

Presidenza del Consiglio dei Ministri



**VULNERABILITY AND CARE IN COMMUNITY
WELFARE. THE ROLE OF THE ETHICAL SPACE FOR A
PUBLIC DEBATE**

10 December 2021

Presentation

In this document, the Italian Committee for Bioethics (ICB) addresses a particular aspect: the relationship between vulnerability and "places of care", understood not only as the institutional apparatus of care, but also as provider of moments of attention and listening. Alongside the two typical forms of intervention, consisting of economic transfers and the provision of services, it seems necessary to give a response to all those existential dimensions that the crisis of aggregational facilities leaves out, starting with the family, and which the economic and political limits of the *Welfare state* fail to take into consideration. It appears increasingly essential to encourage the development of "*Community Welfare*" in which individuals, families, associations attempt, with the state and beyond the state, to build new forms of encounter and assistance. These needs are expressed in the *National Recovery and Resilience Plan* through the creation of the so-called "Community Health Houses" in which health care is supported and strengthened by the creation of places where social care is closely linked to listening to the needs of the weakest and most fragile subjects.

Starting from the reflection on vulnerability, in its profound link with the ethics of care (understood as 'taking care'), the Committee feels the need to draw attention to these experiences and then to define the multiple potential applications of a model called "Ethical space" intended as a place in which to listen, encounter others and exchange personal and professional life experiences, to give voice to individual citizens and the associations representing them. This document aims to point out that ethical problems go beyond the biomedical dimension and affect different dimensions of social life in which particular situations of vulnerability emerge and are especially evident: situations that can be found, not only in health facilities, but also in schools, prisons, courts. The operability of ethical spaces in all these places deserves a specific and detailed examination. The document examines, in a schematic way, some contexts in order to highlight some examples (prison, court, school).

The opinion underlines how ethical space constitutes an important tool for promoting a public debate aimed at informing, training and consulting citizens in order to make them more aware in their choices, strengthening their role in the *governance* of society on emerging ethical problems. It is also an institutional task of the ICB: some initiatives have already been undertaken (conferences for schools and meetings with citizens), however the ICB believes implementation of this area to be necessary and urges the Government to take steps in this direction.

The opinion was drafted by Luisella Battaglia and Salvatore Amato, with the contribution of Profs.: Maurizio Benato, Carla Bernasconi, Cinzia Caporale, Carlo Casonato, Francesco D'Agostino, Lorenzo d'Avack, Antonio Da Re, Paola Di Giulio, Riccardo Di Segni, Mariapia Garavaglia, Marianna Gensabella, Assunta Morresi, Laura Palazzani, Tamar Pitch, Monica Toraldo di Francia, Grazia Zuffa.

A hearing was held also with Dr. Alessandro Bonsignore, President of the Order of Doctors of Liguria.

The opinion was unanimously approved by those present: Profs. Luisella Battaglia, Stefano Canestrari, Cinzia Caporale, Carlo Casonato, Antonio Da Re, Lorenzo d'Avack, Mario De Curtis, Riccardo Di Segni, Silvio Garattini, Marianna Gensabella, Assunta Morresi, Laura Palazzani, Tamar Pitch, Lucio Romano, Massimo Sargiacomo, Monica Toraldo di Francia.

Profs: Salvatore Amato, Carlo Caltagirone, Lucetta Scaraffia, Grazia Zuffa absent from the plenary session, subsequently assented.

Profs. Mariapia Garavaglia, and Luca Savarino absent at the time of voting, subsequently assented.

Despite their not having the right to vote assent was given by: Dr. Carla Bernasconi, the delegate for the President of the National Federation of the Orders of Italian Veterinarians; Dr. Giovanni Maga, the delegate for the President of the National Research Council; Prof. Carlo Petrini, the delegate for the President of the National Institute of Health; Dr. Maurizio Benato, the delegate for the President of the National Federation of MDs and Dentists Colleges.

Prof. Paola Di Giulio, the delegate for the President of the Superior Health Council, absent from the session, subsequently assented.

Prof. Lorenzo d'Avack
President of ICB

Premise

Focusing attention on particularly vulnerable subjects recurs systematically in the activities of the Italian Committee for Bioethics (ICB). It is an issue that has characterised many opinions, even if never explicitly examined. In fact, it was only from the end of the last century that this concept has begun to have in an increasingly clear and systematic manner the function of support with respect to the effective protection of fundamental rights in relation to a plurality of developments which have subjective dimensions and extremely varied articulations.

In this document, the Italian Committee for Bioethics, in emphasizing the ethical and legal relevance of focusing attention on vulnerability, addresses a particular aspect: the relationship between vulnerability and "places of care", understood not only as the institutional apparatus of care, but also as provider of moments of attention and listening. In addition to those conditions that have been taken into consideration by bioethics ever since its beginnings given their particular vulnerability in the context of scientific and technological developments in medicine (the beginning and end of life, illness, subjects participating in experiments) and in addition to the traditional situations of hardship related to poverty, political marginalisation and social discrimination, a whole series of critical situations have emerged, further emphasised by the current pandemic emergency, which dramatically bring to light specific situations of severe hardship and urgently raise the problem of giving a new and broader interpretation to the concept of social solidarity.

Alongside the two typical forms of intervention, consisting of economic transfers and the provision of services, it seems necessary to give a response to all those existential dimensions that the crisis of aggregational facilities leaves out, starting with the family, and that the economic and political limits of the welfare state fail to consider. It appears increasingly essential to encourage the development of "Community *Welfare*" in which individuals, families, associations seek, with the state and beyond the state, to build new forms of encounter and assistance.

In this perspective, the conviction is gaining ground that there should be an adequate focus placed on vulnerability not only through the fundamental protection of rights and the refinement of related social benefits, but it also imposes the need to find new ways to detect individual problems and social expectations. In recent times, there have been, in different countries and in various contexts, several experiences which attempted to provide answers for that relational void present in the, at times, precarious ties which develop within the various forms of health and social care.

In France, the *Espace éthique de l'Assistance publique* has been, for several years, assisting hospital care by providing - in a detailed way, structured at local regional level through regulated and financed national coordination - places for listening and encountering doctors, healthcare professionals and patients, families, guardians and support administrators in which to share life experiences, deal with any difficulties and misunderstandings, offer the possibility to put forward questions and raise ethical doubts, in a framework of protection and listening and without fear of negative consequences. Experiences like this place us in front of the fact that solidarity, the common *interest*, presupposes an ethical moment of *inter-esse* in which to give voice to all situations of vulnerability and to

those waiting for assistance and to prepare ways of interacting and possible responses.

This need is also expressed in the *National Recovery and Resilience, Plan* through the creation of the so-called "Community Health Houses" in which health care is supported and strengthened by the creation of places where social care is closely linked to listening to the needs of the weakest and most fragile subjects.

Starting from the reflection on vulnerability, in its profound link with the ethics of care (understood as 'taking care'), the Italian Committee for Bioethics therefore feels the need to draw attention to these experiences and then to define the multiple potential applications of a model called "Ethical space" intended as a place in which to listen, encounter others and exchange personal and professional life experiences, giving voice to individual citizens and the associations representing them. It should have the purpose of stimulating and promoting a public debate - conceived and possibly implemented in future within an institutional framework, as is the case in France (see the "Estates General of bioethics") aimed at informing, training and consulting citizens on crucial issues of ethics in life sciences and health care. The French experience is limited to the dimension of ethics in the biomedical field. This document aims to point out that ethical issues go beyond the biomedical dimension and affect different dimensions of social life in which particular situations of vulnerability emerge and are especially evident: situations that can be found not only in health facilities, but also in schools and universities, companies (think of all the ethical issues in the workplace, possible discrimination, etc.), halls of Justice, prisons, reception centres for asylum seekers.

The operability of ethical spaces in all these places deserves a specific and detailed examination. In this document we will limit ourselves to examining, in a schematic way, only some contexts to highlight how, starting from the medical and health perspective, it is possible to envisage many additional forms of listening and protection of subjects in situations of fragility and vulnerability.

Vulnerability and the ethics of care

It should be borne in mind that the issue of vulnerability, in its connection with the ethics of care, can be approached from different theoretical perspectives.

On the ontological level, the Greeks loved to define human identity starting from its constitutive vulnerability, which finds its most peculiar distinctive sign in the inevitability of death. The theme, like a guiding thread, runs through the whole tradition (and particularly the sapiential and mystical tradition) of the West.

In the biblical religious experience, the human being is at the apex of creation, but his weakness and limitation are inseparable from his greatness. Weakness in a moral sense, being a creature subject to the instinct of evil, and material weakness, exposed to a hostile nature that imposes a short, insecure existence that is often full of suffering¹. We find the same vision in the Koran². For this reason, places of worship have often also been places of hospitality. It is well known how modern hospitals originate from the commitment to *hospitalitas* of the religious communities of the early centuries who gave assistance to the sick, widows, the elderly, minors and the derelict.

¹ Gen. 3:16-18, 6:5, 8:21; Psalm 8 and 144:3-4.

² Sura 4, 28

The religious admonition on the mortal dimension of human identity has found a significant thematisation in the existential vision of *being towards death*. In this key, the theme no longer has any spiritual or moralistic value, but it is exclusively *ontological*: man is what he is, that is, he possesses an irreducible human identity, precisely because the awareness of his structural vulnerability qualifies his being in the world. Man is such because as soon as man comes to life, he is old enough to die.

The Latin myth of Cura³ can be interpreted as the destiny of the human being to always be handed over to Cura, understood as both concern and solicitude, an appeal to "take care" of things and to "take care" of oneself and others. This perspective requires us to think of vulnerability as constitutive part of our being, so if it is not possible to speak, in the strict sense, of categories of the vulnerable; given that all human beings are vulnerable, what it notes is the varying degrees or burdens of vulnerability and capacity for care⁴.

Expanding the perspective from the individual dimension to social conditions, the concept of vulnerability could be used in a heuristic sense, that is, as a critical tool for identifying and analysing the institutional conditions that could be at the origin of a greater or lesser degree of vulnerability, be it more or less temporary, of people or groups. If our weakness is not due (only) to our mortal condition but, rather, to the inescapable existential dimension of our constitutive dependence on others, then 'vulnerability' and 'autonomy' are not opposite or conflicting conditions: the autonomy of each person is not a capacity given a priori or without graduality and it is the relational context, in its various dimensions, that becomes relevant both in facilitating and inhibiting its development or recovery.

Already from these brief considerations on the relationship between vulnerability and care, it emerges that the ethics of care - one of the most significant areas of philosophical-moral research of our time - can prove to be of great interest for bioethical reflection⁵. The expression *taking care* refers to a plurality of acceptations that all seem to relate to a fundamental attitude of being willing to help, an attitude that stems from the recognition of an essential and constitutive interdependence and translates into a serious commitment to understand the real situation of need and responsibly take charge of it.

³ Reworked by Goethe in *Faust*, the myth of Cura influenced bioethics above all through Heidegger's reflections on the "being of Being as Cure" (*Sein und Zeit* (1927), tr.it. P. CHIODI, revised by F. VOLPI: *Essere e tempo*, Longanesi Milan 2019, § 41, p. 233).

⁴ Vulnerability is constitutive of every living being, according to the definition given by the bioethicist Warren T. Reich: "The word vulnerability (from the Latin to *vulnerare*, to wound) literally means 'susceptible to being hurt'. Figuratively, it refers to the precariousness of a condition marked by the possibility of violation and the limit, often defined by different degrees of weakness, dependence, lack of protection ("*Vulnerabilità*", in G. RUSSO (ed.), *Enciclopedia di Bioetica e Sessuologia*, ELLEDICI, Leumann, Turin, 2004, p.1817).

⁵ There are fundamentally religious perspectives intersecting in it, such as those of Emmanuel Lévinas, and perspectives matured secularly within the theoretical concerns expressed in recent decades by feminist thought. One need only recall Carol Gilligan's lesson concerning the importance of *caring* in the text. *In a Different Voice: Psychological Theory and Women's Development* (1982), tr.it. A. BOTTINI: *Con voce di donna. Etica e formazione della personalità*, Feltrinelli, Milan (1987).

The bioethical relevance of the issue of vulnerability in international declarations

Leaving aside the philosophical and religious perspectives briefly summarised, in general it could be affirmed that the concept of vulnerability does not have a definite linguistic acceptance and a precise ethical and juridical status. Perhaps also for this reason it has come to encompass over time an increasingly large number of situations which have determined, for the most heterogeneous reasons, conditions of marginalisation, exploitation and hardship, if not even social or existential oppression and has, therefore, taken on an undeniable usefulness in highlighting the limits of our social developments in the context of rapid technological changes and ecological imbalances induced by the processes of globalisation and the increase in inequalities between different areas of the world as well as within single countries. We have progressively passed from 'ontological and relational' vulnerability to 'situational' vulnerability: vulnerability is constitutive of the human being, but specific situations/conditions (age, sex, pathology, ethnicity or cultural belonging in a broad sense, economic, social, political conditions, but also environmental and existential-personal conditions in a broad sense) can accentuate it.

Some documents dedicated to biomedical research involving human beings highlight the condition of both ontological and situational vulnerability.

In fact, International Declarations attribute increasing importance to vulnerability, starting with the 1978 *Belmont Report* which recommends taking special care and guarantees to avoid, in enrolment for clinical trials, the exploitation of particularly disadvantaged "*vulnerable subjects*" (racial minorities, the economically disadvantaged or the seriously ill). A recommendation that, starting from the 2008 version, the *Declaration of Helsinki* endorsed, stating that biomedical research on a vulnerable group or on vulnerable individuals is "only justified if it is responsive to the health needs and priorities of the population or community involved and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research" and it cannot be performed on a non-vulnerable population (art. 17).

What was briefly envisaged by the Declaration of Helsinki had already been anticipated in 2002 by the *Ethical Guidelines for Biomedical Research Involving Human Subjects*, developed by the *Council for International Organizations of Medical Sciences* in collaboration with the *World Health Organization (WHO)*, in which it was emphasised that vulnerability does not only concern limitations and conditioning in expressing consent to certain health treatments, but more generally it concerns all the possible repercussions on health due to the relative or absolute difficulties of an economic, social or cultural nature that prevent the full protection of their interests or assertion of their rights⁶.

The progressive expansion of the importance and scope of the concept of vulnerability is also attested by the *Barcelona Declaration* (1998) which includes vulnerability alongside autonomy, dignity and integrity in the fundamental principles of the lines of development in European bioethics, with particular reference to research and clinical practice. If it is above all the intertwining of the aforementioned principles that demonstrates the complex variation of the notion of autonomy and the possibility of its being developed in a relational perspective,

⁶ Principles and safeguards adopted by the Code of Medical Ethics of the National Federation of MDs and Dentists Colleges in Title VII and in particular in art. 48.

it is in particular the fourth principle, vulnerability, which constitutes, in the *Declaration*, the foundation of a public ethics of care based on the anthropological premise that we are all fundamentally vulnerable. This principle, which essentially expresses, as already mentioned, the idea of the finitude and fragility of human existence, requires not only non-interference with the other three principles, but it also specifically entails the duty to assist those who are unable to realize their human potential and whose right to autonomy, integrity and dignity is threatened. It should be noted that the notion of vulnerability has both a descriptive and normative value: in fact, describing a person as vulnerable means at the same time evoking an ethical response of protection and responsibility towards him/her. Hence the profound link between the idea of vulnerability and the ethics of care, a link stressed several times by Warren Reich, who distinguishes different meanings of the term: care as "anxiety" - that is, the responsibility in taking care of the worries of others; care as "concern" - which moves the heart to respond to needs; care as a "service" - which integrates in itself solicitous attention to the soul and body; care as a "task" - which is a precise commitment to look after certain people with the utmost competence.

But to this end it is necessary for society to indicate with the utmost clarity which types of vulnerability it intends to pay attention to and with what resources: in this way, the ethics of care meets the field of justice, both formal (equality of rights) and substantive (equity in the allocation of resources). In the medical field and, in particular, in the area of research, for example, it is a question of defining not only the intrinsic characteristics, but also the situations and circumstances that make patients more vulnerable or increase forms of dependency. This particular attention emerges significantly from art. 12 of the Additional Protocol to the Council of Europe Convention on Human Rights and Biomedicine, concerning Biomedical Research (2005).

The overall message that emerges from the *Declaration* is therefore that vulnerability is, to a very large extent, situational and as such everyone should be committed to reducing it in its various contexts. This consideration, in addition to referring us back again to the crucial theme of *care*, introduces us to that *ethics of accompaniment* that insists on the need to give space, in the health sector, to the well-being of the patient through paying attention to aspects relating to the emotional, psychological, cultural, social sphere of the individual patient. In person-centred ethics, the fundamental requirement of accompaniment is expressed in a concept of care where the caregiver learns to walk alongside the patient, without expecting to impose the itinerary, but leaving the patient free to choose "his/her" path, the main concern being to ensure that this process of awareness does not take place in isolation. Sharing the clinical and existential path of the disease brings into play both family and friends, as well as doctors and health professionals: spaces, times, interpersonal relationships, the entire context of the experience of illness of the patient require a network of material, social and psychological support⁷.

⁷ A synthesis of all this is found in the *Final Report to the European Commission on the Project Basic Ethical Principles in Bioethics and Biolaw 1995-1998 Part B* which moves (§ 4) from the assumption that attention to the weakness and fragility of life constitute the foundation of all moral action. "The vulnerable are those whose autonomy or dignity or integrity are capable of being threatened. As such, all beings who have dignity are protected by this principle. But the principle also specifically requires not merely non interference with the autonomy, dignity or integrity of beings, but also that they receive assistance to enable them to realize their potential. From this premise it follows that there are positive rights to integrity and autonomy which grounds the ideas

The 2005 *Universal Declaration on Bioethics and Human Rights* by UNESCO further broadens the horizon, not only drawing attention to the many "*vulnerable segments of society*" (marginalised due to illness, disability or other personal and social factors), but also to the more complex and wide-ranging problem of protecting the environment, animal life and biodiversity.

The 2013 *Report of the Unesco International Bioethics Committee on The Principle of Respect for Human Vulnerability and Personal Integrity* is probably the most complete international treatment on the topic because it includes in this concept all the situations of marginalisation that arise not only as a result of socio-economic imbalances, but also due to wars, climate change, cultural prejudices. The document presents us with a long series of 'vulnerable subjects' (the poor, unemployed, sick, homeless, exiles, immigrants, prisoners, homosexuals, ethnic minorities) an outline that is possibly too general and vague, but which has the advantage of prompting us to reflect on the fact that, alongside the obvious exploitation and unacceptable suffering of individuals or groups, we must take into consideration situations of vulnerability (such as climate change) which add poverty to poverty, misery to misery, and also the same feelings of vulnerability (cultural inferiority, hierarchical pressures) that widen the spheres of hardship and erode trust in the processes of social integration. For these reasons, the document emphasises the need to move from enunciation of a negative obligation, which requires refraining from placing undue pressure on "weak" individuals or social groups, to identification of a positive obligation to promote solidarity towards all those new fragilities which emerge as a result of technological developments or social or political conditions.

An important contribution is also provided by developments in medical sensitivity in underlining the relationship between vulnerability and fragility. Vulnerability appears as the set of characteristics of a person or group, associated with the situation/context in which they live, which affects their ability to adapt, cope with and anticipate the impact of any negative events in clinical, economic and health dimensions. Fragility, on the other hand, constitutes a more complex and stratified phenomenon, with the physiological bases linked to the progressive decay in which social, economic and environmental determinants must also be taken into consideration as risk or opportunity factors. On the operational level, this is a concept that is widely used and considered clinically useful, especially in taking care of the elderly.

This expansion of the duties of social solidarity also characterizes the jurisprudential elaboration of recent years in which the reference to vulnerability recurs with increasing frequency to remedy the violation of the principles of equality, freedom and personal integrity in relation to irregular migrants, asylum seekers, subjects with mental disorders, prisoners, minors, subjects discriminated against on sexual grounds. This concept, although absolutely

of solidarity, non-discrimination and community". In the next paragraph he reiterates that "vulnerability concerns integrity as a basic principle for respect and protection of human and non-human life" because every life can be "wounded and killed". "The idea of the protection of vulnerability can therefore create a bridge between moral strangers in a pluralistic society, and respect for vulnerability should be essential to policy making in the modern welfare state (...). Respect for vulnerability is not a demand for perfect and immortal life, but recognition of the finitude of life and in particular of the earthly suffering presence of human beings" (§ 6). For this reason, vulnerability does not only concern human beings, but - as Bioethics reminds us in its original global vision - also animals and nature as a whole.

marginal if not completely absent in the past, has been considered in almost 10% of the decisions of the European Court of Human Rights⁸ in the last ten years.

Community welfare

From the international declarations and from the legislative and judicial interventions on various aspects of social situations, the need emerges to build new and more inclusive models of assistance, working progressively for a "*responsive state*" capable of connecting institutional structures to the smallest social and existential situations awaiting attention and protection. The economic, health and social crisis caused by the pandemic has definitively brought to light how the "*welfare state*", even though it remains a fundamental reference point in guaranteeing the universality of levels of social assistance and essential services free of charge for the less well-off, it is not always able to sustain the growth in levels of expenditure and social assistance expectations. This crisis affects the national health service as a whole, but it has a profound impact, above all, on the most fragile sectors of society. If situations of marginalisation increase, the vulnerability of those who already find themselves in a difficult situation is accentuated.

The problem of "relational services" arises, that is, those services in which the personal dimension plays a predominant role due to the delicate relationship that is created between the willingness to listen and the ability to take care. These services require organisational flexibility, moral availability, attention to individual and social diversity which preclude the definition of content and services on the basis of homogeneous criteria. This is why for several years now the need has been envisaged to combine the traditional structures of the *welfare state* with *community welfare*, providing a different form of assistance that joins the activity of the State, involving a plurality of subjects (individuals, voluntary groups, humanitarian organisations, businesses) starting from the requirements and needs that emerge from the bottom, precisely from the individual territorial community and, within it, from the various institutional structures. As the ICB has highlighted in various documents, curing and caring take on different characteristics depending on whether it is a hospital ward or an intensive care unit, a prison or a Centre assisting asylum seekers, or a Residence for the elderly.

In this context, the development of community welfare could find one of its first and natural achievements in the creation, within the most relevant institutional facilities, of Ethical spaces, so that the physical proximity of the provision of a service also becomes, insofar as possible, support and moral closeness, strengthening social bonds and trust in relationships of solidarity.

Therefore, "*community welfare*" neither replaces nor overlaps with the activity of the State, rather it integrates its functioning on the basis of the principle of subsidiarity, favouring and linking the contribution of a plurality of stakeholders, from professional associations to voluntary associations, to the service users themselves. Citizens should not feel that they are the mere consumers of *welfare* services, but they could, in turn, become the architects of rethinking and improving the quality of services.

We would therefore have a circular process (State-community-State) aimed at optimising the common good through the improvement of interpersonal

⁸ For example, there were 7 sentences containing this word in 2000, while in 2013 there were over 70.

relationships in which the institutions would play the role of provider of guarantees, protection and supervision, helping people and social bodies to achieve their purposes. The desirable activation of the Ethical spaces for listening and assistance should increase individual well-being as much as the well-being of the community, consolidating the relationship between democracy and social solidarity.

"Ethical Spaces" could take shape and be implemented, as already anticipated, in different areas and social contexts. The ICB takes into consideration, emblematically, only a few: healthcare facilities, courts, prisons, schools. It is, however, an experience that could and should extend to all "ethically sensitive" areas in which the relational dimension and vulnerability manifest themselves and converge: workplaces, universities, various reception centres for migrants. It is the very diversity of these experiences that brings to the fore how it is not possible to indicate a defined institutional model and a precise organisational structure. The ICB is aware that it is putting forward a project that needs to be defined and consolidated through many further reflections within individual contexts. The future implementation of ethical spaces will derive from the moral solicitation to think differently about the possibility of building more careful forms of assistance and protection of vulnerable subjects, in the various forms in which vulnerability manifests itself in society even beyond the dimension of health.

An opportunity and a model: the Community Health Houses

A fundamental starting point could be represented by the *National Recovery and Resilience Plan* (PNRR), which provides for the creation of the so-called "Community Health Houses" to strengthen, reorganize and improve territorial services, operating a radical rationalization and simplification of bureaucratic procedures. Community Health Houses must constitute a continuous reference point for the population through the establishment of a single access point (PUA), equipped with adequate IT infrastructures, sampling points, multi-specialist equipment, for multidimensional assessments (health and social services) and dedicated services, according to a gender-specific approach to medicine, to the protection of women, children and families and more generally of vulnerable subjects. These facilities will include the services of a multidisciplinary *team* of general practitioners, freely chosen paediatricians, specialist doctors, community nurses, other health professionals.

It is particularly significant that there is also provision made for close integration with social workers and the possibility of including social and welfare services aimed primarily at the elderly, frail, people with disabilities, etc. These services will have to be organised in various ways according to the specific characteristics of individual communities. Ethical spaces could constitute one of the most significant and innovative developments of this radical turning point which should be ingrained in the social dimension of our welfare system.

The need for "proximity medicine" is also attested in the PNRR by the measures to strengthen intermediate health care through the establishment of "Community Hospitals", health facilities with up to a maximum of 40 beds, intended for patients who require health interventions of a medium/low clinical intensity and for short-term hospitalisations. The Community Hospital should also deal with home care, assisting families in adapting the home environment. The fact that the person is not immediately discharged and sent home would therefore

give families more time to adapt their home environment. For this reason, community hospitals should act in close synergy with local services.

As can be seen, in this reform project there is a return to the original design of the health reform centred on the protection and promotion of health as a multifaceted human dimension, stemming from which is the attention paid to the psychological and social as well as the biological determinants of health itself: hence the importance of general practice medicine and assistance, the continuity of care pathways, combining integration of social and health interventions. This design has however been left aside in the evolution of the healthcare system, the deficiencies of which have been exposed particularly during the pandemic (issues to which the ICB has recently devoted its attention). Ethical space can constitute a moment of collective re-appropriation of this model, within the local community, in a *continuum* of health care and social care that is brought even closer to citizens; and extending, with the necessary adaptations, moments for dialogue and encounter to other dimensions of social life in which the problem of loneliness of vulnerable subjects emerges with equally dramatic intensity.

Some examples of ethical spaces

Taking the PNRR as a starting point for an ever-wider realisation of community *Welfare*, the experience of ethical spaces in health care could expand to many other situations in which suffering, a sense of exclusion, isolation is manifest, even outside the limits of a situation that requires attention and understanding, beyond strictly medical and therapeutic profiles.

Ethical Space, Ethics Committees and Clinical Bioethics Services

In our country attention to ethical problems within health facilities does not take place in a homogeneous manner within a defined regulatory framework. The only ones to be jointly regulated and to operate in a homogeneous manner throughout the national territory are the Ethics Committees, set up on the basis of the decree of 8 February 2013, whose revision and restructuring is envisaged by paragraph 7, art. 2 of law 11 January 2018 n. 3. These committees are mainly intended for the scientific and ethical-legal evaluation of clinical trials and carry out only on an exceptional and residual basis other advisory tasks on emerging problems in clinical practice.

In certain regions or in certain territorial realities, specific bodies have been set up to deal with situations that go beyond the scope of pharmacological experimentation. In this regard, the ICB, in the opinion of 31 March 2017 on *Clinical Ethics Committees*, expressed the hope that these bodies would be established throughout the national territory, having “the function of the evaluation of clinical cases that do not fall within the scope of clinical and pharmacological trials, and therefore analyse and discuss the nature of the moral problems that patient care and therapeutic practice can present in the most delicate situations (e.g. beginning and end of life), with vulnerable subjects (e.g.: minors, the incapacitated, the elderly, immigrants), in the management of *incidental findings*; to propose and supervise institutional bioethics training activities; to take care, when possible, of the bioethical awareness of citizens”.

Always operating in a sporadic and non-homogeneous way are the "Clinical bioethics services" active in some hospitals which, in light of a 2001 ICB document, should perform "within health structures, primarily the functions of consultancy, but also of research and the collection of documentation on ethical problems of clinical practice and research. These services, if properly implemented, could be, in the most morally problematic decisions, not only of help to health professionals, administrators and possibly the users themselves who request them, but they could also provide a contribution to ECs (Ethics Committees) in the preparation, carrying out and subsequent verification of its interventions, recommendations, opinions".

The ICB first reiterates the need for an intervention by the legislator to re-order the matter by organising a system that operates in a homogeneous manner throughout the national territory and provides adequate differentiation of competences with regard to the various ethical profiles, with particular reference to clinical ethics committees and clinical bioethics services.

Ethical space can have a role, applied differently depending on the presence or absence of other bodies and services operating in the same area.

When both clinical ethics committees and clinical bioethics services are present, the function of Ethical space is to connect social and individual ethical issues and institutional organizations by identifying any areas of distress and suffering (e.g., regarding patients, family members, health workers) which may emerge in daily practice not directly at the patient's bedside (dealt with by the clinical ethics service) and not with reference to complex and problematic cases (dealt with by the clinical ethics committee). It does not carry out training functions, but it is a place for open discussion with citizens in order to facilitate dialogue and give immediate and direct attention to all those situations of distress and suffering that may emerge in daily practice and rarely fall within the specific types of intervention required by the most serious and problematic clinical cases. Often the condition of vulnerability arises from the many minute and unpredictable situations of daily life that only a widespread ethos, open to a plurality of sensitivities and professionalism, is able to detect and protect both in the provision of care and in the provision of services. Ethical space has the purpose of giving voice to a plurality of people, citizens, associations with beliefs, skills and experiences different from those that are institutionally defined or definable.

The ICB opinion on Clinical Ethics Committees expressed the hope that these would be supported by an ethical space to be understood as an observatory, a documentation centre, a discussion tool, a place for the provision of information and training, for sharing experiences and for interdisciplinary exchange on the more controversial ethical issues in the field of health. "Its functions are to promote organised ethical reflection, identifying and analysing ethical issues relating to hospital practice, to foster the relationship of trust, the 'care pact' between doctors, patients and health professionals, creating concrete opportunities to meet and listen as well as carrying out a role of consultancy and support to ethics committees, through the establishment - where necessary - of research groups and *ad hoc* commissions, in collaboration with universities and scientific institutes, on bioethical issues of great complexity".

When there is only a clinical ethics committee or a clinical bioethics service present in the facility, or in the absence of both, Ethical space has the additional function of raising awareness in healthcare facilities on the importance of ethics and on the need to establish ethics committees and/or clinical ethics services so

that there are appropriate interdisciplinary competencies for the analysis of complex cases.

Ethical space within and beyond the healthcare sector

Ethical space - understood as a place in which to listen, encounter others and exchange personal and professional life experiences, to give voice to individual citizens and the associations that represent them - has a plurality of functions variously structured around the need to:

- identify situations of vulnerability;
- reduce the opportunities that generate them;
- respond to requests for care and assistance.

These needs emerge significantly within healthcare facilities starting from the complex articulation of the relationship between doctor and patient, but they also concern other aspects of relational life. The ICB briefly examines only a few (prisons, courts, schools) among the many, to offer an example of how vast and capable of significant application this perspective of a widespread ethics is in seeking to give voice to the various forms of suffering and marginalisation manifest in our society.

The experience of "imprisonment" underlines how important it is to nourish and cultivate, alongside the unfortunately often inadequate re-education measures, the relational dimension, providing systematic places where inmates, operators, prison guards and family members can examine together the situations marked by deficiencies, operational difficulty, mutual incomprehension, if not tension. The ICB focuses, particularly, on the condition of women both because it is more dramatic also due to its repercussions on minors and because the reduced number of the detained makes experimenting with this new institution easier and more immediate. Starting to create an ethical space in women's detention centres could therefore constitute the first step to activating a path to extend to the entire prison community and provide a significant contribution to the processes of resocialisation and rethinking of prison sentences in light of the adequate implementation of community based legal measures.

The "court" could be the ideal place to build "proximity justice" paying particular attention to the protection of minors. In both civil and criminal justice, the ability to listen to the weakest and most fragile subjects is crucial. Both the custody of a minor to one parent in the case of family separations as well as probationary custody of a deviant minor or the victim of harassment constitute, albeit in a different way, a crucial moment that will have radical repercussions throughout the minor's entire life. Dialogue is decisive in order to make the best possible decision in the exclusive interest of that particular weak subject who is "little" in a world of "grown-ups". Ethical space should be added to the measures already present and whose further strengthening is foreseen by the recent reform of civil trials which pays special attention to families, minors and vulnerable subjects with the extension of assisted negotiation, more careful regulation of removal of the minor from both or one of the parents, the establishment of a single specialised judge within the framework of a new division of competences between

the juvenile court and the ordinary court and provision of a single proceeding and a specialised judge.

In "schools" the dialogic dimension is central and already provides for various moments of encounter between teachers, parents and students. Ethical space would constitute a further place to facilitate the encounter between the educational dimension and the existential dimension in addressing all those problems that may arise in the formation and maturation process as well as those of the minor. The ICB focuses in particular on the issue of disability and on the phenomenon of bullying which, although dramatically widespread, is often among the most hidden.

Concluding reflections: the promotion of the ethical space for a public debate

The ICB, in the face of the ethical problems in the health sector, particularly complex and fast in relation to biomedical progress, and the ethical problems extending beyond the field strictly concerned with health (e.g., prison, courts, school), believes that the ever-emerging importance of debate on bioethical issues should be opened to society. Already the Council of Europe in the Oviedo Convention on Human Rights and Biomedicine in 1997 under art. 28 urged the Member States to have an "adequate public discussion"⁹.

The Committee believes that Ethical space can be a first step in this important direction. The fundamental objective is to raise the awareness of citizens, in a critical way, on emerging ethical issues: encouraging the circulation of information, points of view and opinions, discussing with experts and organising debates, in which opposing arguments emerge, and which provide categories of reference so that the position on bioethical issues is never just "emotional", but also always "rational". Debates must be inclusive and make the voices of those most vulnerable heard.

Public debate can not only make citizens more aware of their choices, but it can also strengthen their role in the *governance* of their society. As happens in France, which periodically organises and structures the "Estates General of Bioethics", involving citizens in the discussion, in order to perceive "social sentiment".

In Italy the debate exists, but it should be further implemented and systematically organised, in various areas, also by means of Ethical spaces.

It is also an institutional task of the ICB to inform society on ethical problems and challenges: some initiatives have already been undertaken (conferences for schools and meetings with citizens), however the ICB believes implementation of this area to be necessary and urges the Government to take steps in this direction.

⁹ See Council of Europe Bioethics Committee (DH-BIO), *Guide to Public Debate on Human Rights and Biomedicine*, 2019 <https://rm.coe.int/prems-009521-ex-061320-gbr-2007-guide-on-public-debate-16x24-web/1680a12679>.