application may also be submitted by other persons, such as the public prosecutor (Greece), an approved social worker (Croatia, United Kingdom) or any citizen when the person concerned represents a threat to public security. The decision on institutionalization is usually based upon the written opinion(s) of one or two independent medical doctors or mental health practitioners. In Rwanda, the judge must also seek the views of the Family Council, an institution which protects and promotes the interest of the family and its members. Usually, the court also hears the person concerned. In Venezuela, for example, the absolute legal incapacity (interdicción) cannot be decreed without the person concerned having been questioned and four immediate relatives or, in their absence, family friends, having been heard.

32. In most responding countries, decisions on involuntary admission can usually be appealed to the higher court. In others, they are appealed to the same court but decided by a different judge (Croatia, Rwanda). Sometimes, involuntary patients or their representatives can apply to a specific Mental Health Review Tribunal or Commission. Complaints may also be lodged with the national human rights institution or commission, where they exist (Fiji, Mongolia). In Costa Rica, decisions on involuntary commitment may be appealed against before the Constitutional Chamber of the Supreme Court of Justice.

33. Different mechanisms exist for the review of such decisions, with a view to obtaining release. In Argentina, the Ministry for Minors and Persons with Disabilities (Ministerio de Menores e Incapaces) and the special representative (defensor especial) appointed pursuant to article 482 of the Civil Code verify that institutionalization is limited to the time strictly necessary to ensure the fulfilment
of the therapeutic needs of the person. In some countries, the review of commitment
decisions is carried out by medical authorities at the institution, without the
involvement of any independent authority.34 In Fiji, the review is entrusted to the
Medical Superintendent and the Ministry of Health. In Greece, the institutionalized
person, his or her next of kin and the public prosecutor may apply for the review of the
commitment decision, and the court decides, taking account of a report on the
patient’s state of health prepared by the director of the psychiatric hospital and
another State psychiatrist.35 In Guatemala, the review is carried out by the Dirección
Ejecutiva of the National Hospital for Mental Health. In Rwanda, the review of
commitment decisions is entrusted to the Family Council. In Spain, the review is
carried out periodically by the judge on the basis of information provided by the
medical authorities. In Sweden, it is carried out by the court four weeks after the
initial admittance, and a four-month extension may be granted. For further extension
of time, a new decision by the court, granting authorization for at most six months at
time, is needed.

V. Involuntary and forced treatment

34. The right to be recognized as a person before the law, along with the basic
human rights principles of dignity and autonomy, endows individuals with the right
to make independent life choices on the basis of their conscience. Other rights, such
as the right to privacy (article 17 of the International Covenant on Civil and Political
Rights) and the right to freedom of thought, conscience and religion (article 18 of
the Covenant), may also be relevant in ensuring the effective enjoyment of the right
to decide autonomously about one’s life. Persons with mental disabilities — and in
particular those residing in mental health institutions — are often deprived of this
right, on the assumption — sometimes erroneous — that they lack capacity for self-
directed action and behaviour. The violation of their right to self-determination may
be particularly serious with regard to involuntary or forced treatment, that is, with
regard to those situations in which persons with mental disabilities are subjected to
medical treatment or scientific experimentation without their prior informed
consent.

35. Article 7 of the International Covenant on Civil and Political Rights, which
ensures protection from torture or other forms of inhuman or degrading treatment,
provides that no one shall be subjected without his free consent to medical or
scientific experimentation. The requirement of free and informed consent is
commonly alleged to be ignored in the practice of many mental health facilities. In
this regard, the Human Rights Committee affirmed that special protection in regard
to such experiments is necessary in the case of persons not capable of giving valid
consent, and that such persons should not be subjected to any medical or scientific
experimentation that may be detrimental to their health.36 The Committee on
Economic, Social and Cultural Rights linked this right to the right to health (article
12 of the International Covenant on Economic, Social and Cultural Rights), stating
that the latter includes the right to control one’s health and body, including sexual
and reproductive freedom, and the right to be free from interference, such as the
right to be free from torture, non-consensual medical treatment and
experimentation.37

36. The Principles on mental illness provide valuable guidance for the
interpretation of these human rights in the context of treatment of persons with
mental disabilities. Principle 9 sets out the basic human rights standards with regard to treatment in mental health facilities. Treatment must be directed towards preserving and enhancing the personal autonomy of the patient, and be provided in accordance with applicable standards of ethics for mental health practitioners, including internationally accepted standards. Thus, patients have the right to be treated with the least restrictive or intrusive treatment, and on the basis of an individually prescribed plan, discussed with the patient and reviewed regularly by qualified professional staff. Principle 11 provides persons held in institutions with protection against forced or involuntary treatment. It states that no treatment shall be given to a patient without his or her informed consent. Informed consent is consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient (principle 11 (2)). The person has also the right to refuse or stop treatment, except as provided for in paragraphs 6, 7, 8, 13 and 15 (principle 11 (4)). In this case, the consequences of refusing or stopping treatment must be explained to him or her. The right to informed consent cannot be validly waived.

37. However, the Principles contain several exceptions to the right to informed consent. Principle 11 permits involuntary treatment when an independent authority finds that the person lacks the capacity to give or withhold informed consent or unreasonably withholds such consent, and is satisfied that the proposed plan of treatment is in the best interest of the patient’s health needs. For individuals placed under guardianship, the Principles provide that the guardian be fully informed about the treatment and consent to it on the person’s behalf (principle 11 (7)). Furthermore, involuntary treatment may also be given if a qualified mental health practitioner authorized by law determines that it is urgently necessary in order to prevent immediate or imminent harm to the patient or to other persons (principle 11 (8)). The Principles also provide exceptions to the principle of informed consent with regard to major medical or surgical procedure and clinical trials and experimental treatment. Principle 11 (13) states that a major medical or surgical procedure carried out on a person unable to give consent can be authorized only after independent review. Similarly, principle 11 (15) states that clinical trials and experimental treatment on persons without their informed consent can be carried out only with the approval of a competent, independent review body specifically constituted for this purpose. 38

38. Principle 11 provides procedural safeguards against abuse of the exceptions provided in paragraphs 6, 7, 8, 13 and 15. Paragraph 10 provides that all treatment shall be immediately recorded in the patient’s medical records, with an indication of whether involuntary or voluntary. The patient’s personal records are maintained by the mental health facility, and the person and his or her personal representative and counsel have the right to have access to the information contained in it (principle 19). These provisions aim at facilitating access to information concerning involuntary treatment, with a view to allowing the person, his or her personal representative, or any interested person, to appeal to a judicial or other independent authority concerning any treatment given to him or her.

39. In most of the responding countries, domestic legislation requests that the person, or — when she or he is subject to guardianship — his or her legal representative, be informed of his or her rights and provide informed consent prior to treatment. In some countries, consent to treatment may also be provided by the
next of kin.39 With some exceptions,40 persons are usually informed that their consent is necessary for the administration of treatment and can always be withdrawn. In Fiji, decisions regarding treatment of persons in institutions are usually taken by the Medical Superintendent, on the assumption that once admitted the person consents “to all treatments and procedures”. Patients and their relatives or guardians are sometimes “informed” of the procedures, but in case of disaccord between them and the Medical Superintendent, the latter’s decision will prevail “if the treatment is critical for the patient”.41 In the Netherlands, the legislation expressly recognizes the right to refuse treatment, but the person’s consent must be explicitly sought only in the case of major examinations or forms of treatment. In other cases, tacit consent is assumed instead.

40. In all the responding countries the principle of prior informed consent is subject to exceptions, which in some cases are so wide that they risk compromising the applicability of the general rule. Usually, these exceptions include the lack of a legal representative,42 the need to adopt urgent measures to protect the patient’s health43 or other persons (Croatia, Mongolia), risk for public health (Spain), and the lack of other alternatives (Costa Rica). In the Netherlands, the person may be treated against his or her will or that of his or her representative only insofar as this is absolutely necessary to avert a serious risk to the patient or others arising from mental disorder. In that case, the person’s closest relatives must be informed, the Inspectorate notified and the measures registered in the patient’s medical records. In the United Kingdom, the common-law principle according to which a valid consent is required before medical treatment can be given is subject to exceptions in statutes. Thus, treatment may be administered without the person’s consent when a second opinion from a registered medical practitioner has ascertained that this is necessary in the patient’s best interest.

41. The requirement of prior informed consent seems to be applied more strictly in the field of major medical or surgical procedure and medical or scientific experimentations. In a few countries, medical or scientific experimentations on human beings are expressly prohibited by law.44 In most responding countries, medical trials or research activities cannot be carried out without the person’s informed consent. When the person is unable — due to his or her condition — to provide a valid consent, medical experimentations can be carried out only when their guardians have been fully informed about the nature, scope and implications of the project and have consented to it (Costa Rica, Croatia). In the Netherlands, for example, research on persons incapable of a reasonable assessment of their interest — in principle prohibited — can be carried out with the consent of the person’s legal representative when the research can only be performed on persons belonging to a specific category and the risks are negligible. In some countries, medical or scientific trials must be also approved by a medical ethics review committee (Croatia, the Netherlands).

42. In the countries that replied to the questionnaire, patients or their legal representatives can usually file a complaint with the competent authority with regard to the treatment received in institutions. In Mongolia, a patient, his or her legal representative or any other interested person have the right to appeal a decision on medical treatment before a court or the national human rights commission. In the Netherlands, people residing in mental health facilities may lodge a complaint before the independent complaints committee which is established in each institution, the Medical Disciplinary Board or the Health Care Inspectorate.
United Kingdom, the patient, his or her legal representative or the next of kin can apply to the High Court for a judicial review of the decision concerning treatment, and the Court has the power to adopt interim measures to prevent the treatment taking place. Complaints can also be lodged with the Hospital Trust or the Medical Health Act Commission, a statutory body with authority to investigate complaints made by or on detained persons.

VI. Conclusions and recommendations

43. One of the major obstacles to the implementation of existing human rights standards for persons with mental disabilities is the lack of specific guidelines on their application. The Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care provide a valuable starting point to clarify the content of general human rights standards with regard to the particular situation of persons with mental disabilities. However, a more detailed analysis of the implementation of State human rights obligations in the context of mental health institutions would be desirable. This clarification could be provided, for example, by the Human Rights Committee in a general comment.

44. The protection afforded by the Principles needs to be strengthened in some cases. The language used is in some cases outdated. The term “patient”, for example, should be replaced by “person”.

45. The Principles lack an explicit right to refuse treatment for persons detained in psychiatric facilities. The generous exceptions to this right contained in principle 11 deprive it of real meaning. Psychiatric detention should not mean giving up a person’s right to choose his or her medical treatment. This right is firmly established under international human rights law. Limitation of rights concerning treatment decisions should always be subject to judicial review.

46. The Principles do not provide any element to evaluate whether the decision on capacity adopted by a court is “necessary” and “appropriate” to protect the interest of the person concerned (principle 1 (7)). Any restriction on a person’s right must be based on a specific finding that the individual lacks the capacity to make decisions by him or herself with regard to that specific activity. The court’s decision must clearly determine the acts that the person concerned can carry out alone and those for which she or he needs assistance. Full deprivation of legal capacity must only be used as a last resort, when no other alternative exists. The judge should always choose the option which, in accordance with the principles of autonomy and proportionality, best accommodates the needs of the person concerned. Decisions on legal capacity should be subject to automatic review by the competent judicial authority at regular intervals set out by law.

47. The criteria set forth in principle 16 (1) for compulsory institutionalization should be reviewed. The serious likelihood of immediate or imminent harm to him or herself may not represent a sufficient reason to justify a measure that infringes dramatically on the enjoyment of several human rights, including the right to liberty and security of person and the right to freedom of movement. The consistency of the second criterion, which refers
to the person’s state of health, with existing human rights standards, should also be analysed. In accordance with the principle of the least restrictive alternative, the decision on involuntary admission should at the very least provide evidence on (a) the risk of serious deterioration in the person’s health conditions and (b) the lack of other viable alternatives, such as community-based rehabilitation. The decision on psychiatric commitment should always be subject to judicial review and reconsidered periodically.

48. Abuses and violation of human rights standards are allegedly common practice in many psychiatric institutions all over the world. Detailed monitoring on the actual implementation of the rights of persons with mental disabilities would be needed to assess respect for such norms in practice. Existing human rights treaty bodies should encourage Governments to provide information on measures adopted in this regard in their periodic report.

Notes


2 The only human rights report entirely devoted to this issue was prepared by a Special Rapporteur to the (then) Sub-Commission on Prevention of Discrimination and Protection of Minorities in 1986 (E.-I. Daes, Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder, E/CN.4/Sub.2/1983/17/Rev.1, United Nations, New York, 1986).


4 See, for example, the Declaration on the Rights of Disabled Persons (General Assembly resolution 3447 (XXX) of 9 December 1975); the World Programme of Action concerning Disabled Persons (General Assembly resolution 37/52 of 3 December 1982); and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (General Assembly resolution 48/96 of 20 December 1993).


6 Universal Declaration of Human Rights, article 6; International Covenant on Civil and Political Rights, article 16.

7 See article 5 of the Declaration on the Rights of Mentally Retarded Persons: “The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests”.

8 This determination shall never be made on the basis of political, economic or social status, or membership of a cultural, racial or religious group, or any other reason not directly relevant to mental health status. Likewise, family or professional conflict, or non-conformity with moral, social, cultural or political values or religious beliefs prevailing in a person’s community, shall never be a determining factor in diagnosing mental illness. A background of past treatment or hospitalization as a patient does not of itself justify any present or future determination of mental illness.

9 See also article 7 of the Declaration on the Rights of Mentally Retarded Persons.

10 Argentina, Guatemala and Panama.
11 Argentina, Armenia, Costa Rica, Croatia, Greece, Islamic Republic of Iran, Mauritius, Mexico and Venezuela.

12 Argentina, Costa Rica, Croatia, Mauritius, Mexico, Panama and Venezuela.

13 Armenia, Costa Rica, Greece, Hong Kong SAR, Mauritius, Mexico, Rwanda, Serbia and Montenegro, Spain, Sweden and Venezuela.

14 Costa Rica, Spain, Panama and Venezuela.

15 In Fiji, persons with mental disabilities who fulfil the requirements as to testamentary capacity may write a valid will (Wills Act).

16 In Mauritius, for example, the person lacking legal capacity may get married with the consent of the Court, which has to seek the views of the treating doctor, the person and the destined spouse, as well as the parents, brothers and sisters of the incapacitated person.

17 See, for instance, article 9 (3) of the Law on the National Human Rights Commission of Mongolia.

18 National Human Rights Commission of Mauritius, reply to the questionnaire, para. 6.

19 See also articles 3 and 9 of the Universal Declaration of Human Rights.

20 Principle 16 (1). On the determination of mental illness, see also principle 4.


22 International Covenant on Civil and Political Rights, article 14; see also the Universal Declaration of Human Rights, article 10.

23 Argentina, Belize, Costa Rica, Croatia, Hong Kong SAR, Netherlands, Serbia and Montenegro and Spain.

24 Armenia, Islamic Republic of Iran, Norway and Sweden.

25 Croatia, Fiji, Greece, Hong Kong SAR, Mauritius, Norway, Rwanda, Sweden, United Kingdom and Venezuela.

26 Article 482 of the Argentine Civil Code.

27 Compulsory Mental Care Act, 1991, section 3.

28 Article 114 of the Argentine Civil Code.

29 Croatia, Guatemala, Mauritius, Mongolia, Netherlands, Rwanda and Venezuela.

30 Argentina, Belize, Fiji, Hong Kong SAR, Greece, Serbia and Montenegro, Sweden and United Kingdom.

31 Hong Kong SAR, Mauritius and United Kingdom.

32 Article 5 of Law No. 7135 of 11 October 1989 (*Ley de la Jurisdicción Constitucional*).

33 See supra, footnote 29.

34 Costa Rica, Mexico and Norway.


36 Human Rights Committee, General Comment No. 20 (1992) on prohibition of torture and cruel treatment or punishment, para. 7.

37 Committee on Economic, Social and Cultural Rights, General Comment No. 14 (*The right to the highest attainable standard of health*), 2000, para. 8.
On the contrary, principle 11 (14) affirms that psychosurgery and other intrusive and irreversible treatments for mental illness can be carried out only where the patient has given informed consent and an independent external body has satisfied itself that there is genuine informed consent and that the treatment best serves the health needs of the patient.

Argentina, Greece and Norway.

Fiji, Guatemala and Mauritius.

Fiji Human Rights Commission, Reply to the questionnaire, p. 8.

Costa Rica, Fiji, Hong Kong SAR, Mongolia, Spain and Venezuela.

Croatia, Hong Kong SAR, Mexico, Mongolia, Netherlands, Spain, United Kingdom and Venezuela.

Argentina, Armenia, Guatemala, Mexico and Panama.