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A BRIEF OVERVIEW OF THE PERCEPTION OF DISABILITY

ABSTRACT: The paper briefly deals with the basic definitions of impairment and disability, expanding on the status of the disabled person, and on the perception of disability by able-bodied people, which stems from the lack of understanding of the life experiences of disabled persons in their world. The social and medical models of disability are briefly mentioned, as well as the course bioethics is (or should be) taking toward a stronger consciousness about disability. The status of the impaired body/ mind and of the disabled person in general is shown through examples applied to the concept of *homo sacer* (forced institutionalization, prenatal diagnostics, and both spatial and psychic states of exemption). At the end of the paper, a brief overview of the treatment of disabled or afflicted people in different epochs is offered.

KEY WORDS: disability, impairment, homo sacer, understanding

INTRODUCTION

We need a safe, familiar world where we function, prosper, and thrive, we try to keep troubles, sickness, abnormality, and calamity away. We need the longing for perfection, be it a nostalgic reactualisation of some golden precious time of a glorious beginning, or an expected peak of desired values, or eternal bliss in a heavenly kingdom, or projection of a glorious utopian dream of scientific ideals. We like perfection, for things to be neat, understandable, traceable; tasks feasible; abilities intact and improved; goals reached; progress made. And yet, one in five people has a disability/chronic illness of some type, shape, or form.

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions, which is why placing it in historical context proves to be challenging – the range of different disabilities is so vast, that historico-societal approaches to impairments are not only different because of their circumstances, but also because of the variety of the types of disabilities in question.

DEFINING AND PERCEIVING DISABILITY

Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or an action; while a participation restriction is a problem experienced by an individual during the involvement in life situations¹. Disability is a contested concept, with different meanings in different communities. Being widely versatile and multifaceted, the concept of disability may be used to refer to physical or mental attributes that some institutions, particularly medicine, view as needing to be fixed (as the basis and general framework for the medical model of disability). It may refer to limitations imposed on people by the expectations and constraints of an ableist society (and this constitutes the gist

¹ Disability is, therefore, not just a health problem, but a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which that person lives – this is the basic understanding as defined by the World Health Organisation (see more on https://www.who.int/topics/disabilities/en/).

of the approach to disability by the social model)². The International Classification of Functioning, Disability and Health (ICF), is WHO's framework for measuring health and disability at both individual and population levels, developed through a collaborative international approach towards a single generic instrument for assessing health status and disability across different cultures and settings. The ICF is structured around the following broad components: a disability is defined as a condition or function judged to be significantly impaired, relative to the usual standard of an individual or group. The term may refer to individual functioning, including physical, sensory, cognitive or intellectual impairment, mental illness, and various types of chronic disease. Disability is conceptualized as being a multidimensional experience for the person involved. This does justice to the experience of living with disability, which affects multiple aspects of the person's (quality of) life. Three dimensions of disability are recognized in the ICF: body structure and function (and impairment thereof), activity (and activity restrictions), and participation (and participation restrictions). The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. Functioning and disability are viewed as a complex interaction between the health condition of the individual and the contextual factors of the environment. The constellation produced by this combination of factors and dimensions is of "the person in the world", which is why it is of importance that these dimensions be treated as interactive and dynamic, rather than linear and static. Within some disability studies, disability can be viewed as a form of social oppression experienced by people with impairments. The "restrictions of activity" refer to the structural dimensions of disablism which are barriers affecting what people can do (for example, environmental restrictions which prevent people with impairments from physically accessing spaces, or logistical circumstances which prevent them from voicing their opinions or having access to those of others). The psycho-emotional dimensions of disablism are barriers that undermine people's psycho-emotional well-being, affecting not what they can do, but who they can be.

When Stephen Hawking died, some aspects of the perception of illness and disability were revealed, simply by the interpretation of the homages offered – various stages of him being "freed" by his wheelchair, finally well. He was not imprisoned by the wheelchair, many from the disabled communities explained, he needed it to move, and be somewhat independent (which is why "being bound by" or "confined to" or any other formulation depicting restraint by the wheelchair is not suitable, as they are used to help move and gain independence), and it is ableist ignorance to think he needed to be "freed". Hawking did all he did not despite the wheelchair, but thanks to it. The wish was kind, still, the able-bodied mourners wished not for him to

² The idea that individuals with physical, sensory or cognitive impairments all together form a subcategory of "the disabled" appeared in the twentieth century, replacing the previous classification in terms of physical, sensory or cognitive conditions. Silvers considers the medical model of disability to be the social model's foil, and on some accounts its antithesis (Silvers, 19). The medical model takes disability to be a problem which requires medical intervention, being the prerogative and the responsibility of medical professionals, while the social model understands disability as a political problem, calling for corrective action by citizen activists to transform the attitudes of people and reform the practices of society.

Scully underlines, however, that the strong social model is just not that interested in the subjective experience of the impaired person, or its psycho-emotional aspects, or the processes through which disability is constructed by cultural representations (Scully, 27). Scully (28-29) and Crow (210) see the social model as too amenable to the traditional Cartesian mind-body dichotomy, and think that it artificially splits the personal and the political apart, and fails to acknowledge that embodied perception disassociates the experiences of disabled people from those of the able-bodied. Silvers claims that this line of criticism does not discount the social dimension of disability, and, despite returning focus to some of the matters that, for the medical model are the essence of disability, should still not adopt the values that drive the medical model (Silvers, 20).

be freed from the wheelchair per se, but his illness/disability. And he was freed from it, in death. When people with disabilities are used for inspiration (Paralympics athletes, successful scientists, scholars, journalists, many kinds of professionals who are known and praised, but also random strangers who are seen by people who have absolutely no knowledge about them, other than the perceivable condition, as "fighters" or "heroes"), it is often the "overcoming of the situation" that is the point of marvel and congratulations³. But Hawking, and all these other people, have not overcome their illness/disability, nor should they; they live with it, and well. Disability is not a pesky task or an awkward situation that would have been overcome with alacrity, had that been at all possible, but a complex set of factors, characteristics and relations that do not go away, and largely comprise of who the person with the disability is. The perspective of the disabled "suffering" and "challenged" individual is not something an able-bodied/healthy person can have. An integrative approach should be able to shed light to different perspectives, to gather insights from them, and offer understanding and inclusion of the disabled, as well as ways to reach some level of Einfühlung for the able-bodied^₄.

THE STATUS OF THE DISABLED PERSON

Bioethics still seems to have a way to improve on these matters, also because disability has not been in the limelight of bioethics for a long time⁵. Disability has always been an excellent candidate for bioethical analysis, though, because of its versatile nature, different experiences, its pluri-perspecivity and the multidisciplinary approaches it combines.

However, while we wait for, and work on, bioethics to shine a light and help improve the perception and treatment of disability, another theory may apply to the disabled, due to the specific status of the impaired body and mind, and the

³ "There are people who think he's a hero because he lived with this degenerative motor neuron disability. Well, no. The alternative to that was dying", as put by C. K. Starkloff, co-founder of the Starkloff Disability Institute (Dastagir). Need not look further than the headlines announcing his death, or the way articles and obituaries recapitulated his life - his accomplishments were extraordinary for anyone (able-bodied or disabled), yet *Buzzfeed News* went with "Stephen Hawking, Astrophysicist With A Paralyzing Disease, Dies At 76" (Vergano); the first sentence in the obituary by *The Washington Post* was "Stephen W. Hawking, the British theoretical physicist who overcame a devastating neurological disease to probe the greatest mysteries of the cosmos and become a globally celebrated symbol of the power of the human mind, died March 14 at his home in Cambridge, England" (Achenbach and Rensberger), and the first sentence by the *CNN* obituary was "Stephen Hawking, the brilliant British theoretical physicist who overcame a debilitating disease to publish wildly popular books probing the mysteries of the universe, has died" (CNN Staff). See Destagir's piece for examples of anger by the members of the disabled community; see Palmer; Powell; Ejiofor on reactions from the disabled community about the reactions by the able-bodied community.

⁴ Comments like "you are disabled, but at least you do not have [insert a life-threatening disease]" are not empathetic (especially because it is not an exclusive disjunction, and only adds a sense of foreboding), nor are comments like "you are in a wheelchair/use crutches/use other aids for locomotion, but at least you have a [insert said aid]" (the fact that so many disabled people lack basic aids and facilities is not going to make the disabled person to whom this is addressed any happier); nor are the many variations of "but you look so good/are too young/beautiful/talented/ decent/hard-working etc." when enraged by the injustice of someone with these favorable attributes being, alas, also disabled.

⁵ Oullette uses "a shadow issue" to describe what disability has been for bioethics, but is, she remarks, no more. In the *Preface* of the collaborative effort aimed at the building of a bioethics fully aware of the essence and nuances of disability, she remarks that she used to rarely hear the phrase "disability perspective" in discussions of bioethics, but that now, disability is a part of the conversation: articles on disability from bioethicists appear, and conferences on disability in bioethics are being held. These transformations are only a basis for what she is hoping for, she writes, "… the movement toward a bioethics that incorporates disability as a central issue and engages disability experts in the enterprise", which takes more than just articles and conferences, but real work on the ground floor, in medical education, in the fields of law and in government, or anywhere that bioethics does its work (Oullette xiii). While Oullette insists throughout the book that bioethicists have a good reason to work with members of the disability community to resolve ongoing conflicts, she additionally systematically lists ways to achieve as much disability-consciousness among bioethicists as possible, in Oullette, 315-365.

status of the disabled person in a community largely comprising of able-bodied individuals. The problems of disability, namely, can be analyzed through the concept of a disabled person as a form of *homo sacer*, but also as a (profane, or non-ritual) form of a scapegoat.

A homo sacer is an obscure figure in ancient Roman law, it is a person outside the law, someone who can be killed without repercussion, but not be sacrificed in religious ritual. According to Agamben, it is someone whose entire existence is reduced to bare life stripped of every right. The one who has been banned from society is not simply set outside the law and made indifferent to it, but rather abandoned by it. The one who has been banned in which life and law, outside and inside, become indistinguishable" (Agamben, 28). This zone of indistinction represents a state of exception in which *homo sacer* is bare life, *zoē*, stripped of political rights and located outside the *polis*. According to Agamben, it is the act of abandonment which separates out those that are considered to be political beings (citizens, bios) from bare life (biological bodies, *zoē*). *Homo sacer* has biological life without political significance⁶.

If one considers the manner in which disabled people can end up being labelled as freaks or invalid by others, then it could be suggested that disabled people are placed in a psychic, not spatial, state of exception (Reeve, 211). In this article, Reeve lists examples situations where the disabled person seems to be treated as a *homo sacred* - the forced hospitalisation of people with mental/cognitive issues, the prenatal diagnostics leading to life/death decisions and the way strangers react to and interact with disabled people are good examples of the state of exception: forced hospitalisation when compared to interment camps, prenatal diagnostics

People will disabilities suffer tremendous violence, but without the "greater good" aspect of the ritual explation through scapegoats. According to two systematic reviews published in *The Lancet*, carried out by Liverpool John Moores University's Centre for Public Health, a WHO Collaborating Centre for Violence Prevention, and WHO's Department of Violence and Injury Prevention and Disability, both children and adults with disabilities are at much higher risk of violence than their non-disabled peers. These massive comparative studies show the scale of the problem, by providing evidence on violence against children and adults with disabilities, and by highlighting the lack of data on the topic from low-income and middle-income countries.

⁶ The act of abandonment splits the biological (*zoē*) and the social/political (bios) and provides the route by which biological life is included within the realm of power (Diken and Laustsen, 20). This leaves *homo sacer* as bare life, outside the *polis*, and like Girard's scapegoat "not protected by norms and rules, which apply to others, and being considered of no worth" (Diken and Laustsen, 21). While Diken and Laustsen are right about the scapegoat being unprotected by norms and rules, it differs from the *homo sacer* in the significance it garners through its explatory function. The scapegoat serves to purify the community from the built-up evil, violence and guilt, thereby attaining a status of a saviour, albeit it sometimes having no value at the beginning of the ritual scapegoating (on the scapegoat mechanisms and the mimetic theory of violence through scapegoating see Girard, *Violence et le sacré;* Girard, *Des choses cachées depuis la fondation du monde;* Girard, *Le bouc émissaire;* see Frazer for a list of examples, also Burkert for the theory of *homo necans*).

The review on the prevalence and risk of violence against children with disabilities, published in 2012, found that overall children with disabilities are almost four times more likely to experience violence than non-disabled children (Hughes et al). The systematic review on violence against adults with disabilities, also published in 2012, found that overall they are 1.5 times more likely to be victims of violence than those without a disability, while those with mental health conditions are at nearly four times the risk of experiencing violence (Jones et al).

The risk of violence toward people with disabilities is also connected to the lack of social support for their caregivers. This cannot be mitigated by simple placement of people with disabilities in institutions, because that increases their vulnerability to violence, especially because the ability to disclose abusive experiences by institutionalised people with communication impairments is hindered ("The Unacknowledged Crisis of Violence against Disabled People"). Research has suggested that an overwhelming 82% of violence against developmentally disabled adults is carried out in institutions, largely because institutions inherently promote the abuse and dehumanization of disabled people (Thornberry, C. and K. Olson). Sexual assault is one severe example, seven times more likely to happen to intellectually disabled people, and twelve times more likely to affect intellectually disabled women than non-disabled people (Shapiro). Most pervasively, disabled people are vulnerable to the people close to them. In contrast to non-disabled people, disabled people face a significantly higher percentage of violence from family members and well-known acquaintances ("Abuse of women with disabilities").

deciding on life/supposed quality of life of a disabled/sick foetus, the interaction including stares, uncomfortable awkwardness, even a well-mannered "are you better yet?"⁷. For example, it can be argued that the disabled foetus is in a state of exception - it could be considered to be *homo sacer*, both inside and outside the law. The non-disabled foetus has an expectation of a 'political life' whereas this is far less certain for the disabled foetus, who, by being labelled as disabled, becomes abjectified (Overboe 226). Prenatal diagnosis and the forced treatment of people with severe mental distress represent examples of the first part of the symmetrical relationship between the sovereign and *homo sacer*: "… the sovereign is the one with respect to whom all men are potentially *homines sacri*" (Agamben, 84). These are examples of structural disablism where decisions made by professionals or politicians (sovereign) result in the exclusion of people with impairments from mainstream life either through incarceration or *simply* by not brought into the world.

What is a disabled person – a useless reject, unable to contribute to society; a parasite, marring the picture of focused productivity; a liability, a burden, a monster? Or is he or she a person who is differently-abled, who offers a fresh perspective to problem solving, navigating situations, comprehending life? Is the disabled person punished by the gods, or redeemed through divine mission? Is it a reminder of everything everyone wishes away, or an inspiration, a vision of strength, endurance, perseverance and courage?

There is a long-lasting line of divine punishment, in the ancient world foretold by prophesies, set up by meddling deities, executed in a didactic-friendly fashion. As the concept of a divine plan migrates from a personal agenda (however fickle of random), to an incomprehensible, ineffable divinity, the cause of the punishment gets obscured. The middle ages abound with stories of demonic intervention, satanic interference, retributive justice due to consorting with such influences. Sometimes disability within religious belief is considered a form of temptation. Sometimes, there is no known reason for the affliction/disability.

A classic example of the first mentioned sub-archetype of disability is Philoctetes, the eponymous character from Sophocle's play. And while the play, the interplay of the characters and the perception of chronic pain and related handicap is still rather important today, to the extent that the *Theatre of War Project*, a theatre company performing for returned veterans started out as a series of public readings and discussions of the text of *Philoctetes* and spiked such interest, that panels, discussions and training sessions with caregivers, medical professionals, and disabled persons turned into actual training for medical students at medical faculties⁸, the initial and final situation of Philoctetes, in the context of causation, points us in another direction. Philoctetes was guilty of a transgression, having sinned precisely where he was told not to. His punishment is not the physical ailment, that is just the epiphenomenon, but rather the fact the he missed the opportunity to become a hero. Being unable to participate in battle renders a warrior) completely useless, for he no longer contributes to the *polis*. The fact that he is in pain is secondary to the fact that he does not contribute. An example of someone who needs not contribute is also quite

⁷ Reeve notes that while there are examples of Foucauldian approaches to disability theory and practice, there is a scarcity of examples where the work of Agamben has been applied to disability studies (Reeve 206). Overboe focuses on the "expressions of life" of disabled people as both marginalized and nullified through geneticism, and Sirnes compares Foucault's perspective on biopolitics with Agamben's, showing that the normality/deviance dichotomy is central to Foucault, while the sovereign/homo sacer dichotomy has a similar position in Agamben. ⁸ See https://theaterofwar.com/about and Marino for more information on the project.

famous. He is a god, though, Hephaestus, and the rules are different for gods. And yet, he is continually mocked by his pantheon, and is the only god who works. He has a workplace accommodating his handicap, so he can work his magic and produce. Hephaestus is a powerful magician with access to occult power precisely because of his deformity⁹.

But the point of integrating disability is to stop weighing its strains on society or debating the measure of a disabled man. In the classical period, in the Middle Ages, demonic abominations, monsters and freaks were not useful. Changelings, the malformed, terata were a burden to be discarded, a waste to be thrown away¹⁰. The Bible, the Midrash and the Talmudic writings share a lot on disability. A large number of disabilities, both physical and mental, are mentioned in the Bible, making part of both profane reality, and of the sacred one, from aspects of which they were excluded, for being unholy, unclean – a form of cultic impurity. The breakdown and the path to inclusion was Jesus' insistence on fellowship, and the theological implications for innocent and meek suffering¹¹. In the ancient period there is a division between the so called deformed, the terata, who were to be exposed, and the weak, who were to be taken care of (of course, this is a simplified one-phrase summary – but – the blind, deaf or feeble-minded were not considered deformed). In Egypt there was no discussion of sin and payment, but of being subject to magical, metaphysical drama of higher forces. From Zoticos to saint Fracis, a strong inclination toward charitable work among ugly laws and demons-induced panic persisted. There were houses of God that truly housed all kinds of people (except the dying and the contagious, which was a matter of rudimentary public health)¹². The talk of monsters and the abstract world of monstrosity sort of continued in the classical period. The enlightenment offered both charity and internment. Due to the enormous numbers of disabled First World War soldiers, rehabilitation emerged, followed by a better understanding of chronic illnesses.

CONCLUSION

While persons with disability make up a large portion of the world population, discussions on disability, and especially, a better understanding of the life experiences of persons with disability are needed, in order to overcome stigma and awkwardness, and build a disability-conscious world, where ableism does not put disabled people in positions of exception, but rather where it is clearly understood that being disabled means much more than being "challenged" or "different", and that the often recited inspirational formulations of "overcoming disability" should really be transformed into "overcoming the misunderstandings about disability".

⁹ A variety of theories have been proposed to account for the god's lameness. One is that it is a consequence of his status as a "magician" in accordance with the principle whereby a special defect is redeemed or compensated for by a special gift or talent (Garland, 61). In his underground volcanic workshop whether on Lemnos, or later on Mt. Etna, Hephaestus is often surrounded by an assembly of disabled figures. The archetypal workplace is imagined as accommodating his crew of oddly-shaped assistants. He is aided in his work by a race of mythical smiths who are set apart by some physical defect, he is included, constantly challenged, adapted, useful (see Ebenstein).

¹⁰ For the Greek practice of exposure, see the discussion in Rose, 29-49, driven through the motifs from story of Oedipus.

¹¹ An extensive research in Stiker for the treatment of disability in the (world of the) Bible, see 23-38; the concepts in Western antiquity, see 39-64; the systems of charity in place, see 65-90; the development, or rather, decline of understanding and treatment of disability during the classical centuries, see 91-120; and for the emergence of rehabilitation post-World War I, see 121-190.

¹² On medieval concepts of the impaired body see Metzler 38-64.

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