

Bioethical reflections on the consent of persons with disabilities in health decision-making

Reflexiones bioéticas sobre el consentimiento de personas con discapacidad en la toma de decisiones en salud

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Abstract

In medical care and health research, it is essential to promote decision-making by patients and/or participants under the principle of autonomy. In particular, this capacity, stated in the Convention on the Rights of Persons with Disabilities, is made concrete through the detection of needs for assistance, adjustments and support that give way to a full and effective capacity for exercise.

The bioethical reflections made from a principled, personalist and human rights perspective offer elements to enhance the auto-

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nomy of persons with disabilities, promoting the figure of personal assistance and emphasizing the best interest, gradualness and permanent judicial review as principles of substitute figures.

Keywords: autonomy, competence, CIF, UN Convention.

1. Informed consent in persons with disabilities

The term informed consent has evolved to highlight its ethical and legal aspects, giving fullness in the daily medical practice to the quality with which medical information is given and received.

Informed consent is the classic institution of health law (1) which is defined as the commitment of the physician and his/her patient to establish a communicative space in order to inform, orally or in writing, the nature, the purposes, the form of application of medicine, the benefits, the risks, the alternatives, and the means of the process. So that the person receiving care can decide and give clear, competent, and voluntary authorization (2), which implies considering the person as a rational moral subject (3), and this process as the tangible expression of autonomy in the areas of medical care and health research (4).

When we place ourselves in these health-illness contexts, care for people with disabilities is inherent. The World Health Organization (5) estimates that more than one billion people-about 15% of the world's population-have a disability. In our country, the National Survey of Demographic Dynamics (ENADID) (6) in 2014 determined a prevalence of 6%, estimating that there are 7.2 million people with disabilities and 15.9 million people with mild or moderate difficulties in carrying out basic activities, who may present a disability condition in the future. Subject to general, family or specialized medical care, health personnel are in frequent contact with people with disabilities, whether or not this may be the reason for the consultation or the procedure leading to consent.

A change of paradigm has been generated in the field of disability. Indeed, the Convention on the Rights of Persons with Disabilities, an international treaty signed in 2006 by the United Nations General Assembly as a global legal recognition that consolidates previous regulations, defines it as the interaction between persons with impairments and barriers. This due to attitude and environment, which prevent their full and effective participation in society, on an equal basis with others. In Mexico, this treaty and its Optional Protocol were ratified in 2007 (7).

From that moment on, the norms relating to human rights are interpreted in conformity with the Constitution and international treaties on the subject, favoring the broadest protection of persons at any time and under any circumstance (8). Thus, every treaty that Mexico ratifies in the area of human rights has constitutional rank.

The right to health protection, as set forth in Article 4 of the Constitution and Article 25 of the Convention, emphasizes the active and responsible participation of individuals in health decision-making, with prior information, which must be accessible in order to overcome barriers to seeing, hearing or understanding, which would call into question the validity of the informed consent process.

This article develops some bioethical reflections in order to empower persons with disabilities to make decisions about their health.

2. Bioethical aspects of the informed consent process in persons with disabilities

Bioethics, as a reflexive and normative discipline, deals with human acts that influence vital processes (9). In this case, the ethical weighting given to informed consent will reflect the quality of the doctor-patient relationship, which is also immersed in its own legal framework.

We will address the principle, personalist and human rights perspective, which coincide on a common point regarding consent: the recognition of the dignity and autonomy of persons.

a) Classical principlism and disability

The principles of beneficence, justice, and respect for persons were listed in the Belmont Report, as the antecedent that should govern research on human beings, based on William D. Ross' 1930 book. *The Right and the Good*, which describes beneficence, non-maleficence, and justice (10). Years later, the philosophers Beauchamp and Childress expanded these principles to four (*non-maleficence, justice, autonomy, and beneficence*), creating the theory known as classical *principlism*.

The principle of *autonomy* recalls the individual's capacity for self-governance to act according to a self-selected, purposeful plan, independent of controlling influences (11). In order for persons with disabilities to make autonomous decisions; health care providers have a responsibility to make information about medical or research procedures accessible. They must identify the individual's expectations and ability to cope with his or her medical situation, in accordance with his or her functional or organic impairment.

The principles of *charity* and *justice* uphold that persons with disabilities should have the means to access the highest attainable standard of health, rehabilitation and education; recognition of their legal personality; physical and mental integrity; a home and family; the free exercise of parenthood; and decent employment, among other rights recognized by the Convention.

Beauchamp and Childress define the principle of *justice* as equal and appropriate treatment, in light of what is due to a person. It is expanded with the term *distributive justice*, which seeks the equitable distribution of goods, benefits and opportunities, and establishes that the burdens and disadvantages that may occur in health poli-

cies are proportional to the entire population, avoiding affecting one sector (11).

John Rawls' egalitarian proposal defends the redistribution of resources and a system of basic goods, which includes health protection guarantees, through social institutions that distribute benefits and burdens, ensuring a principle of equal opportunities that compensates the less advantaged. Like the Convention, it emphasizes that the guarantees of access, quality, opportunity and cost must be explicit as constitutional norms (8) (12), going beyond the historical perception of acts of good will or charity.

The specific needs of persons with disabilities must be evaluated periodically, in order to prevent chronic complications that deteriorate their quality of life. Thus because of the subsidies granted to them (medical specialty care, institutional services and provision of functional aids, orthoses or prostheses), with the aim of containing secondary gains or overestimating disability, both of which are correlated to the principles of *charity and justice*.

Under the principle of *non-maleficence*, any person with a disability of any origin, type and degree, in any health institution, public or private, should have access to comprehensive medical care; otherwise, we would be facing a situation of discrimination. To discriminate is not only to treat differently those who are not equal, but also to treat equally those who are in conditions of inequality (13).

b) Contributions of personalist bioethics in matters of disability

This trend, centered on classical anthropology, has influenced bioethics and is essential in issues of disability because it offers a philosophical basis that highlights the content and meaning of the term *person*, in line with the *pro-homine* rights principle postulated in numerous human rights documents, which recognize the inherent dignity and value of all members of the human family (8).

Personalism as a philosophical-cultural movement declares the person as the center and end in itself, as opposed to the materialism of the late 19th and early 20th centuries. It was promoted by forerunners such as Kierkegaard and Newman, by the philosophers of dialogue (Ferdinand Ebner, Martin Buber and Emmanuel Lévinas, among others) and by the so-called Göttingen Circle, with Edmund Husserl at the helm (14).

Personalist bioethics postulates principles related to the primacy of life as a presupposition for other principles, such as the principle of totality or therapeutics, the principle of freedom-responsibility and, in matters of disability, by the postulates of sociality and subsidiarity.

The principle of *sociality* consists of promoting the life and health of society through the promotion of the life and health of the individual person; that is, the «common good» is sought through «individual goods». This principle is integrated into the principle of *subsidiarity*, which prescribes the obligation of care for the most needy (15).

This last concept is understood, firstly, as the recognition of the conditions inherent or external to the person with a disability that place him/her at a disadvantage or vulnerability, when interacting with attitudinal and environmental barriers, and secondly, as the obligation of the State and institutions to facilitate and strengthen the means that are needed.

c) Human Rights in People with Disabilities

The evolution of the concept of disability can be observed through the models of care historically proposed, from antiquity to the post-war period. Today, the human rights model with a social and integral approach to the person has proposed to promote his or her full and effective participation.

The essence of human rights focuses on the intrinsic dignity of the human being (16), and on the obligation to assimilate him/her

as an integral whole. This influenced by the physical aspect but above all, by the family, social and institutional environment that surrounds him/her, and proposes to place the individual at the center of all decisions that affect him/her.

The parallelism between human rights and the change in the paradigm of disability as a social construct is well known. This paradigm seeks to expand the concept of the disabled person beyond being a passive object of intervention, treatment and rehabilitation (17).

The contributions of the social model, mainly in the United Kingdom and the United States, expanded the participation of disciplines, not only medical and social, but also economic, administrative, political, artistic, sports and environmental. Thus finding their common point in human rights as a project of «visibility» based on four values: dignity, autonomy, equality and solidarity, promoting by the State genuinely inclusive societies (18), and favoring at the individual level the physical and moral autonomy of the person with a disability.

3. Reflections to promote the competence of people with disabilities

Human decision making requires the integration of cognitive, emotional and motivational information; rationality alone is not enough (18). We should question whether in the process of informed consent we limit ourselves to providing cognitive information, or whether we take into account the emotional and motivational reasons that influence people's choices, in order to favor freer decisions.

Autonomy, as the power to make decisions about one's own life by assuming responsibility for them (19), implies being competent to make decisions as a central element. In the framework of the Convention, it is analyzed from the perspective of the meaning of

support, since there is a relationship of immediacy between one concept and the other (20).

The role of health personnel, far from classifying the decision-making of the person with a disability as right or wrong, is to provide assistance or support so that they can develop their own process of determining what they want and what they do not want regarding of their health. It should be remembered that the cognitive (scientific knowledge), emotional and motivational component of the health personnel is also present in the health relationship, and they should not coerce, manipulate or persuade patients or participants in research studies.

Beauchamp and Childress refer to competence as the ability to carry out a task, and its function is to differentiate those who can decide (11) from those who have limitations to do so in a given situation. Arenas *et al.* (18) delve into competence as a threshold concept determined by four components: 1) the ability to understand and remember information; 2) the ability to manipulate information critically; 3) freedom of choice; and 4) the ability to express oneself.

The evaluation of competence is complex in people with or without deficiencies, because even in cases of cognitive impairment the competence to choose may or may not be affected. This would require an *ad hoc* assessment that should focus on the decision-making process (understanding the information, its implications, deciding and communicating the decision), and not only on the choice (18).

The analysis of competence in persons with disabilities can be specified in terms of functional ability with respect to the four points previously cited by Arenas *et al.*, using the International Classification of Functioning, Disability and Health (ICF) proposed by the WHO in 2001 as a multidimensional, person-centered approach.

The ICF is applied to people with and without disabilities to visualize their biological circumstances in relation to their social and environmental environment (21), through an alphanumeric catalog

that graduates the areas involved, and identifies the needs and adjustments that the person requires, enhancing facilitating elements and reducing barriers.

On the other hand, regarding the competence to decide, Bórquez *et al.* (3) point out a continuum between two extreme points: full capacity and total incapacity. The social and human rights model, affirms that disability can coexist with the full autonomy of the person. It is worth noting that «no one makes fully autonomous decisions, since other components of the environment weigh in, such as fear, insecurity, and the existential circumstance» (22), the trust or uncertainty instilled by those who explain consent, beliefs, and the opinion of family and friends, among others. Thus, assistance, adjustments or support for decision-making in health aim to favor the greater autonomy of which the subject is capable.

Health professionals and researchers often rely on their clinical judgment and intuition (18) to determine the competence of individuals, in order to contend with medical information and make decisions; in the face of this subjectivity, prudence must be exercised.

In some cases, the treating physician consults when he or she has doubts about the competence of the patient or user for self-determination. The problem is that in these cases, a mental health diagnosis is usually made, which is not exactly equivalent to a judgment regarding the ability to participate in the health-disease process (3).

Assessment of ability with cognitive tests may serve as a guide, but they are not adequate predictors of competence, and «no diagnosis or clinical judgment of disability should be made on the basis of the results of such tests» (23).

Since 1994, White (18) has proposed instruments to assess cognitive and affective abilities, the ability to make choices, and the ability to understand.¹ Subsequently, some proposals have emerged to evaluate the capacity to consent, such as the *MacArthur Competence Assessment Tool for Clinical Research*, *The California Scale of Appreciation*, the

*Sitges Document*² (23) and the *Deaconess Informed Consent Comprehension Test*³ (18), which would have to be adapted and validated in Mexico.

Other aspects of optimizing the informed consent process in people with disabilities are: 1) unlink physical dependence from moral dependence; 2) proportionality, 3) voluntariness, and 4) non-consent.

Regarding dependency, identified as the need for help from another person to carry out activities of daily living or instrumented activities, the idea that they also depend on the primary caregiver or other people to make daily decisions, decide on treatment, must be dissociated or participate in an investigation.

Proportionality refers to the degree of competence required according to the complexity of the decision. Abellán (22) states that it is directly proportional to the level of risk associated with the decision, according to a sliding scale for capacity.

Muñoz *et al.* (23) propose standards of competence according to the proposed task related to the context. For example, a person may be competent to decide on treatment or participate in research, but not in managing his or her finances. To do this, they summarize a profile of support needs, according to the assessment of five dimensions: intellectual skills, adaptive behavior, participation, health, and environmental and cultural context. It is similar to the scale of intensity of support (SIS) proposed by Verdugo *et al.* (24), which measures frequency, time and type of support in people with intellectual and developmental disabilities.

The voluntary nature of the act in these support models is to ensure that the facilitator, assistant or human support does not coerce or influence people's decisions to accept any medical procedure or participate in any research. The yes of the patient must manifest his or her free acceptance of the proposed procedure and «should even express his or her intention to collaborate and, why not say so, to take joint responsibility» (2).

Despite optimizing the previous parameters, it is necessary to remember that this process also implies that the person does not

consent (25). That is, once the proper support and adjustments have been received, persons with disabilities have the right to refuse procedures or to participate in protocols, and this should be recorded in the medical record with date, scope, and details of the informed risks. This revocation must be made in writing and does not prevent the verbal form, effective because of its immediacy in manifesting the patient's will (20).

4. Another challenge: the legal capacity of people with disabilities

An added challenge to clinical assessment of competence is to harmonize the term legal capacity, since it is capacity, not incapacity, which is universally presumed (24).

Pablo Simón prefers to use the term competence for decision-making in the health field. This to differentiate it expressly from the term «capacity to act in fact» and «*capacity to act in law*», according to Bórquez *et al.* (3). In the English-speaking literature, legal or de jure capacity refers to the term *competence*; in contrast, *capacity* as such is related to natural or de facto capacity.

Muñoz *et al.* (23) define it more clearly, stating that the de facto or natural capacity determines the legal capacity, in line with previous bioethical reflections.

In some countries, civil law distinguishes between *capacity for enjoyment*, such as the legal ability of individuals to acquire rights and obligations. Capacity for exercise, such as the ability of individuals to act on their own behalf (3). In the area of disability, the Convention constantly advocates for such *capacity for enjoyment*, and it is up to the health team, to provide the facilitators and avoid physical and attitudinal barriers, to enhance *exercise capacity* through adjustments or supports.

In Mexico, various legal forms do not necessarily equal incompetence to make health decisions for a person with a disability (es-

pecially intellectual or psychosocial). For example, a ruling of invalidity or permanent disability according to the Federal Labor Law or the Social Security Law; a certificate of disability or a declaration of mental incapacity, which also do not equal a court sentence of interdiction.

Muñoz *et al.* (23) take up the consideration of the insane, the prepubescents and the deaf-mute who cannot make themselves understood in writing as absolutely incapable. However, in light of the Convention and the support models, it is essential to expand the communication alternatives that enhance the capacity to receive, understand and weigh health information, with the corresponding use of the current nomenclature regarding organic or functional deficiencies, according to the ICF.

The greatest challenge in assisting and supporting a person with a disability is to develop his or her own decision-making process, collaborating even with the reasoning process (20), thus replacing the representative figure with the personal assistant.

According to the magnitude of the decision and to safeguard the autonomy-beneficence binomial in people who, despite adjustments and/or support, have difficulty understanding medical information and deciding for themselves, the need for consent by substitution or representation arises. This must be explained both to the person with a disability –if he or she has a certain degree of receptive and communicative capacity– and to his or her responsible family member, guardian or legal representative, who will sign the document if he or she accepts the medical or research procedure.

The objective in these cases is to avoid that people with *difficulty* in making certain decisions run risks that they are not assuming from their personal freedom. On the other hand, to avoid the temptation of overprotection, paternalism, the board of directors (22) and the rush to comply with consent as a requirement, and not as the process that has been emphasized.

This *substitution of the will* of the legally incapable person for that of a representative must reflect the best interest of the represen-

ted person, always considering a criterion of gradualness of legal capacity and its permanent judicial review (18).

So, would consent by substitution have a defined validity in a succession of medical procedures in the medium and long term? According to Article 12, paragraph 4 of the Convention, each case must be evaluated according to the functional prognosis and be recorded in the clinical or research file. Providing for an approximate period of time for legal substitution, since disability is an evolving concept and representation may not be necessary for subsequent acts.

On the other hand, if the spouse, partner, relative or close relative accompanying the patient manifests an unjustified refusal, conflicting decisions or multiple criteria, as a measure of *last resort*, judicial intervention is required. Galán Cortés, emphasizes that it is necessary to limit the powers of third parties to intervene, to avoid that a third party, against the will of the owner, decides for him what risks he has to assume or which assets he has to renounce. Thus, it could be said that expropriating such a very personal decision would amount to the 'reification' of man, according to Sorgi *et al.* (20).

Finally, in emergencies with a certain and imminent risk of a serious evil to the life or health of persons with disabilities, advance medical directives are of importance. It is necessary to inquire whether they expressed or designated the person or persons who are to express consent, and who do not decide in the patient's place, but rather communicate their will or best interest. In the absence of family members or representatives, the physician may dispense with consent (20).

5. Conclusions

Both the concept of disability and that of validly informed consent have undergone paradigm changes, and seek to respond to the ethical and legal needs of a growing population, under the binding force of constitutional rank offered by the Convention.

The doctor-patient relationship is the space par excellence, where this process favors decision-making in health, enhancing the autonomy of people as the tip of an iceberg that reveals complex processes for determining the competence to exercise their legal capacity. Also discovering other topics that can violate their living conditions, such as the management of their own or inherited material resources, access to financing and the possibility of leading an independent life, among others.

Facilitate the *capacity of exercise* through the implementation of assistance, adjustments or support that replace the figure of legal representation, promotes an effective *capacity of enjoyment* through a functional assessment of the hand of the CIF, as an element of synergy between managers and health providers who serve people with disabilities, making tangible other bioethical and human rights principles such as non-discrimination, charity and justice, as well as sociality and subsidiarity.

Bibliographic notes

¹ For more details, see Arenas *et al.*, p. 1315: Table of criteria for assessing competence in health matters according to White's 1994 competence criteria.

² The scores and dimensions assessed by each of the protocols are broken down, with the first two being for research application. Sitges evaluates the ability to give informed consent in six situations and assesses 16 neurological criteria.

³ More information about the test: Miller C, O'Donnell D, Searight H, Barbarash R. The Deaconess Informed Consent Comprehension Test: an assessment tool for clinical research subjects. *Pharmacotherapy*, 1996 Sep-Oct; 16(5): 872-8. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/8888082>

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