

Support for people with intellectual and cognitive disabilities: recognizing moral status in law and philosophy

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1. Introduction: the challenge of disability to moral *status*

To be respected as a person, to lead one's life and to be the subject of autonomous decisions and actions: these values, not only important, are the very backbone of Western culture (QUANTE, 2006, p.146). The first of these attributes is shaped by Kantian moral philosophy, which, in turn, has its cornerstone in the concept of independent rationality (BARBOSA-FOHRMANN; BARRETO, 2017). In the Kantian approach, rationality underlies the special moral status of person (KANT, 2015). In other words, solely people deserve respect as moral subjects, since they are endowed with rationality, from which moral status derives. Thus, independence in the conduction of one's life and autonomy factually manifested in decision-making qualify as two attributes intrinsically connected to this moral recognition as a person (MACINTYRE, 1999). However, according to Carlson and Kittay, people with cognitive disabilities are individuals who have a reduced capacity for rational deliberation, at best. Therefore, a question is worth asking: “[H]ow should one think about these individuals?” (KITAY, CARLSON, 2009, p.1).

At the same time, according to Bariffi, personhood is the door of access to the right to have rights. Legal capacity, in turn, is the gateway to their enacting. Without the full recognition of legal capacity, the genuine exercise of human rights is not possible. Thence the implementing of the list of rights recognized in the UN's Convention of Rights of Persons with Disabilities - CRPD (2011, p. 325) is rather hindered by such provision. This we may say the conceptual frameworks of Ethics which deny moral personhood to people with intellectual and cognitive disabilities converge with that of legal scholars who deny their full legal capacity.

Therefore our main objective herein is to answer the following question: “how can the moral status of people with cognitive and intellectual disabilities be legally recognized?”. We address the *substitute decision-making model* replacement by proposing the support for people with disabilities in decision-making. As the former

model traditionally disregards those subject's will due to their lack of certain abilities, the support in decision-making model seeks to assure the full expression of people with cognitive and intellectual disabilities' will through the provision of assistance. Moreover, we establish a dialogue with MacIntyre's perspective of community and Kittay's care theory.

2. From the substitute decision-making model to the support model for people with cognitive and intellectual disabilities in decision-making legal theory

The absence of specific characteristics among people with severe cognitive and intellectual disabilities' livelihood results in the absence of comprehensive autonomy (FRANCIS, 2009). Through the judgment of these persons as dependent or incompetent subjects, national Private Legislations have defended their pretense need of protection. This has been conceived and configured according to a purely medical model of disability, and a conception that certain persons with disabilities lack the capacity to make their own decisions. Thus, it is an elementary tool of the substitution model of the will in decision-making (BARIFFI, 2014, p. 17).

Nevertheless, grounded on social model, the concept of disability has been dynamically transformed. According to CRPD's article 1, it arises from the encounter between barriers and personal condition, resulting, from this interaction, the inequality of rights and opportunities in comparison with other persons in the same community. In this sense, we first analyze the paradigmatic shift provided by the CRPD through equal recognition before the law and, secondly, we seek to demonstrate how Brazilian law incorporated that treaty's command.

2.1 CRPD's article 12: equal recognition before the law

The CRPD and its Optional Protocol were both incorporated into the Brazilian legal system as equivalent to a constitutional amendment, through the approval of Legislative Decree No. 186, of July 9, 2008, under the special procedure reserved for international human rights treaties.

The Committee on the Rights of Persons with Disabilities noted that there was confusion State Parties' interpretations over the scope of the Convention on the Rights of Persons with Disabilities, as it received reports on compliance with article 12's obligations, which deals with equal recognition of the law. This article commands that

States Parties “shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life“. In the same article, it is said that states “shall take appropriate measures to provide access by persons with disabilities to the *support* they may require in exercising their legal capacity“.

The assurance that legal capacity would be recognized on an equal basis with others would inevitably culminate in a paradigmatic shift in decision-making, from the substitution model to a supportive one (UN, 2014, p. 1). Thereby provided, even though people may need different degrees of support in their legal standing, they should not have it diminished due to mental, cognitive or intellectual abilities. Accordingly, the Committee on the Rights of Persons with Disabilities has promoted an understanding that the legal capacity of possessing rights gives the individual full protection of his or her rights in the legal system and is independent from his or her mental capacities (UN, 2014).

According to Cuenca art. 12 of the CRPD promotes a genuine revolution in dealing with legally-established legal capacity for people with disabilities and the substitution of decision-making, since it shows a rupture with the traditional human rights theory. Historically, it has disregarded the civil capacity of people with disabilities. Thus, this theoretical framework’s development is essential for the implementation of article 12. Therefrom, States Parties should then recognize persons with disabilities as possessors of full capability for exercising rights and all the freedoms they hold for themselves (CUENCA, 2012, p. 133).

2.2. Brazilian Inclusion Statue: changes in the national civil system

Before the CRPD’s incorporation, the Civil Brazilian Code originally set an absolute incapacity for those under sixteen years of age; for those who because of illness or mental disability did not have the necessary discernment for the practice of acts of civil life; and for those who, even for transitory reasons, could not express their will. In spite of that, relative incapacity was revealed as applicable to those over sixteen and under eighteen; to the dipsomaniac, and to those who because of mental disability had reduced discernment; for those who lack complete mental development; and the prodigals. The legal order homogenized those people, so that the characterized by absolute incapacity could perform independently civil acts but their will should be replaced by the will of their representative. However, the partially incompetent ones

demanded the assistance of a third person for the autonomous practice of several civil acts.

After the aforementioned treatise's incorporation, Brazilian civil system remained unchanged for seven years. In 2015, Brazilian Inclusion Law (BIL) performed a dramatic change in the national's civil capacity system, in a way that disability ceased to be an immediate cause or a foundation from which civil incapacity would derive. For those persons –either or not cognitively or intellectually disabled– who are not able to express their will, due to permanent or temporary causes, the private law would recognize partial incapacity. Therefore, the presumption of incapacity derived from the disability setting was over, and the provision of support to supply their willful expression and recognition as morally relevant persons before the law became mandatory.

There was a legislative change, withal, on the civil capacity system, since there are still mechanisms that permit substitute decision-making, such as the interdiction procedure (Code of Civil Procedure, Section IX) and non-voluntary sterilization of persons with disabilities (Family Planning's Act, article 10, § 6º). In this sense, we ask: what moral concept of community might prevent these mechanisms' application? How should we consider care relationships in this community?

3. Moral status recognition through care

3.1 The virtues of acknowledge dependence in Alasdair MacIntyre

Disability as an exceptional vulnerability, contrasting with ordinary present independence and self-sufficiency in a normal course of a human life, is a fundamental dictum of modern philosophy, which centralizes values such as autonomy, self-determination and the ability to lead one's life. Alasdair MacIntyre raises a fierce critique to this way of thinking, for whom dependence is an essential aspect of human existence (MACINTYRE, 1999). Therein, he proposes that any successful ethical theory must comprise three aspects: 1. that we are dependent, 2. that we are rational, and 3. that we are animals. The first and third of these are rarely taken into account by philosophers, while the latter is often overestimated (1999, p. 7-8, 127).

This dependence is more evident when there is a need for the assurance of subsistence, and therefore is more obvious in early childhood and old age. However, between these first and last stages, our lives are characteristically marked by longer

or shorter periods of injury, illness or other disabilities, while some of us are disabled for life. From these concerns, MacIntyre sets out to answer two questions that lead his work *Dependent Rational Animals*: "Why is it important for us to care for and understand what humans have in common with members of other intelligent animal species?" and "What makes attention to human vulnerability and disability important to moral philosophers?" (1999).

On his approach, it is precisely through recognizing that we never completely transcend our animal nature that we can broaden our conception of human flourishing to include individuals with disabilities and other nonhuman animals. Thence, besides the virtues of independence, we must develop the virtues of recognition of the dependence inherent in our animal condition (1999, p. 85).

In this approach, dependents do not have a "special" interest, since their aims are the same as those of the other members of the community. It is as such, due to there being a scale of disability (1999, p. 73-74) in which we all find ourselves, and this condition can only be partially addressed by the nets of care we weave around each other. There is not a single moment when we cease to be dependent, so that we have to improve, in contexts of practice, both our recognition of dependence and our rational independence.

Understanding MacIntyre's approach, we could propose that, in a community, we never completely abandon the state of dependence, so that the help and support of other members belonging to my community are permanently essential to our (since opted for "we") moral development, which never ceases or reaches a degree of complete independence. Therefore, concepts that permeate capacity theory, such as full civil competence as opposed to partial or total civil incompetence, do not work in the MacIntyre community. This is formed by a network of reciprocal interdependence, which when not recognized prevents the very attainment of rational independence. In this sense, we can propose that MacIntyre's moral community is an appropriate analogy to recognize support for people with disability as a natural result from the needs that this subject poses for his networks of giving and receiving.

3.2 Kittay's motherhood position: moral recognition through needed care

Drawing from her personal experience, Kittay develops an Ethics of care attentive to human capacities for love and happiness (KITAY, 2009). In her works with Licia

Carlson, she discusses the issue of cognitive disabilities in political philosophy and she stresses that this field has considered the ability of reasoning as a mark of the character of humanity. This, in consideration of people with intellectual or cognitive disabilities – whose ability for rationality may be diminished without affecting their status as a "person" - can highlight the conceptual limitations of concepts such as justice, rights, respect, care and responsibility (KITTAI, CARLSON, 2009, 1-2).

In this way, she suggests an alternative to Western conceptions of autonomy, guided by the ethics of care, which departs, not from individual attributes, but rather from their stance in caring relationships (1999, p. 25-29). She proposes that human beings are not, in fact, independent, but rather inextricably dependent on one another. Through obliterating dependence - especially that associated with childhood, old age, illness and disability - Western philosophy has contributed to the privatization of care and collective responsibilities upon people who depend. This approach allows the community to avoid its public responsibility in relation to its dependent members. Thence, as stated, the privatization of care makes us forget that any one of us can be in such a state of deep dependence (KITTAI, 2001). It is necessary, therefore, to ask about how care relationships could be structured as to take into account the potential development of autonomy in dependence, guaranteeing the protection of the moral status of the person with cognitive and intellectual disability within the community.

Indeed, it is only in the context of these caring relationships - which must be treated as matters of public relevance and essential to the functioning of society - one can grasp the factual or potential development of autonomy. Kittay also suggests that there is no reason to assume that any human being is severely disabled, in fact, to the point of no longer possessing essential characteristics for humanity (2005). Thus, all human beings would have autonomy, albeit counterfactual.

Whether Kittay wants to reinterpret the Kantian concept of autonomy by means of a relational bias or if she seeks to reinterpret the role of Kantian autonomy, related to the self-determination of moral rules, in the measurement of the personality is not clear. Despite having similar consequences, these perspectives provide thoroughly different paths, especially from a legal point of view. While the first of these theoretical outputs could provide a philosophical foundation for providing support in the full expression of civil capacity, the second one is implicitly opposed to the very perfectionist notion of autonomy for civil capacity.

Therefore, insofar as one part of this theory recognizes the "complementation" of skills from an intersubjective network of relational supports in a context of care, the other criticizes the conception of autonomy underlying the idea of a possessor of rights, member of a moral community. In one way or another, Kittay opposes the stance of the independent exercise of autonomy", which has proved to be exclusive to people with disabilities who may depend on others to express and formulate their beliefs concerning the good (CUENCA, 2012).

4. Conclusion

The selection of certain intellectual, cognitive and mental traits specifies moral importance between persons with certain types of disabilities and persons without such. The parameters for this evaluation - generally defended by those who consider themselves to be endowed with such qualities (MACINTYRE, 1999) - have shown themselves to be determinants of whether to disregard the moral status of people with intellectual disabilities and cognitive disabilities. . Thence, the recognition of the moral status of these subjects became, directly or indirectly, a subject of intense debate among the philosophers of applied ethics, since it proposes a direct challenge to the moral philosophy, embodied in the question: are there less morally relevant individuals? (CARLSON, 2009).

To answer this question is also to provide a path, in legal theory, to either recognize or disregard those subjects' will and their recognition before the law . We conclude that a theoretical framework that provides people with intellectual and cognitive disabilities with moral recognition should embrace a comprehensive understanding of their willful expression. In this way, it is mandatory that national private systems replace tools that permit substitute decision-making for the ones that recognize support for these individuals. In addition, it should consider that the support and the care they receive for willful manifestation is not a question that the capacity's legal systems should deal as a strict private matter. Furthermore, if legal amendment is not followed by the full moral consideration of care, dependence, vulnerability and support, those legal provisions will not result in a truly interdependent moral community in which care relations not only publically matter, but also are determinant for moral personhood and for the possession and exercise of fundamental rights

REFERENCES

Barbosa-Fohrmann, A. P. & Barreto, Gustavo (2017). "Are Human Beings with Extreme Mental Disabilities and Animals Comparable? An Account of Personality". In: Kurki, Visa A. J. et al (eds). *Legal Personhood: Animals, Artificial Intelligence and the Unborn*. Suíça: Springer, 2017.

Barri, Francisco José (2014). *El régimen jurídico internacional de la capacidad jurídica de las personas con discapacidad y sus relaciones con la regulación actual de los ordenamientos jurídicos internos*. Tesis doctoral. Universidad Carlos III de Madrid. Repositorio institucional e-Archivo.

Carlson, Licia (2009). "Philosophers of Intellectual Disability: A Taxonomy". Kittay, Eva & Carlson, Licia (eds). *Cognitive Disability and Its Challenge to Moral Philosophy*, United Kingdom: Wiley-Blackwell.

Cuenca, Patricia (2012). "Sobre la inclusión de la discapacidad en la teoría de los derechos humanos". *Revista de Estudios Políticos (nueva época)*. n. 158, Madrid, octubre-diciembre, 103-137.

Francis, Leslie P. (2009). "Understanding autonomy in light of intellectual disability". In: Brownlee, K. et al (eds). *Disability and Disadvantage*, New York: Oxford University Press, 200–215.

Kant, Immanuel (2015). *Fundamentação da Metafísica dos Costumes*, Tradução: Paulo Quintela. Lisboa: Edições 70, LDA.

Kittay, Eva (2009). "The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield". *Metaphilosophy*, Connecticut, v. 40, 606–627.

Kittay, Eva (2001). "When Caring Is Just and Justice Is Caring: Justice and Mental Retardation", *Public Culture* v. 13, n. 3, p. 557-579.

Kittay, Eva (2011). The Ethics of Care, Dependence, and Disability, *Ratio Juris*, v. 24, n. 1, p. 49-58.

Kittay, Eva (2005). "At the Margins of Moral Personhood". *Ethics*, v. 116, n. 1, Symposium on Disability (October 2005), 100-131.

MacIntyre, Alasdair (1999). *Dependent Rational Animals: Why Human Beings Need the Virtues?*, Carus Publishing Company, Chicago.

United Nations. General comment No. 1 (2014) on Article 12: Equal recognition before the law. CRPD/C/GC/1. Distr.: General. 19 May 2014.

Quante, Michael (2017). *Personal Identity as a Principle of Biomedical Ethics* (Philosophy and Medicine). v. 126. Switzerland: Springer.

Quante, Michael (2006). "Personal identity between survival and integrity". *Poiesis Prax*, Essen, v. 4, p. 145-161.

Quante, Michael (2011). "In defense of personal autonomy". In: *J Med Ethics*, v. 37, p. 597-600.