



**Economic and Social
Council**

Distr.
GENERAL

E/CN.4/Sub.2/1988/NGO/27
2 September 1988

ENGLISH
Original: ENGLISH

COMMISSION ON HUMAN RIGHTS

Sub-Commission on Prevention of
Discrimination and Protection
of Minorities
Fortieth session
Agenda item 11

HUMAN RIGHTS AND SCIENTIFIC AND TECHNOLOGICAL DEVELOPMENTS

Written statement submitted by Disabled People's International, a
non-governmental organization in consultative status (category II)

The Secretary-General has received the following communication which is
circulated in accordance with Economic and Social Council resolution 1296
(XLIV).

{31 August 1988}

The situation of persons detained on grounds of mental illness has been a high priority of Disabled Peoples' International (DPI) since the beginning of DPI. Because the DPI Manifesto strongly supports the right of deinstitutionalization for persons with any kind of disability, any defense of institutionalization must be supported with the strictest scrutiny and with the maximum of procedural and treatment safeguards.

DPI has therefore closely followed the admirable progress made by the Sub-Commission, which, in response to General Assembly resolution 33/53, appointed Mme. Erica-Irene Daes as Special Rapporteur on the issue of human rights and persons detained on grounds of mental illness. Her comprehensive Report, and the draft body of principles, guidelines and guarantees for the protection of persons detained on grounds of mental ill-health (E/CN.4/Sub.2/1983/17 and Add.1) were presented to the Sub-Commission the same year (1983) that DPI received consultative status. From that time to the present we involved ourselves with the issue - the only organization of persons with disabilities to do so. We met on numerous occasions with the Rapporteur, who accommodated our concerns in the draft as it progressed through the sessional working group each year since. At those earlier stages of the progress of the draft, we had no major concerns. We take this opportunity to congratulate Mme. Daes for her outstanding work and for her resolute defense of the rights of persons with mental disabilities.

DPI welcomes the sincere efforts of the sessional working group and the new chair to meet the request of the General Assembly (resolution 42/98) and the Commission (resolution 1988/62) to complete the Sub-Commission's work of the draft principles.

DPI is acutely aware of the urgent need for internationally recognized principles. We addressed the issue of mentally ill detainees in Japan at earlier sessions, and following our mission of inquiry to Japan, worked with patients' rights advocates and the government to urge major reform in domestic law - happily achieved in Fall, 1987.

We are pleased that the draft take account of the variety of human rights violations to which persons in mental institutions are subjected. Of particular importance is the draft's condemnation of degrading and hazardous treatments such as compulsory sterilization and psychosurgery. We note also with satisfaction that the range of civil, political, economic, social and cultural rights are addressed. A major corner-stone of DPI's Manifesto is that all disabled persons have a right to all human rights - rights frequently arbitrarily curtailed in the institutional setting.

None the less, we are compelled to draw to the attention of the Sub-Commission certain concerns we have about the working group's final text which omits protections from the earlier drafts that we consider essential.

1. The Right to Reject Treatment.

The draft does not contain a provision for the right to reject treatment. Inherent in the right to reject treatment is the right to be different. It is also implicit in the right to informed consent. The right to reject treatment has also been recognized by the WHO in its paper on the guidelines (E/CN.4/Sub.2/1988/66).

Any somatically ill person has the right to reject treatment even if it is detrimental to health, as long as the decision does not result in direct harm to the person's life. There is no reason why a mentally ill person should not have the same right. Mentally ill persons are frequently in the best position to assess treatments. The use of neuroleptic drugs provides meaningful illustration. Many institutions still use these drugs for restraint, even though a number of publications have condemned them as harmful, with occasional irreversible damage to emotional and physical being. Alternatives are available. (Swedish studies show other, more reasonable treatment methods). A person's rejection of anti-psychotic drugs as a matter of principle must be respected.

The right to be different as a source for the right to reject treatment is important for mentally as well as physically disabled persons. This right is not only encompassed in the Universal Declaration of Human Rights (art. 2 - "any status") but finds specific expression in article 1 of the UNESCO Declaration on Race and Racial Prejudice: "All individuals have the right to be different, to consider themselves as different and to be regarded as such."

Physically and mentally disabled persons have struggled to overcome the stigma based on the notion that disabled persons "suffer" because their condition is so undesirable. Disabled persons made great gains against this "prejudice of pity" during the International Year of Disabled Persons, and now must insist again that the right to be different belongs to mentally disabled persons.

2. The Right to Judicial Review.

Article 15.2 of the draft principles provides for a "tribunal or other independent and impartial review body established by law" to determine legal rights at issue in institutionalization. The principles do not specifically state that persons detained for reasons of mental illness have a right to review by competent judicial authorities. While most cases of institutionalization are competently handled by review boards of mental health practitioners and patient rights advocates, certain mentally ill persons have to seek the special protection available from a State's normal judicial bodies.

Review of compliance with procedural safeguards is a fundamentally legal not a medical question, and as such, should be before competent legal bodies. The Universal Declaration of Human Rights provides that "[e]veryone has the right to recognition as a person before the law (art. 6) and that [e]veryone has the right to an effective remedy by the competent national tribunals ... (art. 8, emphasis added). The draft principles should not imply any variance from minimum standards already established. Institutionalization is a serious restriction on liberty and the rights of persons, and as such, all normal legal recourses must be available.

While DPI recognizes the expertise of mental health practitioners, the separation of powers between medical and judicial bodies is an essential element of due process. (See, art. 9, International Covenant on Civil and Political Rights). All detained persons are entitled to habeas rights.

3. Right to review medical records.

The draft principles provide that the access of a patient and the patient's representative may be denied based on a finding by the review body that this would cause "serious harm to the patient's health or to the safety of others." (Art. 17.3 in E/CN.4/Sub.2/1988/WG.3/CRP.1 at p. 19 (English text)). Lack of access to one's medical record is a serious problem for mental patients. In many cases, the finding of probable harm is a pretext for protection of the mental health practitioner or an institution against legal action for misconduct. Denial of access in such circumstances is unacceptable.

Medical records are also essential even in situations not related to legal action. Medical records contain information that could impair a person's right to employment, social security or other protected rights. Ensuring that records are accurate and not prejudicial is thus necessary to protect those rights. While DPI would strongly prefer that medical records are always available for review by patients or their representatives, we would accept some limit related to serious harm to a patient, provided that the representative is allowed access, and the patient's right is reviewable by judicial authority.

DPI hopes that these and other concerns are addressed before final promulgation of the draft principles. We will prepare a more detailed critique of the draft principles as they finally emerge from the Sub-Commission. Issues we recognize as needing more research include the issue of attorney liability for injuries resulting from patient disclosure, disability rights in States with constitutional provisions protecting disabled persons (i.e. Canada, Portugal, Spain, USSR, etc.), and medical alternatives to narcoleptic drugs.

Finally, we take this opportunity to reiterate that this issue properly belongs under the detention agenda item. We urge both the Commission and the Sub-Commission to ensure that all further deliberations of persons detained on grounds of mental ill health be under the appropriate agenda item.