Presidency of the Council of Ministers

NATIONAL BIOETHICS COMMITTEE
PSYCHIATRY AND MENTAL HEALTH: BIOETHICAL GUIDELINES OUTLINE AND RECOMENDATIONS

24 November 2000

1. Protection of the right to health, which in Italy has the status of constitutional right and must be interpreted as including mental health, entails, from the bioethical standpoint, a preliminary reflection on the actual definition of equitable treatment and access to treatment in accordance with the principles of human dignity. Nevertheless, defining (or redefining) the criteria governing the equitable treatment of psychiatric patients itself necessarily involves a complex approach in which respect of the patient's rights can be reconciled with the security of the community. While reference to these rights places this issue in a strictly regulatory dimension, the understanding of the context in which they arise may draw upon such fundamental, wide-ranging ethical principles as the principle of justice (defined as the obligation imposed on the physician, clinical psychologist and other qualified practitioners, to take into account the social consequences for third parties of each healthcare action and to reconcile the good of the individual with the collective good, avoiding any imbalance and respecting equity in the distribution of resources and services), the principle of beneficence (defined as the duty of the physician, the clinical psychologist and of the other qualified practitioners to pursue the welfare of the patient, protecting his life and health also in the field of preventive care), the principle of autonomy (defined as the duty of the physician, the clinical psychologist and of the other qualified practitioners to respect the free and responsible will of the patient, who enjoys the right to receive diagnostic and therapeutic information and to express consent, including the right of refusal).
   Generally speaking there has been a radical change in the cultural paradigm of the physician-patient relationship. The traditional model based exclusively on the principle of beneficence is being replaced and flanked by one based essentially on the principle of autonomy, thus introducing the primacy of the self-determination of the person in the case of illness together with a therapeutic alliance including, in addition to the treatment, also looking after the patient. Care must nevertheless be exercised to avoid underestimating the asymmetric nature of the contract and the purely legal and ethical nature of the equality between the parties thereto with regard to personal rights, without however any prejudice to the unbridgeable difference in their respective knowledge. While it is undeniable that any objectivizing subordination of the patient is ethically unacceptable insofar as it is detrimental to human dignity, this cannot be used to legitimate a reversal of the relationship as the price paid would be not only a questionable undervaluation of the scientific and professional skills but also detrimental to the objective priority interest of the protection of life and health. The principle of guarantee is thus an essential point of reference in contemporary medical ethics.

2. In contemporary medical ethics, the protection of the patient's subjectivity thus takes on a paradigmatic value insofar as it is an essential condition for the construction and development of freedom, which is essentially defined as a process of liberation arising out of a fundamental ethical need of the person. The protection of the mental patient's subjectivity thus has an ethical connotation insofar as it consists of educating to feel and to want to be free and thus of promoting true freedom. A concept of freedom thus defined is closely related to the principle of autonomy, which is related to the absolute respect of the person. But in order to avoid any dangerous misunderstanding it must be pointed out that protection of the patient's subjectivity does not consist in believing that he is free (despite the evidence of pathological conditioning of a cognitive and/or affective nature) but rather in helping him to become free.
It is aimed at restoring communication which has been impaired or interrupted by the mental disorder and thus makes listening possible. Above and beyond the diagnostic and

clinical methods used in the anamnesis, the fact of listening and being a good listener has also a high ethical value as it means accepting and acknowledging the patient not as someone other than myself but as another self that gives meaning to relating to him- and thus to my-self. The ethical value of listening thus consists in a deliberate act of self-limitation that the psychiatrist, clinical psychologist and the other qualified practitioners perform by shunning the recurrent temptation towards narcisism and feelings of omnipotence in order to adjust to the real dimension of the encounter.
Lastly, as far as the complex question of the intrinsic limits imposed on the informed consent given by psychiatric patients is concerned, it is first necessary to clarify the progressive and variable nature of sanity/insanity. Also in the case of schizophrenia it must be borne in mind that the path trodden is extremely variable and differentiated: between the two extremes of a chronic state with serious cognitive deterioration and substantial impairment, on the one hand, and the attainment of acceptable conditions of health on the other, there is a wide range of intermediate states in which phases of relapse and remission alternate, or an acceptable degree of well-controlled stabilization is achieved. From this emerges a radical criticism of two extreme approaches: one aimed at excluding always and in any case the mental patient's capacity to correctly perceive the information and express valid consent; the other is characterized by naive optimism in the opposite direction. In actual fact it must above all be pointed out that between the absolute lack of discernment characterizing madness and "normality" there is an infinite series of intermediate steps, in which cognitive deficits and affective alterations can lead to the reduction of the latter but not its total absence. This does not in any case justify withholding the information but involves the ethical (but also clinical) criterion of caution in evaluating in each case if, how, when to provide the information and above all a pondered choice of the ways and means suitable for each individual patient with reference to his or her situation and bio-psycho-physical and existential context. To this end, for the purpose of reconciling the principle of beneficence with the principle of autonomy, and to avoid any sidetracking and naivety, it is essential to adopt the criterion that "informing means in the first instance communicating inside the relationship".

3. To the extent to which it is possible to find any correspondence between the ethical plane and the purely regulatory plane, these criteria and ethical guidelines must be considered in the light of several fundamental human rights. It is indeed necessary to stress the fact that persons affected by mental/affective disorders/problems must be guaranteed the same rights as all the other members of the community, regardless of the concrete opportunity they may have to exercize them. The particular vulnerability of these subjects actually entails ensuring a strengthening of the acknowledgment of their full citizenship which must be concretely defended and promoted, in the first instance through the respect of certain rights and/or by the fulfilment of certain fundamental duties, such as:
- right to treatment without any coercion and in full respect of human dignity with access to the most suitable techniques of medical, psychological, ethical and social action;
- right to the elimination of any kind of discrimination (sexual, cultural, religious, political, economic, social, ethnic) in the form of treatment, even when the latter is restrictive of their freedom;
- right to rehabilitation and reinsertion, also through access to housing and employment;
- right not to be subjected to any form of physical and/or psychological abuse;
- duty to protect from the consequences of forms of self-destructiveness (self-accusation, declarations of unworthiness, etc.) versus the family, employers, judicial authorities;
- duty to attain optimal conditions of hospitalization and communication with the exterior;
- duty to defend parenthood, to be implemented in full respect of the prevailing interest of children under the age. To this end it is necessary to arrive at a trade-off between the duty

of beneficence versus patients and the right of the under-the-age child to a healthy and balanced development.

4. As far as the question of the assistance to psychiatric patients in Italy is more specifically concerned, general consideration must be given to law no. 180 of 1978, subsequently transposed into arts. 33, 34 and 35 of the National Health Service (SSN) statutes. Law no. 180 definitely represents a scientific, cultural and civil milestone as it abolished the mental asylum institution and opened up new horizons for the organization of a healthcare system without asylums and established the conditions for the restoration of full citizenship to psychiatric patients. The Italian model, backed by the World Health Organization, has influenced mental health policy in many other countries seeking to replace the asylums with more effective and efficient local forms of care. Nevertheless, more than twenty years after its introduction, it is now more than ever necessary to make a serious examination of its concrete application above and beyond the admittedly important completion of the shutdown of the Psychiatric Hospitals. This closure, as a result of the absence or inefficient functioning of the alternative structures, such as psychiatric diagnosis and treatment services of the hospitals (as structures intermediate between the local district and the hospitals) runs the risk of causing new problems, in the first instance for the individual's health, but also for the equilibrium, the economy and even the health of the family, who has to bear most of the, often unsustainable, cost of supporting the sick member. Indeed in those cases in which the service fails to provide truly effective therapeutic and rehabilitation programmes at the local level involving a strong commitment to the patient, it is the families that remain the main referents of the care, something that often leads to abandonment or even triggers violent reactions often leading to the serious episodes reported by the media. This type of phenomena awakens dormant prejudices regarding mental illness and the stigmatization of psychiatric patients. These prejudices readily lend themselves to being instrumentalized in such a way as to increase the fear of the 'social dangerousness' of the mental patient in public opinion and the political world and increase the demand for greater control which might again be implemented coercively and thus not in a therapeutic way respecting the patient's rights.
Several fundamentally important questions emerge from this scenario which are directly related to the responsibility of the institutions in the implementation of law no. 180. These questions are centered in particular around:
- improved training of psychosocial workers and GPs;
- establishment of rehabilitation structures at different protection levels;
- greater attention concentrated on psychiatric care of minors, in particular on the mental problems that emerge at the adolescent stage;
- the establishment of rehabilitation structures for minors;
- stronger preventive and earlier diagnostic action;
- care of the seriously ill who refuse both medical and psychiatric care and are prone to violent behaviour;
- information and public debate to combat prejudice towards the mentally ill.

In this connection it is recommended that the 1998-2000 "Protection of Mental Health" objective project be implemented. This measure, if properly applied, could contribute to solving many of the psychiatric healthcare problems and to raising the level of service effectiveness and quality. It could thus make a decisive contribution to the further development of the "Italian laboratory" in the mental health field that has aroused so much interest and appreciation in many different countries. More specifically, the 1998-2000 mental health objective project has the advantage of making a correct approach to the issue of groups at risk regarding both mental health and possible suicidal outcomes, mental health education and early intervention. As far as children's mental health in

particular is concerned, the objective project has the merit of having acknowledged that the individual's development from childhood to adulthood is a continuum, although it does not make any clear distinction between the areas of psychiatry, psychology, neuropsychology and rehabilitation, in particular with reference to the differences in objectives, methods and organization in the action taken, which has negative repercussions also on psychiatric healthcare. Lastly, mention must be made of the positive emergence of a health pact aimed at coordinating and integrating the formal and informal agencies that, each in their own way, can contribute to constructing a community mental health project. The Objective Project also calls for research to be undertaken by the Superior Health Institute to evaluate the effectiveness of primary preventive action. It also entails the University psychiatric institutes taking operational responsibility for all the district and hospital structures involved in providing mental health services for a community of about 150,000 inhabitants. This measure is the only one that guarantees high quality training for psychiatric practitioners and is capable of linking together research carried out in the observational field provided by the local district with practical trials of the effectiveness of the action. In view of their objective importance, these acquisitions are bound to change the physiognomy of psychiatric healthcare in the years to come.

5. In view of the foregoing, the National Bioethics Committee has formulated the following more specific recommendations:
- allocate to national and regional institutions, and allow them to spend, the national and regional health funds required to establish at least all the services envisaged in the Objective Project, also in view of the importance attributed by the WHO to mental health;
- give greater publicity to simple and correct information concerning mental illness also in schools and avoid the risk of reductionist interpretations of mental illness. More generally, it is recommended that balance and understanding be maintained when dealing with the bio-psycho-social complexities of mental illness;
- promote periodic national campaigns against the stigmatization of and prejudice towards persons affected by mental disorders and problems in order to render effective the respect of equality, the right to information and the fight against discrimination;
- re-examine the concept of "incapacity", situating it inside the continuum that runs from the extremes of normality to the total loss of all cognitive ability. Also from the legal point of view it should be noted that the majority of psychiatric disorders reduce but do not eliminate sanity completely. It is thus recommended that a reappraisal be made of the civil law institutions of interdizione and inabilitazione (disqualification) and to introduce more flexible forms of safeguarding than the existing ones which take into account the new needs of protection of those suffering from mental disorders and which avoid stigmatizing them. It is emphasized in particular, in view of the experiences of other European countries, that the figure of 'support manager' should be introduced also into the Italian legal system;
- bring to completion the process of closing down the public and private mental hospitals. In each single case, however, it is necessary to ensure that the alternatives introduced to cope with the emergency do not actually retain their previous mental hospital characteristics. It must also be considered that there are still 9 private mental homes with some two thousand inmates that, after twenty years since the beginning of the de-asylumization process provided for by law no. 180, are completely unjustified from the ethical and clinical point of view;
- guarantee that the family receives adequate support and, whenever necessary, in collaboration with the therapeutic team, take on an active role in the therapeutic/rehabilitation programme of the sick member, pursuing the objective of the

latter's autonomization. Guarantee a reference emergency organization also providing night-time and holiday service.
- carry on a constant primary and secondary prevention activity versus the mental/affective disorder or problem starting from the biological and affective-relational aspects going back to the perinatal period and covering the entire life span, by ensuring the best educational, employment, social security and healthcare conditions; formulate an early diagnosis and ensure that young people are taken on board at the first significant symptoms; introduce special programmes in schools in collaboration with the families and, without arousing any unjustified alarm and risk of "psychiatrization", help recognize and prevent mental problems and disorders. The psychiatric pathologies of the adult are actually always rooted in the period of development and the extent of the psychiatric problems of adults will be dependent on the quality of the treatment received at the earlier stages of life. This kind of initiative is thus essential for the concrete attainment of the right to health (which is implemented also by means of prevention), and access to treatment, and to sustain and promote solidarity with subjects at risk;
- guarantee that special attention is paid to the direct and indirect signals of mental distress in subjects during the period of development in order to determine the underlying distress; guarantee different care levels for acute situations and rehabilitation for consolidated conditions. During the period of development, encourage day hospital and outpatient healthcare activities, and reduce hospitalization. Unfortunately, it is necessary to guarantee an adequate number of hospital beds for psychiatric emergencies and for acute forms requiring continuous care and extended observation in structures other than the psychiatric diagnosis and treatment services that can satisfy not only healthcare and protection needs but also the needs and rights specific to this age group;
- guarantee and maintain the acceptance of responsibility in the more serious and difficult cases even when the treatment is not accepted by those directly concerned. Reference is made in this case to the general principles of protection of the mental patient, the risk/benefit parameter as the general rule for treatment avoiding the extremes of using disproportionate medical measures and abandonment;
- lay down national parameters for the accreditation of mental health structures. Quality control of the services is actually itself a criterion of guaranteed equitable treatment and fair allocation of resources earmarked for health. The 65 neuropsychiatric care centres (with 7149 authorized beds, 6144 of which accredited or covered by conventions, that is, funded by the Regions) must be aimed at avoiding rendering the patients' condition chronic and to be converted, as far as possible, into open residential rehabilitation structures that, if possible, have an operating relationship with one or two mental health departments;
- involve and support "family doctors" in view of the fact that many patients go to them for mental health problems of varying degrees of seriousness. The GP must be trained to recognize conditions of mental distress, to be able to evaluate its nature and seriousness, and to know how to use the psychiatric services both for consultancy and to identify the more serious situations requiring specialist intervention at an early stage;
- ensure the training of physicians, general paediatricians, psychosocial practitioners, professional nurses, social assistants and professional and voluntary educators. For this purpose it is necessary to extend all the practitioners' bioethical knowledge and to lay down several minimum objectives so that training may be effective and ethically grounded. These include: greater attention paid to the users' health needs than to the practitioners' needs; an open attitude must be displayed to the skills and contributions of the different professional figures; suitable tools must be provided for the management by the practitioners of the various dimensions of the individual, the family, the group and the community, as well as for the promotion of mental health in the community, such as the

development and implementation of specific mental health programmes; special attention must also be focused on research and training concerning bioethical problems related to the protection of mental health;
- acknowledge the right of psychiatric patients to a sex life although it is advisable at the same time to investigate ways and means of informing them properly and getting them to take responsibility for their sex life;
- revise the pharmaceutical 'ticket' system in order to ensure that new generation drugs (such as atypical antipsychotics) that have proved more effective and to have fewer side effects are accessible to all;
- review the nature and tasks of the "Judiciary Psychiatric Hospital" and the relevant legislation and to promote action by the Ministry of Justice to institute a convention with specific structures for minors having committed offences and who suffer from psychiatric disorders. More specifically, it should be pointed out that the existing Judiciary Psychiatric Hospitals are, both from the institutional and the medical standpoints, in clear contradiction with law no. 180 and with any modern approach to mental health action;
- by means of suitable structures to prevent the risk of the psychiatric diagnosis and treatment services becoming a mere repetition of mental hospital practices and consequently increasing the proneness to chronic conditions rather than recovery from the illness. More specifically, all forms of mechanical restraint must be done away with as they are detrimental to the patient's dignity;
- ensure that the mental health departments, as laid down in the recent DGL 239/99, perform healthcare services in the prisons. The protection of the psycho-physical integrity of convicts is indeed an elementary duty of justice and also an indispensable prerequisite for any rehabilitation. The prisons must become places in which everyday life is no longer itself a cause of mental distress and disorder and which allow psychiatric assistance to be provided. It must also be observed that the alternatives to prison - including admission to mental health departments - have proved to be extremely effective in the countries having adopted them, for example, Sweden, as measures to replace prison detainment.

Conclusions

The laws of the Republic, from the Constitution down to the "Protection of Mental Health objective projects" state that the State guarantees the exercise of the "right to health" and thus of the right to mental health. However, the experience of the reform and, even before that, of the law establishing the mental hospitals, shows how laws by themselves are not enough to ensure effectiveness in the mental health field. This is because exercizing the right to mental health is strongly dependent on the culture and on the state of the social relations in the local conditions, on the level of professional training and skills possessed by individual practitioners and groups of practitioners, as well as on the policies of the local administrators and managers. As can be seen from the preceding treatment, it emerges that the majority of problems related to mental health are laboriously managed by persons who suffer alone in the family, with their peers, with GPs, within the private physician and psychologist circuit and the dimension of popular religious feeling where the search for salvation is also accompanied by the hope of regaining health. The public health service is addressed in the case of situations defined as serious, which are the more dramatic ones from the point of view of individual and family distress, more alarming from the social point of view and more liable to lead to isolation and marginalization. It often happens that the DSMs (Mental Health Departments) fail to take on board in all their complexity and for their full duration situations that we have defined as "serious" and ultimately abandon them either to the families or to a healthcare circuit with inadequate resources when it is not openly a continuation of the mental hospital approach.

It was precisely to answer this kind of question that, also in Italy, it was decided that an organization of services based on Community Psychiatry would be more effective and respectful of the person's dignity than the mental hospital. Community Psychiatry involves the work of a multiprofessional team operating in a given district and in a position to intervene within 24 hours at the patient's home, in the surgery, the hospital, and homes offering various degrees of protection aimed at rehabilitation; it has links with the municipalities and the other health services, works in close collaboration with the users and the family associations, and has access to the available opportunities of vocational training, employment, culture, assistance, leisure time. Treatment is provided at the biological, psychological, social, pedagogic and cultural level.

To remedy the conditions of abandonment in serious situations and in general on the topic of psychiatric assistance and its chronic shortage of human, structural and financial resources, strong action by the Regions is essential to ensure a renewed commitment regarding the crucial aspect of the distress, and to give a positive signal to the families and to public opinion.

On the expectation, but not taking for granted, that all the Local Health Services (Aziende Sanitarie) have released resources to support the activities of the multiprofessional teams of the Mental Health Departments and that they have the necessary scope and instruments for their work, the most important condition for what we have defined as the most serious situations to be managed in a way in which the rights and dignity of the person and the families are respected is that the managers and practitioners should take responsibility for caring. This is because psychiatric assistance has to cope daily with high levels of distress of the persons and families involved, their strong social stigmatization, the problems of protection, of the freedom of choice and consent to treatment even to the limit of coercion, with the need for continuity in longterm "caring" in psycho-social rehabilitation processes, with the singularity and multiplicity of the world views of the persons, groups and cultures. As a result of these peculiarities and of the objective of ensuring that the mentally ill receive available optimal treatments, local health authorities, professional organizations and scientific gatherings must guarantee continuity of training, the verification of the quality of the services provided by all practitioners and the evaluation of the outcomes at the level of Mental Health Departments and of District Medicine. We are thus referring not only to physicians and psychologists, but also to professional nurses, professional educators, social assistants, social health and social welfare practitioners.

Fresh objectives to be pursued by the Regions and the Health Centres consist of information and training aimed at users and their families in support of self-help and of increasingly authoritative and competent associations and voluntary organizations.

In the context of these reasons, the terms federalism, regionalism and localism mean the assumption of full responsibility by the administrators and managers of the Local Health Services vis-à-vis the guarantees to be provided for mental health activities in all the local communities, without exception.