

THE RELEVANCE OF THE ETHICS OF VULNERABILITY IN BIOETHICS

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Article abstract

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THE RELEVANCE OF THE ETHICS OF VULNERABILITY IN BIOETHICS

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ABSTRACT:

The concept of vulnerability is central to current developments in bioethics, not only because of its analytic nature, but also due to its capacity for criticism. However, this concept has not been sufficiently developed, neither in the area of moral philosophy nor in bioethics. For this reason, it is necessary to define and analyze the conceptual framework in which the notion of vulnerability has been developed within the scope of bioethics. Thus, the purpose of this paper is to indicate how the concept of vulnerability in the field of bioethics has been developed and what the main problems that derive from this approach are. Secondly, the paper analyzes some of the main philosophical approaches that I consider should be articulated in the expansion of a critical bioethics approach focused on the notion of vulnerability. To address this issue, I analyze the reflections that we find in the work of Martha Fineman, emphasizing the main relevant aspects for bioethics. Finally, I highlight the main implications of a theory of vulnerability for bioethics.

RÉSUMÉ :

Le concept de vulnérabilité est au cœur des développements actuels de la bioéthique, non seulement en raison de sa nature analytique, mais aussi en raison de son potentiel critique. Cependant, ce concept n'a pas été suffisamment développé, que ce soit dans le domaine de la philosophie morale ou de la bioéthique. Pour cette raison, il est nécessaire de définir et d'analyser le cadre conceptuel dans lequel la notion de vulnérabilité a été développée en bioéthique. Ainsi, le but de cet article est d'indiquer comment le concept de vulnérabilité a été développé dans le domaine de la bioéthique et quels sont les principaux problèmes découlant de cette approche. Deuxièmement, l'article analyse certaines des principales approches philosophiques qui devraient selon moi être articulées à une approche bioéthique critique centrée sur la notion de vulnérabilité. Pour traiter ce problème, j'analyse la réflexion de Martha Fineman, en soulignant les principaux aspects pertinents pour la bioéthique. Enfin, je souligne les principales implications d'une théorie de la vulnérabilité pour la bioéthique.

INTRODUCTION

Over recent decades, concern for human vulnerability seems to have been at the centre of reflections in different fields, such as sociology and health care. Despite the fact that traditionally this concept has not been sufficiently addressed, neither in the field of moral philosophy nor in bioethics, remaining under-theorized, in recent years a wide range of scholars have been interested in exploring this concept. One of the first contributions was conducted by Florencia Luna (2006, 2008, 2009, 2013), exploring vulnerability in regard to bioethics, mainly in the research context. In addition, one of the most relevant contributions is the huge analysis that Henk ten Have provides (2016) to comprehend how this concept has been understood in bioethics, through different conceptions of and philosophical approaches to vulnerability. Also, the work of Mackenzie, Rogers, and Dodds (2014) has had an important influence on the endeavour to clarify the concept, as well as the more recent research of different authors collected in Straehle (2016). In spite of this, the vulnerability concept retains some opacity, and there is a controversy about its meaning and the way to understand it in bioethics.

Within bioethics, the concept of vulnerability has been developed mainly in relation to biomedical research ethics and secondarily in the area of public health. In both cases, the focus has been on the categorization of vulnerable groups. Undoubtedly, this approach has been very useful in alerting researchers to the damages associated with biomedical research if the minimal protection principles are not respected, especially under certain circumstances, such as in situations where there is a lack of capacity to give informed consent or in situations of potential exploitation. In terms of public health, the issue of vulnerability has generated a vast body of literature concerning how to address social and health problems with regard to different populations. Through classifications of vulnerable populations, political and protection measures have been developed in different contexts. While not neglecting the fact that in clinical ethics there is a tendency to consider disease as a specific form of vulnerability, the main approach in bioethics is to focus on vulnerable groups or populations. This discourse on vulnerable groups has had an important impact on practical aspects of bioethics, such as the institution of compulsory research ethics committees,¹ among others. However, this understanding of the vulnerability concept represents the most standard interpretation, reflecting the diverse fields in which it has been developed, which gives rise to some problems.

I argue that vulnerability *is* and *must be* a central and key concept within bioethics. Thus, in the first part of this paper, I examine how the concept of vulnerability has evolved in the field of bioethics and what main difficulties arise as a result of this conception. In my view, the main problem in focusing on the discourse of vulnerable groups is that this perspective excludes other reflections concerning an extended understanding of vulnerability as a human condition.

From a philosophical perspective, it is essential to explore the controversy surrounding universality and particularity with regard to vulnerability (Wisner, 2016; Zagorac, 2017). To address this issue, in the second part of this paper I discuss some of the characteristics of the category of vulnerability in light of the analysis that we find in the work of Martha Fineman. The concept of vulnerability as a human condition has some normative implications that it is necessary to investigate. The main goal of this article is to analyze the ontological conception of vulnerability that is at the base of a theory of general vulnerability in bioethics. Finally, I highlight the main implications of a theory of vulnerability in bioethics.

As MacIntyre (2006, p. 23) points out, human vulnerability has generally been neglected throughout the history of philosophy; it has predominantly been feminist philosophy that has highlighted the importance of human interdependence and its links. Other than the work of Robert Goodin (1985),² it has been only in recent years that a greater interest in this concept has been aroused. According to Hoffmaster (2006), ethics has not paid attention to vulnerability for three reasons:

1. Vulnerability is the antithesis of the individualistic ethics predominating in Western societies.
2. Vulnerability is not addressed in ethics because philosophy ignores the body.
3. Ethics has been prominently rationalist and therefore feelings have been displaced or have not been taken into account.

In general terms—and considering that vulnerability has been an under-theorized concept—we can find two principal ways of thinking about vulnerability that have been developed in ethics:

*Ontological or universal vulnerability.*³ This conception is linked to its Latin origin “*vulnus*” and the possibility of suffering that is inherent to human beings. In the philosophical approaches that address this concept, it is common to think of vulnerability in relation to being fragile, susceptible to damage, and also to suffering. In a broad and general way, these perspectives highlight that it is an ontological, anthropological, inherent, and shared condition. In addition, another shared feature of these perspectives is that they link our vulnerability with our inherent sociability—i.e., with the inevitable fact that we are dependent on one another.

Contingent or situational vulnerability. Another type of response to the issue of vulnerability emphasizes different forms of inequality, dependency, basic needs, deprivation of liberties, etc. These social, economic, and political aspects make some people more vulnerable than others. In this regard, this approach is focused on the economic and social inequities that make some people more vulnerable than others.

One of the challenges we have to face in the context of critical bioethics is how to understand the relationship between these two ways of conceptualizing vulnerability, as critical bioethics is concerned about inequalities worldwide.

TRACKING THE VULNERABILITY CONCEPT IN THE CONTEXT OF BIOETHICS AND IDENTIFYING THE MAIN PROBLEMS

When one analyzes the bioethical literature, it is apparent that the notion of vulnerability has developed mainly in the context of the ethics of biomedical research. In this regard, the principal approach adopted concerning the concept in bioethics has been marked by different international documents. These documents have been articulated with regard to regulations concerning vulnerable populations. One of the first documents to provide an approach to the concept in this specific area is the Belmont Report (1979).⁴ This text focuses on the respect for persons, on beneficence, and on justice in the context of medical research, and the issue of vulnerability is argued with regard to each principle. Another text, the Declaration of Helsinki,⁵ mentioned vulnerability in its fifth revision in 2000, but only in the introduction to principles (art. 8):

Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.

Five years after this revision of the Declaration of Helsinki, another indispensable document was developed: the Universal Declaration on Bioethics and Human Rights.⁶ This text contains the first statement of bioethical principles accepted by governments. Article 8, “Respect for Human Vulnerability and Personal Integrity,” is as follows:

In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

Following the recommendations in all these documents, among others, we can find some of the most significant implications of the vulnerability concept with regard to biomedical research:⁷

- (a) An additional justification for involving vulnerable people in research is needed. Although involving vulnerable people in research is a useful tool for trying to avoid exploitation or recruitment without consent, people who are included under

the term “vulnerable populations” may then not benefit from progress in research. As a result, these populations may be subject to some forms of discrimination, as the access to scientific advances could be limited for them. For example, pregnant women are excluded systematically from research, when it could be possible to ask them if they want to participate in clinical research or not.

- (b) The second implication is that vulnerable populations need extra protection when involved in research. But we have to consider that all the participants in research need to be protected, regardless of whether they are considered more vulnerable. Due to risks associated with research, it is extremely important to balance the risks and benefits for participants, independently of their potentially greater vulnerability.
- (c) The third implication is that researchers should be more responsive to the needs of vulnerable populations—especially with regard to informed consent—and must be alert to ways of avoiding exploitation. The main problem is that avoiding exploitation leads researchers to limit their consideration of vulnerability to the issue of informed consent and thus to not take into consideration other aspects related to vulnerability.

Undoubtedly, reflections concerning vulnerable groups have been very useful in alerting researchers to the damages associated with biomedical research if the minimal protection principles are not respected, especially under circumstances such as the incapability to give informed consent, or in situations of potential exploitation.⁸ The use of minimal protection principles for vulnerable populations exerts a widespread influence of understanding within bioethics. However, there are several criticisms that have been made in recent years with regard to the population-based approach to vulnerability in bioethics.

One of the main criticisms of the concept of vulnerability in research ethics is that the term itself is nonsense because of the “hyper condition of vulnerability.” As Levine et al. (2004, pp. 46-47) argue, it is a concept that is both too broad and too narrow at the same time. On the one hand, it is too broad because there are so many vulnerable groups that it results in a paradox: the term loses its sense of special protection for some populations. The list of vulnerable groups is so extensive that ultimately each of us belongs to such a group (for example, women, the elderly, and so on). On the other hand, the concept is too narrow because it focuses on difficulties only with regard to consent. Attitudes and politics regarding protection are directed almost exclusively towards improving the informed-consent process, which is insufficient to ensure proper protection of vulnerable people. This implies a restrictive conception of vulnerability, which neglects many other factors that are decisive in understanding how a person is located in a position of greater vulnerability, such as in poverty and precarious living conditions. By reducing vulnerability to informed consent, there can be

many situations not detected by researchers in which people are vulnerable, thus meaning that these people cannot be adequately protected.

Another criticism regarding the concept is related to “labelling.” The categorization of people into vulnerable groups results in a form of labelling, which can lead to discrimination and stereotyping, as such groups seem to be established as something fixed and static. After an intensive analysis of the principal arguments against the use of the concept of vulnerability within the field of biomedical research, Florencia Luna (2008) addresses the problem of labelling in biomedical research ethics using the metaphor of layers. She points out that there are many potential sources of vulnerability, and each of these constitutes a different, overlapping layer. This metaphor of layers presents a contextual and variable concept of vulnerability, moving away from the fixed and static view. Luna (2008) proposes that if we think about the idea of layers, we can understand that there may be different situations in which sources of vulnerability overlap, all operating on the same person. We all have some unavoidable layers of vulnerability because of our finite condition, arising from the fragility of being human, but if we add different circumstances and conditions, we add more layers. In this way, it is also easier to identify the different elements that locate a person in a situation of special vulnerability; once these elements have been identified, it will be possible to try to modify these circumstances.

In addition, another problem that has been pointed out is that, while protection measures are established based on the analysis of vulnerability, the door is then open to unjustified versions of paternalism. Protections for the vulnerable carry the danger of being paternalistic. There is a tendency in all the approaches that Rogers (2014) analyzes (research-ethics, clinical-ethics, and public-health approaches) to engage in labelling, with its associated risks of discrimination and paternalism. Moreover, there is no complete description of the responsibilities owed to the vulnerable in terms of protection, remedies, compensation, benefits, or aid. From her perspective, this points to the need for a better explanation of the theoretical connections between vulnerability and justice. In this regard, the notion of vulnerable populations can undermine individual autonomy and result in potential damage as a consequence of such unjustified forms of paternalism. Mackenzie (2014) also considers that, to counter the risks of objectionable paternalism, we should respond to vulnerability through fostering the value of autonomy.

Finally, from my perspective, the main problem presented by the group-based approach is that it centres all reflection concerning vulnerability in bioethics on research ethics and public health, and restricts reflection only to the concern for vulnerable groups. The consequence is a too-narrow focus in bioethics, which is why this field needs a broader reflection on vulnerability. In addition, as Martha Fineman (2012) has highlighted,

the designation of vulnerable (inferior) populations reinforces and valorizes the ideal liberal subject, who is positioned as the polar opposite of the vulnerable population. This liberal subject is thus constructed as

invulnerable, or at least differently vulnerable, and represents the desirable and achievable ideals of autonomy, independence, and self-sufficiency (p. 86).

In this regard, the entire discourse of mainstream bioethics has been built around this ideal of autonomy within the liberal perspective. The main problem is the dominance of the rhetoric of the liberal subject, which perpetuates the myth of the independence, self-sufficiency, and autonomy of the subject also within bioethics. Focusing on the vulnerability concept as a core feature in bioethics is a challenge in terms of reversing this dominance of the “autonomy myth.”⁹

HOW DO WE FACE PROBLEMS WITH REGARD TO VULNERABILITY?

Henk Ten Have’s (2016) analysis underlines some of the problems that have to be addressed with regard to the concept of vulnerability within bioethics. First, the fact that there are different kinds of vulnerability is widely accepted within the field. Some reflections on vulnerability create taxonomies of the multiple forms of vulnerability, such as the contribution of Rogers, Mackenzie, and Dodds (2012, pp. 24-25). These authors structure a distinctive taxonomy of different forms of vulnerability, as well as different states of it. Within their taxonomy of vulnerability, first, there is inherent vulnerability, which is intrinsic to human condition. For them, inherent vulnerability is related to our corporeality and our dependence on others. This vulnerability is ever-present, but may vary in degree, depending on factors, such as age, gender, health status, and disability. Second, situational vulnerability refers to features that depend on the specific context of the person. Situational vulnerability is context specific and it is affected by the personal, social, political, economic, and environmental circumstances of individuals or social groups. This kind of vulnerability refers to a sociological notion of the term, since, as Mackenzie et al. emphasize, it refers to how the vulnerability that is initiated—for instance, by an earthquake—is mediated by a social context. They identify another kind of vulnerability—pathogenic—which is generated by a variety of sources, including morally dysfunctional or abusive interpersonal and social relationships and sociopolitical oppression. Pathogenic vulnerability occurs as a consequence of social-policy inventions that attempt to reduce some other kind of vulnerability, but which have the paradoxical effect of increasing overall vulnerability. Pathogenic vulnerability is generated by social relationships characterized by disrespect and prejudice. Pathogenic vulnerability is more clearly political than other kinds, because it is related to the disparities of power between those who design the rules, for instance, of “protecting the vulnerable humans in a research,” and those who are subjected to those rules. The most interesting aspect of this kind of vulnerability is that it emerges when a response aimed at ameliorating vulnerability in fact generates a new vulnerability and possibly also exacerbates existing ones. In my view, this kind of vulnerability shows how the notion of vulnerable groups or populations could be potentially dangerous, because it can contribute to creating new forms of vulnerability in the attempt to minimize it. This point is especially relevant from the institutional perspective, since, the

majority of the time, vulnerability emerges precisely because of the institutional framework.

In addition to this taxonomy of vulnerability, the authors distinguish between different states of vulnerability: dispositional and occurrent. The distinction between dispositional and occurrent refers to states of potential or actual vulnerability, and it serves to separate vulnerabilities that are not yet or not likely to become sources of harm from those that require immediate action to limit harm. These two states of vulnerability will also require different actions to ameliorate vulnerability, depending on whether it is dispositional or occurrent. Through this distinction, the authors try to clarify the opacity that usually accompanies the perspectives on vulnerability in bioethics.

Other authors consider it better to opt for a conceptual clarification, such as the distinction proposed by Kottow (2003, pp. 470-471) between susceptibility and vulnerability. He recognizes that vulnerability is a common feature of human beings. When individuals become biologically weak or diseased, they are susceptible to increasing their predisposition to additional harm and require social actions to treat their situation. Thus, he considers the problem to be that mislabelling people as vulnerable—a characteristic that all humans share—leads researchers to avoid registering the deprivation that these people suffer and to neglect their ethical obligation to offer them real help. The distinction between vulnerability and susceptibility marks the difference between being intact but fragile (vulnerable) and being injured and predisposed to additional harm (susceptible).

In spite of the potential of these different contributions to clarify the concept of vulnerability, globally the main and most-accepted distinction is expressed as the distinction between universal and particular (or situational) vulnerability. The notion of particular vulnerability is assumed in relation to vulnerable groups. There are many criticisms of the classification of individuals in vulnerable groups, especially because such classification is considered potentially harmful in that it can lead to stigmatization for persons included in some group, as I have considered. One of the main reasons why it is difficult to accept the universal condition of vulnerability within the mainstream discourse of bioethics is because it is difficult to reconcile this conception with the liberal autonomy principle, which is at the centre of mainstream bioethics.

To gain a better understanding of vulnerability as a philosophical concept and of the important role of the ethics of vulnerability within bioethics, I defend the importance of a notion of universal vulnerability in bioethics. To this end, I analyze Fineman's vulnerability theory.

UNIVERSAL VULNERABILITY AS A CRITICAL CONCEPT

All human beings are involved in networks of relationships; our own vulnerability, fragility, and dependence on others lead us to develop links with others

(Guerra Palmero 2009, p. 81). Universal vulnerability refers to our own and shared fragility and dependence as an ontological condition of our humanity. In this part of the paper, I analyze one of the main theories from which it is possible to develop an ethics of vulnerability for bioethics. In particular, I focus on the work of Martha Fineman. I consider the theory of vulnerability developed by Martha Fineman one of the most important theories on vulnerability that can contribute to introducing an ethics of vulnerability into the field of bioethics.

Martha Fineman has developed one of the most influential theories of vulnerability in recent years. She has emphasized that vulnerability is universal and constant: it is a human condition. From her perspective, “the concept of vulnerability reflects the fact that we all are born, live, and die within a fragile materiality that renders all of us constantly susceptible to destructive external forces and internal disintegration” (Fineman 2012, p. 71). Vulnerability defines what it is to be human, and this conception reminds us of our corporeality and fragility. This feature is common to all human beings, and it is because of the universality involved in the vulnerability concept that we must consider it as *the* human condition, on the basis of which it is possible to articulate a series of social-protection and state responsibilities

In *The Autonomy Myth*, Fineman (2004) thoroughly develops a theory of dependency.¹⁰ She argues that political rhetoric and popular ideology in the United States have become so fixated on the myth that citizens should be autonomous that they fail to recognize the inevitability and normality of dependency. Fineman argues against the prevailing autonomy myth, because dependency is an unavoidable feature of any society and it is not a feature that is taken into account from the liberal perspective. She later expanded on the work that she did in theorizing dependency, focusing on the concept of vulnerability (Fineman 2010, p. 255):

The concept has evolved from those early articulations, and I now think it has some significant differences as an approach, particularly in that a focus on vulnerability is decidedly focused on exploring the nature of the human part Vulnerability is posited as the characteristic that positions us in relation to each other as human beings and also suggests a relationship of responsibility between state and individual. The nature of human vulnerability forms the basis for a claim that the state must be more responsive to that vulnerability.

By emphasizing the vulnerability concept as *the* human condition, it takes on a critical dimension as it calls into question the dominant model of the liberal subject. It challenges this dominant model focused exclusively on autonomy and highlights the shortcomings of the model. The autonomous and independent subject is a fiction and through it inequalities are perpetuated. The focus on vulnerability leads us to think about our individual and collection obligations, in order to provide assistance.

Vulnerability theory tries to confront the individualistic autonomy model. The image of the subject in vulnerability theory is built in opposition to the image of the autonomous subject of the liberal model in modern philosophy: that sovereign subject (autonomous, rational, etc.) sets aside the corporeality, fragility, and interdependence that form human life. We can understand our humanity in a broader sense only by recognizing our universal vulnerability and interdependence. This view contrasts radically with the liberal view of the autonomous subject and is a criticism of that perspective.

Martha Fineman's theory also emphasizes the importance of our bodies and of our dependency. In this regard, her way of understanding vulnerability allows a new ethical perspective, which is focused on our corporeality. The tradition of Western philosophy has neglected the importance of considering our bodies within discourse and thought. Human vulnerability and dependency have no place, let alone a central place, in philosophical approaches that equate morality with rationality, and moral agency with rational agency. Vulnerability has little to do with our contemporary morality, as it is antithetical to our emphasis on individualism and rationality. As Fineman highlights, only by recognizing our vulnerability can we understand our humanity.

Another important aspect in Fineman's approximation is the fact that vulnerability is not only a negative condition. For Fineman, vulnerability can provide positive or negative results, but it must be first accepted and not ignored. Indeed, recognizing the positive aspects of vulnerability can improve the experiences of people in terms of isolation and exclusion:

Properly understood in the context of the human condition, vulnerability is also generative. Importantly, our vulnerability presents opportunities for innovation and growth, creativity and fulfilment. It makes us reach out to others, form relationships, and build institutions (Fineman 2012, p. 96).

The main aspect that Fineman highlights is that recognizing the inevitability of vulnerability will lead to a better understanding of the concept and will redefine our responsibilities as a society, which means that vulnerability also contains positive aspects. We live in deep networks of radical interdependence that the ideology of individualism denies. The ideal of an autonomous and self-transparent being does not foster ethically responsible behaviour. On the contrary, the liberal self, theorized in terms of the prevailing notion of autonomy—an individualistic and narcissistic self—promotes the ethics of violence. It is in this conception of the subject as vulnerable—in opposition to the idea of the sovereign subject, the owner of oneself, conscious and transparent to oneself—that the possibility of responsible and nonviolent ethical practice opens up. Vulnerability challenges the modern illusion of self-sufficiency and allows us to discover and invent life together.

PARTICULAR VULNERABILITY: SOCIAL AND POLITICAL ASPECTS CONCERNING VULNERABILITY AND VULNERABLE GROUPS' PROBLEMS

The various approaches to the concept of vulnerability agree that we all share a common vulnerability, but this common vulnerability is distributed in different ways. Thus, universal vulnerability becomes exacerbated in certain social, political, and other situations. The notion of particular vulnerability implies that we need to discover the mechanisms of this unequal distribution to try to resolve the inequality. Recognizing that inequality is assigned differently can be directed to developing specific social policies.

Fineman emphasizes that vulnerability is a human feature that can be expressed in different ways. Each individual is positioned differently, and vulnerability is dependent on the different positions we occupy in the social space, or on the ways in which we are supported by social institutions. The result is that human beings are not vulnerable in the same way or to the same degree. This can appear to contradict with our anthropological vulnerability, which is a constant in people's lives. But we do not have to consider these two perspectives to be irreconcilable. As Fineman (2010, p. 31) has argued:

While human vulnerability is universal, constant, and complex, it is also particular. While all human beings stand in a position of constant vulnerability, we are individually positioned differently. We have different forms of embodiment, and also are differently situated within webs of economic and institutional relationships. As a result, our vulnerabilities range in magnitude and potential at the individual level. Vulnerability, therefore, is both universal and particular; it is experienced uniquely by each of us.

Our individual experiences of vulnerability vary according to the resources we have to deal with it. It is true that, as Fineman remarks, society cannot eradicate our vulnerability, but what it should do is act as a mediator compensating for our different positions through particular programmes, institutions, and structures. In this regard, Fineman has extensively argued that it is vulnerability as the human condition that generates the responsibility to provide support. As Ten Have (2016, p. 107) has stressed, based on Fineman's approach, the argument that links vulnerability and responsibility is that the shared human condition generates moral obligations for others. Indeed, these obligations are not the result of voluntary choice or commitment, but arise from vulnerability. While we are all vulnerable, some people are located in a worse position than others in the social space, because of social inequities and their limited access to resources. Thus, it is not enough to provide equal protection to all, because social conditions are not the same for everyone. The degree of dependence involved in vulnerability can vary, so that some people have more needs than others. Indeed, the universality of the concept does not mean that people are homogeneous. Therefore, as a society we have to promote the necessary resources to face inequalities. As Martha Fineman (2008, pp. 4-5) remarks:

The general tendency under a sameness of treatment equality framework is to focus on individuals and individual actions. The task under this approach is to identify the victims and the perpetrators of discrimination, as well as to define what were the prohibited activities, the individual injury, and the specific intent involved in each occurrence. Unless they are tied to individuals and discrimination, systemic aspects of existing societal arrangements are left out of the picture. It is as though existing material, cultural, and social imbalances are the product of natural forces and beyond the ability of the law to rectify. While it may be beyond the will of the law to alter, existing inequalities certainly are not natural. Inequalities are produced and reproduced by society and its institutions. Because neither inequalities nor the systems that produce them are inevitable, they can also be objects of reform.

In bioethics, as I have shown, the most extensive view of vulnerability is related to vulnerable groups. However, the use of the designation vulnerable also results in their stigmatization, since the term vulnerable population has an air of victimhood, deprivation, dependency, or pathology attached to it (Fineman, 2010, pp. 27-28). Consequently, should we avoid using this categorization in bioethics? Is that possible? I would like to analyze the most complex aspects concerning the possibility of avoiding this designation within the field of bioethics, as well as the advantages and disadvantages in such a change of perspective. Some of the advantages of the use of the terminology of vulnerable groups in bioethics are as follows:

1. Researchers must take into account the fact that these people may have certain characteristics that require more protection so that they are not damaged due to their particular circumstances. An example of this is the capability of a soldier to consent when part of a hierarchical structure, which may influence the decision to participate in an investigation.
2. Similar resources can be offered to people who are in similar situations of vulnerability—that is, when their circumstances may require similar responses from institutions. This can lead to the implementation of more operational measures, since, through this categorization, the labelling of people within groups who have similar needs, one can try to provide some formalized or standardized resources.

However, there are two main problems posed by the concept of vulnerable groups. First, there is the risk of stigmatization if we carry out labelling: people can be trapped inside categories that correspond to vulnerable groups. Hence, an association can be made between the categorization of vulnerable groups and victimization, need, loss, lack, etc. In this regard, we must also consider the way in which people viewed as belonging to vulnerable populations within bioethics perceive themselves as belonging to these groups or as being distant from them.

The second problem is that categorization and labelling can lead to paternalistic forms of response to vulnerability. A mode of protection of vulnerable people centred on forms of paternalism can be highly harmful because it denies people the capability to decide for themselves, delegating decision-making about what is better or worse for the people involved to others and discounting their views (Rogers, Mackenzie, and Dodds 2012).

Vulnerability theory understands that the designation of universal and constant vulnerability implicitly means that vulnerability should not be used as a variable in degree and comparative concept. One of the main points highlighted by Fineman is that no individual or group should be considered more or less vulnerable, uniquely vulnerable, or specifically or especially vulnerable. This aspect is very important: she rejects the categorization of vulnerable groups or populations because this is related directly to stigmatization and victimhood and is needless: “This targeted group approach to the idea of vulnerability ignores its universality and inappropriately constructs relationships of difference and distance between individuals and groups within society” (Fineman 2012, p. 85). What vulnerability theory proposes is that instead of using this designation:

we can think about spaces, places, and positions or relationships as indicators of the proximity of, exposure to, or probability for vulnerability to be manifested or realized in the form of dependency. By the same token, we can think of these same spaces, places, and positions as sites for the production of resilience – these are or should be thought of as sites of state responsibility.¹¹

Consequently, bioethics has the huge challenge of trying to avoid this denomination. Human beings do not become more or less vulnerable because they have certain features or characteristics, or because they are at a particular stage of their lives, but they do experience the world with different levels of resilience. Resilience is the remedy for vulnerability, even if it is an incomplete remedy: “although nothing can completely mitigate vulnerability, resilience is what provides an individual with the means and ability to recover from harm, setbacks, and the misfortunes that affect her or his life” (Fineman, 2015, p. 622). It is important to point out that nobody is born resistant. On the contrary, resilience occurs within and through the institutions and relationships. That is why within vulnerability theory, the concept of vulnerability as our shared condition lead us to focusing on the state and institutional responsibility on providing resources for increase or foster resilience.

What might actually be more problematic is overcoming the risk of paternalism associated with designating groups as vulnerable. One of the most important problems that arise when we use vulnerable groups as a scope of reflection is the fact that this designation can imply an inevitable sense of paternalism. Luna’s metaphor of layers is useful for overcoming stigmatization, as it understands particular vulnerability as something flexible, dynamic, and no static. Fineman’s proposal that we speak about spaces that generate greater vulnerability, rather

than groups, is also useful in trying to avoid the stigmatization associated with the categorization of vulnerable groups. In addition, vulnerability theory accentuates the importance of the role of the state and institutions in trying to improve people's support. Fineman suggests that vulnerability has a creative dimension, and she understands that it can lead to the generation of resilience as a way of overcoming vulnerability.

From my perspective, the only way of avoiding the paternalism that can be associated with interventions made by the state and institutions to try to protect people is to actively reject it. This is why it is necessary to rethink a new way of understanding autonomy as a concept of relational autonomy. Of course, it is true that it is necessary to cultivate resilience. But even when we are working with resilient people in an attempt to provide protection and assistance measures, if we do not focus on actively avoiding paternalism by fostering autonomy rearticulated in a relational sense, actions undertaken for protection may be paternalistic. As Mackenzie and Stoljar (2000) highlight, there is no single way to understand the term "relational autonomy"; it is more like an "umbrella term" that contains different points of view. Following the analysis of Jennifer Nedel-sky (1999, 2011), and bringing the concept of relational autonomy into bioethics and the clinical context, we have to consider how this concept can help us to face unjustified paternalism. Firstly, autonomy must be understood as a capability. This means that autonomy is not a "natural" characteristic of a human being. It is a fundamental element of human existence, but it needs to be developed. More specifically, in the field of medical care, it is really important to realize that if the conditions of the possibility for autonomy are not given, the principle of autonomy will be only a myth or an illusion. In this way, we can conclude that autonomy and vulnerability are not incompatible. Far from it—these two terms are strongly related. We cannot think about vulnerability without considering autonomy, and, vice versa, we cannot think about autonomy without considering the inevitable and universal vulnerability that we have.¹²

SOME CRITICISMS OF VULNERABILITY THEORY

Having analyzed the general conceptual framework on the basis of which it is possible to develop the concept of vulnerability in bioethics, I now wish to highlight what is in my view the basis for an ethics of vulnerability in bioethics. Not only has Fineman's theory of vulnerability had a very significant impact, but it is also indispensable. I would like to summarize briefly the main arguments developed by Fineman and also some of the criticisms of this theory. In brief, the three main arguments in Fineman's vulnerability theory are as follows:

- 1) Vulnerability is *the* universal and inevitable condition of our embodied humanity. Dependency is intermittent; however, vulnerability is a constant feature of the human condition, which carries with it the imminent or ever-present possibility of harm: "understood as a state of constant possibility of harm, vulnerability cannot be hidden" (Fineman 2008, p. 11).

- 2) In addition, vulnerability is a constant in the human lifetime, but it is also context specific, being dependent on social and economic circumstances. Thus, it is experienced differently by each individual.
- 3) Fineman approaches the subject of vulnerability by focusing on the conception of state responsibility. While the rhetoric of autonomy supports a non-interventionist state, within the vulnerability-theory approach the role of state institutions is to provide protection from the vicissitudes of fortune, “collectively forming systems that play an important role in reducing, alleviating and compensating for vulnerability” (Fineman 2010, p. 269). Such systems cannot make us invulnerable, but they do provide us with resources that promote resilience.

In Fineman’s (2008, p. 9) view, “vulnerability raises new issues, poses different questions, and opens up new avenues for critical exploration.” I strongly believe in the potential of the concept of vulnerability to help examine new problems and develop new solutions to the principal issues in the bioethics field. However, before I look more closely at the main implications of vulnerability theory for bioethics, it is necessary to analyze the main criticisms that have been made with regard to Fineman’s theory in relation to this field.

Catriona Mackenzie (2014) has developed a taxonomy of vulnerability and has extensively analyzed the concept of vulnerability in relation to bioethics. She argues against the three main proposals of Fineman’s theory. Although she considers vulnerability theory to be a good approach and to have many possibilities for development, she distances herself from Fineman’s theory. Her main criticisms are as follows.

First, in Fineman’s analysis of vulnerability the ontological conception is overly salient. For Mackenzie (2014, pp. 37-38), Fineman gives too much importance to the ontological vulnerability emanating from our own corporeality. Although Mackenzie acknowledges that Fineman’s theory includes the different ways in which people experience vulnerability based on their resources, Fineman overemphasizes universal vulnerability. The problem from Mackenzie’s viewpoint is that this attitude does not pay much attention to the social, economic, or political structures that generate greater vulnerability.

From my perspective, the emphasis on recognizing ontological vulnerability does not presuppose a deficit in the way of understanding how social and political conditions clearly affect people’s needs. “Undeniably universal, human vulnerability is also particular: it is experienced uniquely by each of us and this experience is greatly influenced by the quality and quantity of resources we possess or can command” (Fineman, 2008, p.10). Indeed, I consider an emphasis on our shared vulnerability a fundamental ethical concept and a normative tool necessary for dealing with dominant discourses that have not taken into

account this inherent characteristic of the human condition. In bioethics, the approach to vulnerability as universal concept is fundamental for developing health professional-patient relationships that take into account all the dimensions of the subject, particularly when that subject has to deal with illness. It is also important for political developments concerning public health because the approach to vulnerability is entirely different from the approach to autonomy and the individual responsibilities derived from them. In addition, as I have shown in the previous section, there is no contradiction between the recognition of ontological vulnerability and a close attention to particular vulnerability in Fineman's theory. As Fineman (2008, p. 10) points out:

Because we are positioned differently within a web of economic and institutional relationships, our vulnerabilities range in magnitude and potential at the individual level. Undeniably universal, human vulnerability is also particular: it is experienced uniquely by each of us and this experience is greatly influenced by the quality and quantity of resources we possess or can command.

The second argument made by Mackenzie concerns the fusion of autonomy with the liberal conception of autonomy. Although Mackenzie agrees with Fineman's critique of the liberal model of the subject and the understanding of autonomy that derives from this conception, from Mackenzie's perspective it is a mistake to conceive autonomy only with reference to in the liberal view. According to Mackenzie, we must consider autonomy relationally. The problem for Mackenzie is that Fineman views vulnerability and autonomy as opposing terms. Mackenzie sees this as a mistake, for she argues that autonomy must be reconceptualized in a relational way.¹³

It is true that Fineman initially theorizes the notion of vulnerability in opposition to the liberal discourse of autonomy. However, I think that it is also true that we must challenge the liberal model of autonomy, even when we defend a relational model of autonomy. That is, to emphasize the importance of a discourse contrary to that developed within the liberal conception of autonomy is fundamental. Another question raised by Mackenzie's critique is whether Fineman's criticism of the liberal notion of autonomy implies a complete rejection of the concept of autonomy.

In my view it is possible to articulate a notion of relational autonomy from Fineman's theory of vulnerability. This is also suggested by Fineman (2010, pp. 260-261) in some way:

Autonomy is not an inherent human characteristic, but must be cultivated by a society that pays attention to the needs of its members, the operation of its institutions, and the implications of human fragility and vulnerability.... Autonomy understood through a lens of equality would carry social and reciprocal duties to others; it would not be confused with selfishness, self-absorption and egocentric attention to only one's own circumstances.

Although she does not develop a new conceptualization of autonomy, I am of the view that there is no contradiction between Fineman's approach and relational theories of autonomy. In my opinion, is not only possible but also absolutely necessary to develop a new concept of relational autonomy with regard to vulnerability theory. This concept is essential within bioethics.

The last criticism made by Mackenzie is the lack of specificity in Fineman's analysis of justice and equality. She considers Fineman's response to this issue unclear because it sometimes refers to equal access to resources, sometimes to equality in terms of position, and occasionally to capabilities. She supports the role of capability theory in addressing this issue and demonstrates its conceptual connections with relational approaches to autonomy and its importance for an ethics of vulnerability.

One of the interesting aspects of Fineman's theory is that it opens up reflection on the responsibilities of both the state and the individual to provide the necessary resources for individuals to try to increase their resilience as a way to face vulnerability. Her approach does not imply a lack of clarity with regard to our real responsibilities and the measures that we should implement, but rather it is a broad discourse that can include different areas of reflection on this issue. In the specific field of bioethics, reflection on vulnerability implies that the institutions responsible for care practices, biomedical research, and public health policies must become aware of the importance of carrying out their obligations towards individuals and take into account the vulnerability of individuals as one of the key elements. Undoubtedly, this will generate particular forms of very diverse institutional responses that it would be impossible to address in all their variety. What is important is to draw attention to how, starting from the reflection on vulnerability, it is possible to think about the responsibilities of the institutions:

The nature of human vulnerability forms the basis for a claim that the state must be more responsive to that vulnerability. It fulfils that responsibility primarily through the establishment and support of societal institutions. Additionally, those institutions are themselves vulnerable to a variety of internal and external corruptions and disruptions and this realization is the basis for the further claim that these institutions must be actively monitored by the state in processes that are both transparent and inclusive (Fineman 2010, pp. 255-256).

CONCLUSIONS: IMPLICATIONS OF AN ETHICS OF VULNERABILITY FOR BIOETHICS

The foregoing analysis of the theoretical approach and development of the vulnerability concept is useful for establishing a theoretical framework for the necessary development or implementation of an ethics of vulnerability in bioethics. In particular, Martha Fineman's theory of vulnerability can be articu-

lated as the theoretical basis from which to develop an ethics of vulnerability in this field. Reflections concerning vulnerability have certain important implications for bioethics, which are detailed in the following paragraphs.

a) Criticisms of the liberal model of autonomy

The vulnerability concept is developed within a critical theory held up against the liberal conception of the autonomous subject has been extended within ethics and politics and also in bioethics. Indeed, mainstream bioethics is articulated in relation to informed-consent theory as a model for respecting personal autonomy. In some respects, it has been necessary to focus on autonomy because of the dominance of paternalism in the relationship between health-care professionals and patients. The problem is that this considerable emphasis on autonomy leaves out of the bioethical discourse other kinds of principles and concepts that are of great importance for our understanding of our responsibilities and concerns within health care—for instance, vulnerability, dignity, caring, and solidarity. A critical approach to bioethics needs this framework, which focuses on the vulnerable subject rather than on the autonomous subject. In the same way that Fineman indicated the importance of the vulnerability concept as a critical tool, I consider this conception to be essential in bioethics:

Vulnerability thus freed from its limited and negative associations is a powerful conceptual tool with the potential to define an obligation for the state to ensure a richer and more robust guarantee of equality (Fineman 2008, pp. 8-9).

As a universal feature of human beings, vulnerability should be located at the centre of our ethical reflections. These reflections face the challenge of changing the relationships between professionals and patients, focusing on what patients think and on what is really important to give them better care.¹⁴ However, at the same time, it is important to highlight that patients are both vulnerable and autonomous; moreover, the same is true for health-care professionals. The shared vulnerability in patients and health-care professionals should be recognized instead of hidden (Carel, 2009).

b) Vulnerability as a normative challenge

Vulnerability theory offers different conceptual tools for developing a more complex approach to issues in bioethics.

For example, thinking about dependency, about a more complete understanding of disability, and about ways to better respond to people's needs in this regard changes substantially when we start by recognizing that we are all vulnerable. Vulnerability is the expression of human relationality and dependency. Being vulnerable challenges us to become human. Anthropological vulnerability affirms that human existence always begins in a normative context" (Ten Have 2016, p. 115).

Usually, vulnerability is used as a descriptive tool, with a pragmatic aim of trying

to fix a particular situation, but not as a normative element. Thinking about vulnerability as a common feature of the human condition has a normative force because it demands a response, generating responsibility and implied obligations. These obligations are especially important from the perspective of the institutions and the state. Once we have redefined the concept of vulnerability and placed it at the centre of our reflections, many possibilities open up in terms of implementing measures to improve relationships—for instance, those that arise predominantly in the clinical context. Understanding it in this way, vulnerability could be used not only as a descriptive tool, as it is usually employed in research and consequently in bioethics, but above all as a normative tool, which urges us to action.

c) Vulnerability as a way of improving relationships between professionals and patients

In bioethics, understanding vulnerability implies being alert to the manner in which relationships are enacted in the health-care system. Relying on vulnerability theory especially, we can develop greater empathy, as well as skills and strategies aimed at improving communication and relationships between health professionals and patients.¹⁵ Becoming aware that all humans are vulnerable is important for health professionals. Facing disease, disability, suffering, and death accentuates the experience of vulnerability both in patients and their families and friends, as well as among health professionals. Vulnerability as a shared condition in health care and has an impact on the way of understanding vulnerability in regard to the relationships among patients, health-care professionals, and institutions. Vulnerability can lead us to better understand our shared condition and the effect this condition has on relationships in health care.

Kirsti Malterud and co-authors (2005a, 2005b and 2009) have explored vulnerability extensively in regard to health-care professionals. In particular, their studies analyze by way of qualitative research how vulnerability can be a strength in the context of health care. They describe two kinds of situations that compel physicians to expose their vulnerability: their identification with the patients' circumstances and their experiencing of feelings of uncertainty. Vulnerability experienced by doctors in one of these two situations and revealed to patients can increase the doctors' responsiveness to sensitive matters. In addition, as Carolyn Ells (2012, pp. 180-185) has stressed, expressing vulnerability can help people engage with one another and care for one another in a more meaningful way, as well as help others cope with difficult situations. It can trigger feelings of empathy and consequently motivate action. Recognizing everyone as vulnerable can contribute to improving human warmth, respect, and care within health relationships, in all directions, including care for professionals.

d) Reflection on social justice

The vulnerability approach can play an important role in global bioethics because it can provide a new way of thinking about the state's and international institutions' responsibilities for global problems. Global bioethics has among its most urgent and complex concerns the enormous inequalities in health worldwide. The right to health, defined within the framework of human rights, implies that everyone has the right to an adequate standard of living assured to him or her and to his or her family. An adequate standard of living refers to both health and well-being, and factors in especially food, clothing, housing, health care, and social services. As the General Observation on the Right to Health of the United Nations noted in 2000,¹⁶ the right to health encompasses not only timely health care, but also health determinants, such as access to drinking water and adequate sanitary conditions, adequate provision of healthy food, adequate nutrition, adequate housing, healthy working and environmental conditions, and access to education and to information on health-related issues, including sexual and reproductive health care.

With regard to global access to health care, there is an urgent need to direct attention towards social justice in connection to vulnerability. Concerning this approach, Henk ten Have (2016) conducts an important analysis of the impact of globalization and neoliberal policies on increasing vulnerability around the world. Using this framework, he makes some arguments that show why social justice should be considered to be among the main concerns for bioethics (Henk ten Have, p. 173). His first argument is that, in general, justice in healthcare is centred on access to health-care systems and distribution of resources for those who are damaged. In this regard, justice should consider how those needs arose. The second argument is related to globalization: neoliberal policies benefit the private health-care sector, while public health services have become weak and less accessible. The third argument is if we interpret vulnerability not as individual weakness but as the consequence of an exploitative order produced by neoliberal globalism, it will focus attention on structural injustice. This concern about the structural injustice is common to vulnerability theory, whose major claim concerns the obligations and responsibilities of both the state and institutions. This is an essential concern also in relation to the right to health, as a fundamental subject for global bioethics.

e) Rethinking autonomy in bioethics

In my view, the recognition of universal vulnerability suggests that we will also have to rethink the autonomy model. This consideration involves the need to link autonomy and vulnerability instead of setting them in opposition to one another. For this purpose, it is fundamental to develop the notion of relational autonomy. Autonomy is not to be understood only as a feature of an individualistic, self-sufficient being. We are all vulnerable and we are all socially constituted beings requiring social support and relationships to exercise and develop our capabilities, among which is the capability of autonomy. The development of autonomy requires certain conditions in terms of opportunity; these condi-

tions can be provided only in the context of social relationships, which are what makes autonomy possible. In addition, recognizing this relational element also implies the recognition that, on many occasions, the exercise of autonomy can be frustrated or blocked by different relationships.

By highlighting the alliance between vulnerability and relational autonomy, this approach goes beyond the mere protection of vulnerable people: it is about seeking social support to promote autonomy and empowerment for the people. Finally, ethical reflection about vulnerability should be guided by the value of relational autonomy for two reasons:

To counter the sense of loss of control associated with vulnerability,
To avoid the risk of unjustified paternalism that may result from the practices and policies to “protect the vulnerable.”

Recognizing vulnerability reveals that there are obligations and duties toward patients that need to be assumed by institutions and the state. These obligations include the creation of the conditions for fostering and promoting patients’ autonomy, relationally understood. To this end, we need to incorporate the vulnerability theory into bioethical reflection.

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NOTES

- ¹ It is assumed that these organizations safeguard the integrity of research and the safety of participants involved in research.
- ² For a long time, this study was considered the most influential approach to the vulnerable subject in the field of bioethics. Indeed, it was one of the earliest works addressing this issue in bioethics and the social sciences.
- ³ I use the terms “ontological vulnerability” and “universal vulnerability” without distinction, since I consider them to have the same meaning.
- ⁴ Today the Belmont Report is considered to be an essential reference for researchers and groups working with human beings in research for ensuring that projects comply with ethical regulations. The report explains and unifies the basic ethical principles of different reports of the National Commission and the regulations that incorporate its recommendations. The three fundamental ethical principles that permit the use of human subjects in research are respect for people, beneficence, and justice.
- ⁵ The Helsinki Declaration is a document embodying a number of ethical principles related to human experimentation, developed for the medical community by the World Medical Association (WMA). It is widely regarded as the main document on the ethics of human research. It is updated regularly. There is an extended analysis concerning the evolution of the Declaration of Helsinki in Carlson, Boyd, and Webb (2004).
- ⁶ The Universal Declaration on Bioethics and Human Rights adopted by the United Nations Educational, Scientific, and Cultural Organisation (UNESCO) on October 19, 2005, is important in seeking global minimal standards in biomedical research and clinical practice. It aims to provide a comprehensive framework of principles that should guide biomedical activities to ensure that they conform to international human rights law. It is also interesting to see Evans (2012, pp. 170-173).
- ⁷ To implement this analysis, see Ten Have (2016). In particular, chapter 3, “Vulnerability in the Context of Healthcare and Bioethics,” is devoted specifically to showing the importance and impact of the main international documents.
- ⁸ The minimal principles of protection are set out in the Declaration of Helsinki as follows: “a) To promote and safeguard the health, well-being and rights of patients, including those who are involved in medical research; b) Medical progress is based on research that ultimately must include studies involving human subjects; c) The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments); d) Medical research is subject to ethical standards that promote and ensure respect for all human subjects and protect their health and rights; e) While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects; f) It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-deter-

mination, privacy, and confidentiality of personal information of research subjects; g) Physicians must consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration; h) Medical research should be conducted in a manner that minimizes possible harm to the environment; i) Medical research involving human subjects must be conducted only by individuals with the appropriate ethics and scientific education, training and qualifications. Research on patients or healthy volunteers requires the supervision of a competent and appropriately qualified physician or other health care professional; j) Groups that are underrepresented in medical research should be provided appropriate access to participation in research; k) Physicians who combine medical research with medical care should involve their patients in research only to the extent that this is justified by its potential preventive, diagnostic or therapeutic value and if the physician has good reason to believe that participation in the research study will not adversely affect the health of the patients who serve as research subjects; l) Appropriate compensation and treatment for subjects who are harmed as a result of participating in research must be ensured.”

⁹ These ideas are also expressed in Luna and Vanderpoel (2013). In this paper, the authors challenge the traditional way of thinking about vulnerabilities in the research field and they develop a layered account of vulnerability. They show the relevance and applicability of an approach to vulnerability that is more nuanced and respectful towards persons.

¹⁰ See Fineman (2004). In this work, Fineman provides a critique of how autonomy is understood in a very narrow way within the liberal paradigm—in relation to self-sufficiency and the individuality of being. She challenges the rhetoric that creates dichotomous pairs between desirable and stigmatized models, such as the dichotomy between independent and dependent. According to her approach, society should be organized around “caretaking relationships,” particularly those involving children or elderly dependents. Moreover, she insists that because each of us is “inevitably dependent” at various stages in our lives, it is important to recognize that society as a whole has a vital role in providing assistance.

¹¹ See Fineman (2015). The myth of autonomy has produced institutional arrangements that do not take into account the dependency inherent in the human condition. As already noted, Fineman points out that all humans are dependent at some point in their lives. This “inevitable dependence,” in Fineman’s terms, can be found in children, often in old age, and at other stages in most people’s lives as a result of physical or mental illness. The inevitable dependence creates the need for care. Fineman stresses that the consequence of this is a secondary form of dependency experienced by caregivers. Due to this, the state has a responsibility to meet dependency needs and to support caretaking.

¹² I have developed the concept of relational autonomy in Delgado, J. (2012) “La autonomía relacional, un nuevo enfoque para la Bioética,” Trabajo fin de master, Facultad de Filosofía, UNED.

¹³ In fact, Mackenzie agrees with Fineman’s criticism regarding the liberal subject. Moreover, she also acknowledges that Fineman leaves the door open to the possibility of theorizing about the relational notion of autonomy, but does not develop it. See Mackenzie (2014).

¹⁴ Patient-centred care is a new model of relationship that has been developed in recent years (see Epstein and Street 2011).

¹⁵ I prefer to use the term “patient,” even if usually, in a “critical approach to bioethics,” the word “patient” is avoided, specifically because of the passiveness and powerlessness that it suggests, and because of the hierarchy between this person and his or her health practitioner that it reinforces. However, the term “patients” also contains the idea of “those seeking professional help,” while other words, such as “clients” or “users” do not reflect this position whence people look for professional help.

¹⁶ See United Nations High Commissioner for Human Rights, “The Right to Health, World Health Organization,” <http://www.ohchr.org/Documents/Publications/Factsheet31.pdf>

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