pensar
Revista de Ciências Jurídicas
e-ISSN:2317-2150
DOI: 10.5020/2317-2150.2019.8744

Obstetric violence against pregnant woman with disability

Violência obstétrica contra a gestante com deficiência

Aline de Miranda Valverde Terra*
Ana Carla Harmatiuk Matos**

Abstract

The article aims at advocating, based on bibliographic review and legislative analysis, for the self - determination of sexual and reproductive rights for all women. Such autonomy must encompass even the "birth plan" in a humanized conception. The protection of this right for people with physical, psychic or intellectual disabilities is specifically pursued in accordance with the UN Convention on the Rights of Persons with Disabilities, incorporated into the Brazilian legal system with constitutional amendment status, as well as the Statute of the Person with Disabilities.

Keywords: Pregnant. Disabled person. Birth plan. Obstetric violence.

Resumo

O artigo tem como escopo pugnar, com base em revisão bibliográfica e análise legislativa, pela autodeterminação dos direitos sexuais e reprodutivos para todas as mulheres. Tal autonomia deve englobar inclusive o "plano de parto", numa concepção humanizada. Dedica-se, de modo especial, à defesa desse direito para as pessoas com deficiência física, psíquica ou intelectual, na esteira do que determina a Convenção da ONU sobre os Direitos da Pessoa com Deficiência, incorporada ao ordenamento brasileiro com status de emenda constitucional, bem como o Estatuto da Pessoa com Deficiência.

Palavras-chave: *Gestante. Pessoa com deficiência. Plano de parto. Violência obstétrica.*

1 Introduction

In 2006, at seven months of pregnancy**,** the bag burst. Eva addressed the maternity hospital, where she was hospitalized for two days, and forwarded home. Upon returning to the hospital, three days later, according to the guidance he received, was received with assaults and accusations: "Why didn't you come earlier?", "Would you like to force a natural childbirth?", "Whoever runs the procedure is me." Eva was, so, forwarded to the operating room, and heard from one of the professionals who attended it that would "bear the consequences" of her choices. The medical team attempted to perform the Kristeller maneuver, and one of the nurses, without consulting her, lay on her belly. Eva reacted to the procedure and had her hands tied. The baby didn't survive. The mother heard that her son's death occurred because she had "forced" the childbirth. Eva didn't even have access to the medical records.[1]

* Doctor and master's in Civil Law from the State University of Rio de Janeiro. Adjunct Professor, Department of Civil Law, State University of Rio de Janeiro. Professor of the Department of Civil Law at the Pontifical Catholic University of Rio de Janeiro and postgraduate courses at UERJ and PUC / Rio. Editorial Coordinator of the Brazilian Journal of Civil Law - RBDCivil. Visiting researcher at the Max-Planck Institute of Comparative and International Private Law (Hamburg - Germany). Rio de Janeiro-RJ- Brazil. E-mail: ammvalverde@hotmail.com.

** Doctor from the Federal University of Paraná. Master's in law from the Federal University of Paraná. Master's in Human Rights from the Universidad Internacional Andalucía. Tuttora Diritto at the University of Pisa - Italy. Professor at the undergraduate, master's and doctorate degrees at the Federal University of Paraná. Vice-Coordinator of the Post-Graduate Program in Law at the Federal University of Paraná. Director of the Southern Region of IBDFAM. Vice-President of IBDCivil. Curitiba-PR-Brazil. E-mail: a.c.matos@uol.com.br.

1 The episode is narrated in the Época magazine article, under the title "Victims of obstetric violence: the invisible side of childbirth" (LAZZAREI, 2015).

This is just a shocking account amid thousands of others depicting a regrettable reality affecting one in four women in Brazil.[2] An *Obstetrical violence*, an abusive practice against pregnant women who, despite of not being recent,[3] begins to gain more and more attention from national jurists.

This article proposes, in fact, to analyze obstetric violence against a particular group of pregnant women: the ones with disabilities. In order to do so, it will be verified how the medical model of disability contributed to the adoption, by the civil codification of 1916 and 2002, of an abstract model of disability, and how this model led to de-personification of people with disabilities, to naturalize all forms of violence practiced against them, including obstetrics. Next, it will be analyzed how the adoption of the social model of disability through the Statute for the Person with Disability has broken with this logic, changing the disability regime and promoting the legal and social autonomy of people with disabilities, which has a direct impact in the imperative of observance of their will in relation to all procedures related to gestation, including in relation to the guidelines conveyed in their childbirth plan.

2 Obstetric violence: New Lights on a very old problem

According to the informative booklet launched by the São Paulo State Public Defender (PDGE-SP), In 2013, obstetric violence is characterized by

> [...] appropriation of the body and reproductive processes of women by health professionals, through dehumanized treatment, abuse of medicalization and pathologization of natural processes, causing the loss of autonomy and the ability to freely decide on their bodies and sexuality, negatively impacting women's lives (SÃO PAULO. DPGE-SP, 2013).

The dehumanized treatment is always verified when the woman has her dignity debased, either through acts that violate her psychic integrity, as it happens when the medical team dispenses the woman with humiliating treatment, cursing or depreciating her, as well as when they damage their physical integrity, such as what happens when procedures are adopted without their consent, such as: Intestinal showed, trichotomy (scraping of pubic hair), physical immobilization, examinations of constant and unnecessary touches, maneuver of Kristeller (a procedure whereby the health professional "pushes" the pregnant woman's belly in order to accelerate the expulsion of the fetus), routine episiotomy (surgical cutting in the perineum region to enlarge the birth canal) and even cesarean section without anesthesia. You take care of abusive practices, many without scientific support, adopted by the physician's exclusive decision, without the free and informed consent of the parturient.[4] It is, in fact, routine procedures in hospitals in the country, ineffective or inefficient, some recognized unsafe, and that cause discomfort, pain, humiliation or embarrassment.[5]

The abuse of medicalization, in turn, is identified whenever unnecessary medical interventions are performed, carried out for the sole purpose of benefiting the physician or hospital in which the delivery is carried out, and whose results could be achieved through less severe interventions for the pregnant woman, such as when using Indiscriminately the synthetic version of Oxytocin to expedite labor and cesarean section without clinical

---

2 "25% of the women interviewed reported having suffered some form of institutional violence, highlighting the realization of painful and negative touch examination for pain relief (10%), absence of explanation regarding the procedures adopted and cries of professionals during care (9%), negative attendance (8%) and sweating and humiliation (7%). Furthermore, the study showed that about 23% of the interviewees suffered verbal coercion by the professionals, through phrases such as 'don't cry that next year you're there again' (15%), 'at the time of doing did not cry, did not call mom' (14%), 'if scream I stop and I will not take care of you' (6%), 'if you keep screaming will hurt the baby, he will be born deaf' (5%)" (FUNDAÇÃO PERSEU ABRAMO, 2010, p. 173 et seq.).

3 For example, see the following page from Henci Goer, which refers to the article published more than 50 years ago, in the United States, about the obstetric violence that was then already verified: "'Cruelty In Maternity Wards 'was the title of a shocking article published just over 50 years ago in Ladies' Home Journal in which nurses and women told stories of inhumane treatment in labor and delivery wards during childbirth (SCHULTZ, 1958). Stories included women being strapped down for hours in the lithotomy position, a woman having her legs tied together to prevent birth while her obstetrician had dinner, women being struck and threatened with the possibility of giving birth to a dead or brain damaged baby for crying out in pain, and a doctor cutting and suturing episiotomies without anesthetic (he had once nearly lost a patient to an overdose) while having the nurse stifle the woman's cries with a mask"(HENCI, 2010).

4 "Informed consent is one that is based on the integral fulfillment of the medical duty to explain to the patient, comprehensively and loyally, the treatment proposed, what the probable effects and what possible risks, albeit unusual. Similarly, the physician is required to explain to the patient the possibilities of treatment" (DIAS, 1996, p. 292).

5 This reality has been faced by the Brazilian courts: TJ-RS, 6th CC, Appellate Civel n. 70021336938, Reporting Justice Artur Arnildo Ludwig. J. 13.9.2009.

indication, contradicting the will of the pregnant woman to perform natural childbirth, for simple convenience of obstetrician's agenda.

Finally, the pathologization of natural processes is characterized by the use of procedures, sometimes also dispensable and disproportionate, with the objective of promoting greater safety for the pregnant woman and for the baby, as is the case when a cesarean section is performed because the pregnant woman has not yet reached sufficient dilatation.

For years, there has been a certain naturalness to all these practices, resulting largely from the medicalization of childbirth, whose scope focuses on attributing to such professionals the absolute control over all stages of pregnancy, from the phase prior to conception until the postpartum period, putting in their hands all decisions concerning the gestational process, as well as the dissemination of the conception according to which health professionals have the right to freely access the female body.[6] This posture, added to the perpetuation of uncritical education to students of Medicine of painful procedures and, not uncommon, prescindibles, ends up normalizing those practices previously mentioned, establishing an institutional culture that does not recognize them as violations of the rights of the pregnant woman.

An eloquent example of this institutional culture is the episiotomy, disseminated in medical schools as the first opportunity for students of any specialty to practice surgical skills, cutting and suturing the vagina of poor women. Emblematic of this purpose was the expression coined to illustrate this disproportionate and non-consensual exposure of the female genitalia in university hospitals: "vagina school".[7]

In this scenario, the disregard for the wishes and desires of the pregnant woman became naturalized and institutionalized in such a way that, often, she cannot even perceive herself as the victim of obstetric violence. That is exactly what happened to Kelly, who only understood what had happened to her after sharing her experience in a closed group of mothers in a social network. According to her report, on her arrival at the maternity hospital, the husband was prevented from accompanying her, denied her a right guaranteed since 2005 by Law n. 11.108, which requires hospitals, maternities and similar to allow an accompanying person, at the choice of the pregnant woman, in labor, during childbirth, and in the immediate postpartum (up to 10 days postpartum).[8] But not only this. When she began to feel the severe pains of contractions, she heard from the medical team: "At the time of doing it, didn't you like it?" and "do not scream, it will scare the other mothers."

After the baby's birth, they gave her what they called "husband's point", to "stay married": not enough episiotomy was done without Kelly's knowledge, the doctor, when suturing, gave one more point, to tighten the opening of the vagina. The pains resulting from the procedure performed in her absence accompany Kelly since then (LAZZAREI, 2015). It is then realized that

> [...] the issues of health, of being born and dying, originally the object of female concern and care, passed to the hands and minds of men with the development of modern medicine. The same process occurred with the childbirth, with the physicians assuming the position traditionally occupied by the midwives, devaluing the sensitivity and the role of mothers (COSTA; LUNA, 2016, s.p.).

In order to combat episodes such as these, the World Health Organization (WHO) published on September 23, 2014 an official statement on the prevention and elimination of obstetric violence, which it was qualified as a violation of fundamental human rights. According to WHO, reports of abuse include

---

6 The "Standard hospital procedures" in childbirths can be regarded as a way of exercising power over female bodies, revealing techniques of domination and reinforcing non-optional obedience. In this sense, we approach these criticisms with the reflections about the so-called *docile bodies*: "It is docile a body that can be subjected, which can be used, which can be transformed and improved"(FOUCAULT, 1997, p. 132).

7 The term "school vagina" was used by interviewed in a group survey, held as part of an event entitled "The School Vagina: Seminar on Violence Against Women in Teaching Health Professions", on March 2015, at the Faculty of Public Health at USP, to refer to the training of medical professionals (DINIZ; NIY; ANDREZZO; CARVALHO; SALGADO, 2016, p. 253).

8 The Law n.11.108/2005 included art. 19-J in Law n. 8.080/1990, with the following wording: "Art. 19-J. The health services of the Unified Health System - SUS, from the network itself or from the agreement, are obliged to allow one accompanying person to be present during the labor, childbirth and immediate postpartum period. §1st The accompanying person referred to in the caput of this article shall be indicated by the parturient. §2nd The actions intended to enable the full exercise of the rights referred to in this article shall appear in the regulation of the law, to be prepared by the competent body of the Executive Power.

> [...] physical violence, profound humiliation and verbal abuse, coercive or non-consensual medical procedures (including sterilization), lack of confidentiality, failure to obtain informed consent before performing procedures, refusal to administer analgesics, serious breaches of privacy, refusal of hospitalization in health institutions, negligent care during childbirth leading to preventable complications and life-threatening situations, and detention of women and their newborns in institutions after childbirth due to inability to pay (WHO, 2014, s.p.).

The seriousness of the situation is, in fact, unquestionable, and reveals a frontal violation of the fundamental right to humanized childbirth, guaranteeing the pregnant woman the choice of a non-standardized model of childbirth, which responds to her uniqueness and personality, giving her power to decide the procedures to be followed and those that do not want them to be adopted, returning to female protagonism.[9] By the way, the World Health Organization corroborates the proposal of humanized childbirth, which focus is on the transformation of the birth into a positive experience for the woman and the baby, and defines practical guidelines for the various protagonists of that moment: mother, doctor, midwife, doula, nurses, companions, among others (WHO, 2018).

There is, however, a group of women who are even more defenseless, hypervulnerable,[10] who are in a situation of greater helplessness and who suffer more intensely and cruelly with violent and hostile practices related to gestation: women with disabilities. In this perspective, Heloisa Helena Barboza (2009, p. 110-111) understands that the elderly, as well as children, adolescents and people with disabilities, are circumstantially affected and fragile, that is, they are "violated" and demand the application of norms that understand the materially reproduced inequality so that their dignity is preserved (BARBOZA, 2008, p. 61).

This population contingent, given the gender and disability overlaps, experiences specificities that make its precariousness even more evident (BUTLER, 2015, p. 46-47). This reality stems, to some extent, from the historical adoption of a disability regime based on the medical model of disability, which not only denied capacity and autonomy to the person with disability, resulting in their objectification and complete disregard of their desires and wishes, but also understood deficiency as a "problem" exclusively of the person who presented it, imposing - on it more often than not - the insurmountable onus of adapting to society. This is what we see next.

3 The medical model of disability and the abstract disability regime of the person with disability: open doors to obstetric violence

In Brazil, as in the rest of the world, the concept of disability has undergone profound transformations in order to keep abreast of innovations in the health area, as well as the way in which society relates to the part of the population that presents some type of disability.

The medical model of disability considered only the physical pathology and the symptom associated with it that gave rise to a disability. This model was adopted by the Civil Code of 1916 and reproduced in the Civil Code of 2002, which established abstract discipline of disabilities based on the "all or nothing" system: the person with mental disability, who did not have the necessary discernment for the practice of acts civilians, would be considered absolutely incapable, being denied the autonomous exercise of any act of civil life; it was imperative that a representative be appointed to express in his place the necessary will to practice such acts. The will of the representative, therefore, completely replaced the will of the person with disability. If, however, the person with mental disability flaunted reduced judgment, he would be considered

---

9 "Humanized childbirth is essentially that childbirth centered on woman, with respect to autonomy and female protagonism. Natural childbirth is the childbirth that happens without interventions such as oxytocin, analgesia and forceps. It is possible to have a humanized childbirth not entirely natural, because some interventions may be necessary. Therefore, the fundamental is this resumption of female protagonism in childbirth" (WOLFART, 2012, s.p.). Recent decision of the Court of Justice of São Paulo faced a case of obstetric violence, affirming that humanized childbirth is a fundamental right: TJSP 00013140720158260082. 5th Chamber of Private Law. Reporting Justice Fábio Podestá. Trial date October 11, 2017.

10 "The diffusion of the term originates in the decision: STJ, REsp 1.064.009 / SC, 2nd T., Reporting Justice. Herman Benjamin, j. 04.08.2009, DJe 27.04.2011. In this line, Adolfo Mamoru Nishiyama and Roberta Densa explain: "The hyper (from the Greek hypér) prefix, high-grade designative or that which exceeds the normal measure, plus the word vulnerable, means that some consumers have greater vulnerability than the measure normal, because of certain personal characteristics" (2010, p.13 et seq.). See also Konder (2015).

relatively incapable, and the validity of his expression of will was linked to his assistant's joint expression of will. For the acts of civil life, in general, it was also required the manifestation of the assistant.

The medical model ended up denying to many people with disabilities, at first, the exercise of a portion of autonomy in relation to acts that they would have full conditions to exercise freely, producing an exclusionary regime, which removes from the person with disability the possibility of even about the most prosaic acts of life. In fact, although absolute or relatively incapable, the person with disability will rarely be deprived of any possibility of autonomous manifestation of will, and it is necessary to ensure spaces of freedom within which he/she can exercise his/her autonomy, however small and simple.

In addition, and even more serious, the codified disability system allowed, as a rule, the dissociation between ownership and exercise of the rights inherent to the human person. In an abstract, all-or-nothing system, this ultimately prevents the person with disability from practicing any and all acts directly linked to the realization of their life project and the free development of their personality. And more, in the extreme, such a model may even deny the very quality of the human person, since the abstract and absolute dissociation between ownership and exercise of rights inherent to the human person ends in practice by promoting the disregard of the rights, fomenting a process of reification of the person with disability, who happens to be, at most, a "almost someone", like Quasimodo, thus qualified by Victor Hugo in his "The Hunchback of Notre Dame".[11]

The establishment of a single discipline for the verification of the capacity necessary for the validity of patrimonial and existential acts, along the lines of the codified model, is, however, incompatible with constitutional axiology. The Brazilian legal system assigns priority protection to existential legal situations, and instrumentalizes the juridical patrimonial situations to their realization. In this direction, it seems wrong to equate, a priori and abstractly, the requirements regarding the element will for the practice of patrimonial acts and for the practice of existential acts. The difference between the acts of patrimonial and existential autonomy is, above all, a constitutional basis (PERLINGIERI, 1999, p.18), which must be reflected in the identification of different validity requirements of the will for the exercise of each one of them.

In this context, the practice of obstetric violence against women with disabilities has become even more "normalized" and institutionalized than that practiced against women without disabilities.[12] Now, if deficiency was a physical pathology plus its symptom, care was taken exclusively to affect the person of the carrier, who should then make every effort to adapt to society. From this perception, if it were not the society that should create mechanisms to overcome the barriers that prevented the full inclusion of people with disabilities, such as requiring hospitals and clinics, for example, the use of equipment adapted to various physical disabilities, or professionals are able to deal with the specificities inherent in each type of disability?

Picture of this unpreparedness is the emblematic case of a deaf parturient who, although she knew that she was pregnant, did not know that they were twins. After the birth of the first child, as the medical staff, for total ignorance and unpreparedness, could not communicate with the woman, the second child eventually died.[13]

The physical barrier, however, contains only one of the forms of violence against pregnant woman with disability. Even when only physically handicapped, with preservation of their full autonomy and civil capacity, it is evident that in the reality of life their will is repeatedly disregarded, as evidenced by the reports made

---

[11] In the author's words: "He baptized his adopted son and gave him the name of Quasimodo, because he wanted to remember the day he was found, or because he wanted to characterize by that name how poor the little creature was incomplete and badly made. Quasimodo, in fact, one-eyed, hunchbacked and lame, was not more than an almost" (HUGO, 1832, p.180).

[12] Butler (2015, p. 68) points out that commotion reactions are tacitly regulated by certain types of interpretive frameworks, making people feel more horror and moral repulse over human lives. According to the author, the moral response to violence arises from the conception that it is just or justified, a feeling created by a regulatory power, because the commotion is always transmitted from another place, predisposing the perception of the world in a certain way, accepting certain dimensions and resisting others. Hence, he says that the differentiation of the affective response and moral valuation are the frameworks that make certain lives worthy of protection and others not, for "they are not wholly lives."

[13] The episode is narrated in the Carta Capital magazine under the title "We need to talk about violence against women with disabilities" (PRATES, 2016, s.p.).

by Joyce, person with visual impairment, when she was admitted to a maternity hospital in Guaxupé, Minas Gerais, in 2007, she received the news that there was meconium in the amniotic fluid, without any additional examination or information about anything that might indicate the seriousness of the situation. Joyce then asked her to call her doctor, but she was not taken care of. The team decided to perform a cesarean and did not admit the accompanying person to the surgical center. After two unsuccessful attempts to anesthetize her, she chose to continue her "cold-blooded" surgery. "The anesthesiologist pulled my hair, so I did not faint in pain," Joyce reported (LAZZAREI, 2015).

Taking care of a person with intellectual disability, the situation is even more dramatic: if the codified regime considered it a priori incapable, devoid of autonomy even for the practice of existential, self-referential acts, if its will was irrelevant to the law, how to demand respect for their desires by doctors? In an abstract system of incapacity, it seemed, as it were pointed out, it was impossible to dissociate the capacity for the practice of patrimonial acts from that necessary for existential acts.

Even if the mentally disabled pregnant woman flaunted sufficient functionality to understand the consequences of a choice about her pregnancy, if she were incapable, the codified system ignored her will, refusing to the holder of the existential right any portion of autonomy and capacity to exercise it, which ended up denying her the very quality of a human being, leading to her objectification. And the most perverse consequence of this process is the naturalization of violent and cruel acts against pregnant woman with disability, because if they are refused the status of human person, there is no dignity to be guarded, admitting that it is directed all kinds of violence.

In Brazil, the most emblematic and shocking example of this phenomenon of reification of the person with disability from the denial of the ownership rights inherent to the human being happened at the Hospital Colônia de Barbacena, founded on October 12, 1903. The Colônia Hospital de Barbacena became known to the public in the 1980s, because of the inhuman treatment it offered patients, who were denied the most basic rights inherent to the person. Italian psychiatrist Franco Basaglia, a pioneer in the anti-asylum struggle in Italy, visited Brazil and visited the hospital in 1979. At a press conference, he said: "I was in a Nazi concentration camp today. Nowhere in the world have I witnessed such a tragedy "(CASTELO BRANCO, 2015, s.p.).

The patients arrived at the site in large freight cars, known as "train of the crazy". It is estimated that at least 60,000 people died of cold, starvation, disease and electroshock at the Hospital Colônia de Barbacena. Faced with the degrading condition of asylum, in order to protect their pregnancies, women they smeared their bellies with feces for not to be touched by the officials; when they were able to carry the pregnancy to term, after childbirth, they were forcibly removed from babies, who were often adopted irregularly. There were not even childbirth rooms. The parturients had their children in the general wards (DUARTE, 2009, p.188).

The overcoming of this process of denial of the autonomy of the pregnant woman with disability and, consequently, of the obstetric violence to which she is subjected with greater intensity, obviously passes for the change of conception about the own deficiency, as it is to be examined.

4 The social model of disability and the disability regime established by the Statute for the Person with Disability: on the way to guarantee access to humanized childbirth

The Statute for the Person with Disability overcame some criticisms of the codified disability regime, establishing a different regulation for the capacity of persons with disabilities in relation to, above all, what is relevant to this analysis, to the practice of existential acts, and partially mitigated the abstractivization of the regime. In this regard, it should be stressed that the adoption of a new model of disability contributed decisively to these changes.

The International Classification of Functioning, Disability and Health - ICF, published by the World Health Organization in 2001, began to combine the medical model of disability with the social model, which considers the subject disability as a problem created by society and whose main challenge is the full integration of the individual into society. Under such perspective, disability is not an inherent attribute of the individual but, "a complex set of conditions, many of which are created by the social environment." In

fact, the solution of the problem requires a consistent social action in the realization of the "environmental modifications necessary for the full participation of people with disabilities in all areas of social life". Is the disability a matter of a political question? (WHO, 2004, p. 22).

The integration of the medical model and the social model inaugurates the biopsychosocial approach to disability, which offers an understanding of different health perspectives: biological, individual and social. In this context, disability is necessarily "a result of both the limitation of body functions and structures and the influence of social and environmental factors on this limitation" (IBGE, 2012, p. 71). According to the International Classification of Functioning, Disability and Health, deficiencies "are problems in body functions or structure, such as a major deviation or a loss" (WHO, 2004, p. 14), which is not always, however, capacity or functionality limitation.[14]

This model was expressly adopted by the UN Convention on the Rights of Persons with Disabilities, approved by Legislative Decree n. 186, on July 9, 2008, becoming part of the Brazilian legal system with constitutional amendment status. Also, in the preamble of the Convention, it is recognized that disability, an evolving concept, "results from the interaction between people with disabilities and the barriers due to attitudes and the environment that prevent their full and effective participation in society on an equal basis with other persons" (Convention on the Rights of Persons with Disabilities, 2011, p. 22). By the way, says Mary Keys (2017, p. 265): "*previous reliance only on a narrower medical approach is no longer considered appropriate, and instead a social and human rights approach focused on removing barriers to participation is essential to the achievement of equality"*.

The Statute for the Person with Disability[15] contemplated the same model, already in its 2nd article, according to which "a person with disability is defined as having a long-term physical, mental, intellectual or sensorial impairment, which, in interaction with one or more barriers, may obstruct their full and effective participation in the society on an equal basis with other persons". Pursuant to § 1st:

> the assessment of disability, when necessary, will be biopsychosocial, carried out by a multidisciplinary and interdisciplinary team and will consider: I - impairments in the functions and structures of the body; II - socio-environmental, psychological and personal factors; III - the limitation in the performance of activities; and IV - the participation restriction.

This new perspective of disability allowed the reformulation of the Brazilian disability regime of the person with disability. According to the Statute for the Person with Disability, "the person with disability has ensured the right to exercise their legal capacity on an equal basis with other persons" (article 84). It is further stated that

> disability does not affect a person's full civil capacity, including: I - marrying and forming a stable union; II - to exercise sexual and reproductive rights; III - exercise the right to decide on the number of children and to have access to adequate information on reproduction and family planning; IV - to preserve its fertility, being prohibited the compulsory sterilization; V - to exercise the right to family and family and community life; and VI - exercise the right to custody, guardianship, custody and adoption, as adopter or adopting, on an equal basis with other persons (article 6th).

Faced with this new regulation, it is noted that the rule became the capacity and autonomy of the person with disability. Thus, it remains clear that any medical decision about woman with disability must be submitted to her, including all those that, in any way, concern their reproductive autonomy and their family planning. It means, definitively, that the choice between a normal childbirth or cesarean section, the choice of a contraceptive method or tubal ligation, the decision about episiotomy and trichotomy, among others, should be made, whenever she flaunt enough functionality to understand the consequences of such decisions

---

[14] The ICF understands capacity as the "ability of an individual to perform a task or action" and functionality as "an interaction or a complex relationship between health condition and contextual factors (i.e. environmental and personal factors)" (WHO, 2004, p. 20).

[15] In Brazil, the Statute came to provide approximately 45.5 million people who, according to the 2010 Demographic Census, reported having at least one of the deficiencies investigated, which corresponds to 23.9% of the Brazilian population. Regarding each of the deficiencies analyzed, 18.8% of the people reported having visual impairment; 5.1%, hearing; 7.0%, motor; and 1.4%, mental or intellectual (IBGE, 2012, p. 73).

by the woman, who should be informed about all the procedures, their advantages and disadvantages, as well as the risks involved. The information, of course, must be provided in an accessible manner, in clear language and compatible with the possibility of understanding the pregnant woman with a disability, and the doctor should use, whenever necessary, a multidisciplinary team, in order to guarantee the most perfect apprehension of information.

Such decisions, as a rule, cannot even be submitted to the curator. According to the Statute for the Person with Disability, the guardianship is exceptional, constituting "extraordinary protective measure and proportional to the needs and circumstances of each case, and will last the shortest possible time", under the terms of article 84, *caput*, §§ 1st and 3rd. In addition, according to article 85, *caput* and paragraph 1st, "the guardianship shall only affect the acts related to property and negotiating rights" and shall not achieve "the right to own body, sexuality, marriage, privacy, education, health, work and voting".

By the diction of the mentioned devices, in principle, the restriction of the real capacity of people with disabilities only seems possible for the practice of legal acts and businesses related to patrimonial legal situations. In relation to the exercise of existential rights, the Statute for the Person with Disability prevents the restriction of civil capacity (article 6th), in addition to expressly excluding from the scope of the guardianship some existential rights, among which those related to sexuality and to the body itself (article 85, § 1st).

However, it cannot be ignored that, in extreme cases, considering the exacerbated vulnerability of the person with disability, in view of the serious impairment of their functionality, it will not be able to manifest itself even on existential, self-referential issues that only concern it. In these cases, in order to better support it, there is no other solution but the protective intervention of the curator, who must seek the presumed manifestation of the person based on his biographical history, not proceeding purely to a substitution of will (BARBOZA; ALMEIDA, 2016, p. 265; MENEZES, 2016, p. 532).

The solution is justified. Although Law flaunt an important transforming role in society (PERLINGINGER, 2002, p. 2-3), it must be recognized that there are limits to this transformation. The fact that the Statute for the Person with Disability determines that people with disabilities are fully capable of performing certain existential acts will not, in fact, make them capable of exercising them on their own. Depending on the degree of disability, on the impairment of its functionality, from a practical point of view, the person will not be able to exercise such acts autonomously, and the Law will need to intervene in order to ensure its adequate support and protection.

Therefore, the Convention recommends meeting the preferences of the person with mental or intellectual disability and observes their potential for self-determination. However, there are extreme cases that require an exceptional reading, such as the picture concerning the person with disability who does not have the means to express their will, the presence of factors indicating a strong intensification of their vulnerability, or a context of other violences and abuses.

Indeed, in exceptional cases, it will be admitted that flexibilization of § 1st of article 85 - which prohibits the guardianship for the rights referred to therein - and of article 6th - which prohibits the restriction of civil capacity for the exercise of the rights that it lays down - to admit that, in a specific and punctual situation, for the practice of certain existential act, the curator submits the matter to the judge, who will decide if the person with disability may or may not practice it. If in the concrete case, based on a biopsychosocial analysis by a multidisciplinary team, the judge concludes that the mitigation of the civil capacity of the person with disability is the only adequate instrument for the realization of the constitutional principle of promoting the protection of the human rights of persons with disabilities and respect for the dignity inherent to it, can remove the rule of the Statute for the Person with Disability, authorizing the curator to manifest according to the "will and preferences of the person," that is, according to his biographical history.

In any case, the rule has become, repeat to exhaustion, the full capacity of the person with disability to practice civil acts, and even if there is some limitation of their capacity, this will not affect the exercise of certain existential rights. Thus, two different legal regimes are inaugurated: one for the exercise of property rights and the other for the exercise of existential rights. It is a fundamental change aimed at guaranteeing

to a considerable portion of the Brazilian population the necessary autonomy to control their existential decisions, interrupting the perverse cycle of disempowerment of people with disabilities.

This new perspective is particularly relevant for pregnant women with disabilities, as it recognizes them not only the autonomy to decide, whenever they flaunt the necessary functionality, on all issues related to reproduction and family planning, such as the right of all medical care is offered to them in the most accessible way possible, with the removal of all physical and informational barriers to the full exercise of this autonomy. In this treadmill, not only medical equipment should be adequate and adapted to pregnant women with any type of disability, as doctors and nurses must be specially qualified, in order to be able, for example, to communicate in Brazilian Sign Language (LIBRAS), in order to avoid the tragedy reported pages above.

It is also necessary to ensure the right of pregnant women with disabilities to make use of the childbirth plan, an instrument developed during prenatal care and which establishes the procedures to which the pregnant woman agrees to submit and those that she does not accept. Taking care of a pregnant woman with a psychic disability, the childbirth plan, as a unilateral existential juridical business, will be valid if it presents sufficient functionalities to understand the consequences of its choices and through its exclusive manifestation of will.

In this way, the aim is to combine the protection of person with disability with emancipation and substantive freedom in the prospective work of law, which, according to Luiz Edson Fachin (2015, p. 86), "is the hermeneutic work of permanent reconstruction, correct and adequate, of the meanings that apply to the signifiers that integrate the theory and practice of Civil Law."

The recognition, in this specific case, that the pregnant woman with disability flaunt the necessary functionality to exercise her autonomy in relation to decisions on pregnancy, therefore, leaves no possibility for the curator to interfere in these matters, including in the childbirth plan. If the doctor chooses to ignore the will and wishes of the pregnant woman - whether or not she is embodied in the childbirth plan -, and to follow the possible orientation of the curator - which, in other words, has not power to act in this field, in principle, except, in an exceptionally situation, as already mentioned -, can be held jointly responsible with the curator for obstetric violence.

It is always relevant to remember that, although they are fundamental rights, of immediate applicability by control of conventionality, only half a decade after the Convention was internalized in Brazilian law, with a material and formal status of Amendment to the Constitution,[16] was the promulgation of the Brazilian Law of Inclusion, or Statute for the Person with Disability - Law n. 13.146/2015 - in an attempt to bring domestic legislation into line with the Convention paradigm and give effectiveness of the rights it lays down.

Hence the denunciation of the difficulties of guaranteeing positive rights in an international treaty aimed at protecting a vulnerable group and the formal and material obstacles placed instead of effective human rights practices. In this way, Joaquín Herrera Flores argues that human rights should be seen as institutional and social processes that allow the opening and consolidation of spaces for the struggle for human dignity, recognizing and respecting plurality and diversity as milestones of a material conception and concrete dignity. The author emphasizes the need to reaffirm these rights day by day and through various agents: "legal norms may fulfill a function more in accordance with what happens in our realities" if we put them into operation - from above, but especially from below-, assuming from the beginning a contextual and critical perspective, that is, emancipatory (FLORES, 2009, p.18).

There is no obstacle, of course, to the fact that the pregnant woman with a disability opts for a supported decision (article 1,783-A, CC), which does not affect her civil capacity, and contains an instrument "aimed at assisting the person who feels weak in the exercise of its autonomy," but that it has "the conditions, itself, for

---

[16] The signing of the treaty took place on 03/30/2007 and its ratification occurred in 2008 by the National Congress following the procedure established in the 5th article, §3rd of the Federal Constitution. Never forgetting the theme "control of conventionality" of the Brazilian norms of domestic law, which Flávia Piovesan (2012, p.91) stresses, is that the protection of human rights (*human rights approach*) is the apex of the international system and that "control of conventionality" is an important instrument for the realization of protective measures to human rights contained in international treaties.

making its own choices and entering into any legal business without the need for assistance or representation" (MENEZES, 2016, p. 42-44). Thus, the instrument of the Supported Decision-Making could be used to increase the self-determination of the person with disability capable and that requires some kind of support to understand the context of a situation that demands their choice. National doctrine is discussed about the objectives of Supported Decision-Making. Among these debates is the one about its (in) dispensability for the exclusively realization of patrimonial acts and the discussion on whether the reference to "civil acts" would also cover existential relations, such as those related to reproductive rights.

However, as David Sanchez Rubio (2014, p. 43) warns, it is not enough to affirm a right or a judicial recognition, since the juridical norms and the juridical phenomenon are in continuous process of signification and resignification, which makes the struggles incessant in search of the recognition and effectiveness of human rights, so it is hoped that the Supported Decision-Making will truly become an emancipatory practice for the current Brazilian reality.

It is not unreasonable to point out that in any situation, no matter how severe the disability - even if, in a very exceptional hypothesis, the pregnant woman cannot express her will - by the simple (and unaffordable) fact of being a subject of law, endowed with inherent human dignity, it will always have the fundamental right to humanized childbirth. Although the term is polysemic, the proposals of humanization of childbirth, in general,

> [...] have the merit of creating new possibilities of imagination and of exercising rights, of living motherhood, sexuality, parenthood, bodily life. Finally, reinvention of childbirth as a human experience, where before there was only the precarious choice between cesarean as an ideal childbirth and the victimization of violent childbirth (DINIZ, 2005, p. 635).

And this is a right of all women, regardless of their physical, psychic, social or racial condition.

5 Conclusion

The central nucleus of the theme of this work is to protect the self-determination of sexual and reproductive rights, including the "childbirth plan", for all women in a humanized conception, which requires specificities for people with physical, mental or intellectual disabilities, as well as the untying of a substitutive approach to the will, without neglecting the protection of its interests.

It is not uncommon, however, that the medical-scientific knowledges of health professionals overlaps and impedes the individual freedoms of pregnant women and leads to the harmful practice of obstetric violence, which includes offenses against sexual and reproductive rights, as well as freedom and autonomy of woman, in an obvious violation of fundamental human rights. If the practice of obstetric violence is already serious in itself, the offense is even greater when it is attempted against people in situations of hypervulnerability, such as people with disabilities who have always been stigmatized and deprived of autonomy in the face of the medical model of disability, contemplated in the civil code of 1916 and 2002.

The internalization of the New York Convention on the Rights of Persons with Disabilities and, later, in 2015, the edition of the Statute for the Person with Disability substantially changed the legal treatment of persons with disabilities.

Firstly, disability is conceived from a complex of biopsychosocial conditions, considering external social and environmental factors, but also individual aspects. Subsequently, a new juridical regime is given to the disabilities considered as exceptional, when patrimonial and existential acts are delimited, and the person with disability becomes, as a rule and a priori, absolutely capable of exercising his/her self-determination, especially in the which relates to acts of a very personal nature.

This new perspective therefore appears as an important mechanism that respects and protects the autonomy of the pregnant woman to decide on the issues of family planning, gestation, childbirth (enabling her to decide, in the "childbirth plan" or through supported decision-making, on the procedures it accepts or does not submit to) and the body itself, in the exercise of their existential rights and freedoms in a humanized way. To this end, barriers (physical, communicational, knowledge, etc.) that prevent the exercise of self-

determination and the decision-making power of the person with disability should be reduced in relation to their personality, combining formal protection and material of the dignity of pregnant woman with disability.

Conquests and setbacks constitute the dialectical dynamics of movements and practices of recognition and affirmation of human and fundamental rights of vulnerable groups. People with disabilities go through the same difficult journey. Nowadays, there is an urgent need for reflection in order to expand the understanding of the norms outlined in the Convention, otherwise autonomy will remain restricted and conditioned to inferior cultural standards, hence the need for critical and emancipatory judgment for effective self-determination.

References

BARBOZA, Heloisa Helena. Vulnerabilidade e cuidado: aspectos jurídicos. *In*: PEREIRA, Tânia da Silva; OLIVEIRA, Guilherme de (coord.). **Cuidado e vulnerabilidade**. São Paulo: Atlas, 2009. p. 106-118.

BARBOZA, Heloisa Helena. O princípio do melhor interesse do idoso. *In*: PEREIRA, Tânia da Silva; OLIVEIRA, Guilherme de (coord.). **O cuidado como valor jurídico**. Rio de Janeiro: Forense, 2008. p. 57-72.

BARBOZA, Heloisa Helena; ALMEIDA JÚNIOR, Vitor. A capacidade à luz do Estatuto da Pessoa com Deficiência. *In*: MENEZES, Joyceane Bezerra de (org.). **Direito das pessoas com deficiência psíquica e intelectual nas relações privadas**: Convenção sobre os direitos das pessoas com deficiência e Lei Brasileira de Inclusão. Rio de Janeiro: Processo, 2016. p. 249-274.

BRASIL. **Lei n. 11.108, de 7 de abril de 2005**. Altera a Lei n-8.080, de 19 de setembro de 1990, para garantir às parturientes o direito à presença de acompanhante durante o trabalho de parto, parto e pós-parto imediato, no âmbito do Sistema Único de Saúde – SUS. Disponível em: http://www.planalto.gov.br/ccivil_03/_Ato2004-2006/2005/Lei/L11108.htm. Acesso em: 8 dez. 2018.

BRASIL. **Lei n. 10.406, de 10 de janeiro de 2002**. Institui o Código Civil. Disponível em: http://www.planalto.gov.br/ccivil_03/LEIS/2002/L10406.htm. Acesso em: 8 dez. 2018.

BRASIL. **Convenção sobre os Direitos das Pessoas com Deficiência**. Protocolo Facultativo à Convenção sobre os Direitos das Pessoas com Deficiência: decreto legislativo nº 186, de 09 de julho de 2008; decreto nº 6.949, de 25 de agosto de 2009. 4. ed. rev. e atual. Brasília: Secretaria de Direitos Humanos, Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência, 2011. Disponível em: http://www.pessoacomdeficiencia.gov.br/app/sites/default/files/publicacoes/convencaopessoascomdeficiencia.pdf. Acesso em: 8 dez. 2018.

BUTLER, Judith. **Quadros de guerra**: quando a vida é passível de luto? Rio de Janeiro: Civilização Brasileira, 2015.

CASTELO BRANCO, Thayara. O Holocausto manicomial: trechos da história do maior hospício do Brasil! **Justificando**, São Paulo, 03 maio 2015. Disponível em: http://justificando.cartacapital.com.br/2015/03/05/o-holocausto-manicomial-trechos-da-historia-do-maior-hospicio-do-brasil/. Acesso em: 28 fev. 2018.

COSTA, Mariana V. de M.; LUNA, Maria J. de M. A violência obstétrica e a dominação masculina de Bourdieu. *In*: SEMINÁRIO INTERNACIONAL DE DIREITOS HUMANOS DA UFPB, IX. João Pessoa, 2016. **Anais [...]**. João Pessoa: Universidade Federal da Paraíba, 2016. Disponível em: http:www.ufpb.br/evento/lti/ocs/index.php/ixsidh/paper/view/4245/159. Acesso em: 6 set. 2018.

DIAS, João Álvaro. **Procriação assistida e responsabilidade médica**. Coimbra: Coimbra Editora, 1996.

DINIZ, Carmen Simone Grilo. Humanização da assistência ao parto no Brasil: os muitos sentidos de um movimento. **Ciência e Saúde Coletiva**, Rio de Janeiro, v. 10, n. 3, p. 627-637, jul./set. 2005.

DINIZ, Carmen Simone Grilo; NIY, Denise Yoshie; ANDREZZO, Halana Faria de Aguiar; CARVALHO, Priscila Cavalcanti Albuquerque; SALGADO, Heloisa de Oliveira. A vagina-escola: seminário interdisciplinar sobre violência contra a mulher no ensino das profissões de saúde. **Interface - Comunicação, Saúde, Educação**, Botucatu, v. 20, n. 56, p. 253-259, jan.-mar. 2016.

DUARTE, Maristela Nascimento. **De "Ares e Luzes" a "Inferno Humano".** Concepções e práticas psiquiátricas no Hospital Colônia de Barbacena: 1946-1979. Estudo de caso. 2009. Tese (Doutorado em História) - Instituto de Ciências Humanas e Filosofia, Universidade Federal Fluminense, Niterói, 2009. Disponível em: http://www.historia.uff.br/stricto/td/1100.pdf. Acesso em: 4 set. 2018.

FACHIN, Luiz Edson. **Direito civil**: sentidos, transformações e fim. Rio de Janeiro: Renovar, 2015.

FLORES, Joaquín Herrera. **A (re)invenção dos direitos humanos**. Tradução de Jefferson Aparecido Dias, Carlos Roberto Diogo Garcia e Antônio Henrique Graciano Suxberger. Florianópolis: Fundação Boiteux, 2009.

FOUCAULT, Michel. **Vigiar e punir**. Petrópolis: Vozes, 1997.

FUNDAÇÃO PERSEU ABRAMO. **Mulheres brasileiras e gênero nos espaços público e privado**. Brasil, São Paulo, 2010. Disponível em: https://apublica.org/wpcontent/uploads/2013/03/www.fpa_.org_.br_sites_default_files_pesquisaintegra.pdf. Acesso em: 5 set. 2018.

HENCI, Goer. Cruelty in maternity wards: fifty years later. **The Journal of Perinatal Education**, [*S.l.*], v. 19, n. 3, p. 33-42. 2010. Disponível em: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2920649/?tool=pmcentrez&report=abstract#bib24. Acesso em: 5 set. 2018.

HUGO, Victor. **O Corcunda de Notre Dame**. Tradução de Jorge Bastos. Rio de Janeiro: Zahar, 2013. Disponível em: https://sanderlei.com.br/PDF/Victor-Hugo/Victor-Hugo-O-Corcunda-de-Notre-Dame.pdf, p. 180. Acesso em: 11 set. 2018.

INSTITUTO BRASILEIRO DE GEOGRAFIA E ESTATÍSTICA - IBGE. **Censo demográfico de 2010**. Brasil, 2012. Disponível em: https://biblioteca.ibge.gov.br/visualizacao/periodicos/94/cd_2010_religiao_deficiencia.pdf. Acesso em: 8 dez. 2018.

KEYS, Mary. Article 12 [Equal Recognition Before the Law]. *In*: DELLA FINA, Valentina; CERA, Rachele; PALMISANO, Giuseppe. **The United Nations Convention on the Rights of Persons with Disabilities**: a commentary. Switzerland: Springer International Publishing, 2017. p. 89-106.

KONDER, Carlos Nelson. Vulnerabilidade patrimonial e vulnerabilidade existencial: por um sistema diferenciador. **Revista de Direito do Consumidor**, São Paulo, v. 99, p. 101-123, maio-jun. 2015. Disponível em: http://konder.adv.br/wp-content/uploads/2018/01/Carlos-Nelson-Konder-Vulnerabilidade-patrimonial-e-vulnerabilidade-existencial-In-Revista-de-Direito-do-Consumidor.pdf. Acesso em: 11 set. 2018.

LAZZERI, Thais. Vítimas da violência obstétrica: o lado invisível do parto. **Época**, São Paulo, 04 ago. 2015. Disponível em: https://epoca.globo.com/vida/noticia/2015/08/vitimas-da-violencia-obstetrica-o-lado-invisivel-do-parto.html. Acesso em: 3 set. 2018.

MENEZES, Joyceane Bezerra de. O direito protetivo após a Convenção sobre os direitos da pessoa com deficiência, o novo CPC e o Estatuto da Pessoa com Deficiência. *In*: MENEZES, Joyceane Bezerra de (org.). **Direito das pessoas com deficiência psíquica e intelectual nas relações privadas**: Convenção sobre os direitos das pessoas com deficiência e Lei Brasileira de Inclusão. Rio de Janeiro: Processo, 2016. p. 509-544.

MENEZES, Joyceane Bezerra de. Tomada de decisão apoiada: instrumento de apoio ao exercício da capacidade civil da pessoa com deficiência instituído pela Lei Brasileira de Inclusão (Lei n. 13.146/2015). **Revista Brasileira de Direito Civil - RBDCivil**, Rio de Janeiro, v. 9, p. 31-57, jul./set. 2016. Disponível em: https://rbdcivil.ibdcivil.org.br/rbdc/article/view/53/47. Acesso em: 9 set. 2018.

ORGANIZAÇÃO MUNDIAL DA SAÚDE - OMS. **Classificação internacional de funcionalidade, incapacidade e saúde**. Lisboa, 2004. Disponível em: http://www.inr.pt/uploads/docs/cif/CIF_port_%202004.pdf. Acesso em: 3 set. 2018.

ORGANIZAÇÃO MUNDIAL DA SAÚDE – OMS. **Prevenção e eliminação de abusos, desrespeito e maus-tratos durante o parto em instituições de saúde**. Suíça, 2014. Disponível em: http://apps.who.int/iris/bitstream/handle/10665/134588/WHO_RHR_14.23_por.pdf;jsessionid=C49D2B650CF14F6CBFB75244721125D6?sequence=3. Acesso em: 3 set. 2018.

PERLINGIERI, Pietro. **Perfis do direito civil**: introdução ao direito civil constitucional. Tradução de Maria Cristina De Cicco. Rio de Janeiro: Renovar, 1999.

PERLINGIERI, Pietro. **Perfis do direito civil**: introdução ao direito civil constitucional. Tradução de Maria Cristina De Cicco. 3. ed. Rio de Janeiro: Renovar, 2002.

PIOVESAN, Flávia. Direitos humanos e diálogo entre jurisdições. **Revista Brasileira de Direito Constitucional – RBDC**, São Paulo, n. 19, p. 67-93, jan./jun. 2012.

PRATES, Deborah. Precisamos falar sobre violência contra mulheres com deficiência. **Carta Capital**, São Paulo, 21 nov. 2016. Disponível em: http://justificando.cartacapital.com.br/2016/11/21/precisamos-falar-sobre-violencia-contra-mulheres-com-deficiencia/. Acesso em: 3 set. 2018.

RUBIO, David Sanchez. **Encantos e desencantos dos direitos humanos**: de emancipações, libertações e dominações. Porto Alegre: Livraria do Advogado, 2014.

SÃO PAULO. Defensoria Pública do Estado de São Paulo - DPGE-SP. **A violência obstétrica existe**. São Paulo, 2013. Disponível em: https://www.defensoria.sp.def.br/dpesp/repositorio/41/violencia%20 obstetrica.pdf. Acesso em: 5 set. 2018.

WHO. **Individualized, supportive care key to positive childbirth experience, says WHO**. Switzerland, 2018. Disponível em: http://www.who.int/mediacentre/news/releases/2018/positive-childbirth-experience/en/. Acesso em: 14 maio 2018.

WOLFART, Graziela. A retomada do protagonismo feminino no parto. **Revista do Instituto Humanitas Unisinos**, São Leopoldo, n. 396, p. 11-14, 2 jul. 2012.

Recebido em: 14/12/2018
Aprovado em: 15/02/2019