

Phenomenology and Physical Disability: for a Non-normate Body Policy

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Fenomenologia e disabilità fisica: per una politica del corpo non-normato

Gaining disability among the areas of phenomenological reflection is urgent political action. The aim of this article is twofold: contributing to the debate about physical disability, from a particular starting point (i.e. the meanings of the real experience) and revealing the structures that socially inform the bodies in their relationships with others. Experiencing physical disability means living a compromised body. The compromised lived-body reorganizes, in fact, the experience of space, time, relationship with the self and with the others, the knowledge of the world and endures an inequitable and ableistic socio-cultural organization. In this context, the concept of disappearance is discussed. The compromised body disappears before a norm produced by the able bodies and is excluded from the shared project of a world-together-with-others. In this sense, the phenomenological reflection could rethink and support the social participation of people with a physical disability.

Guadagnare la disabilità tra gli ambiti di riflessione della fenomenologia è un'azione politica urgente. Con questo contributo, si vuole concorrere al dibattito intorno alla disabilità fisica, partendo dai significati dell'esperienza concreta e disvelandone le strutture che socialmente informano questi corpi nelle loro relazioni con gli altri. Vivere la disabilità fisica significa vivere un corpo compromesso che riordina l'esperienza propriocettiva di spazio, tempo, relazione con il sé e con gli altri, definisce la conoscenza del mondo e subisce una ingiusta e abilistica organizzazione sociale e culturale. In questo ambito, si introduce il concetto di dis-apparenza: il corpo compromesso dis-appare di fronte a norme prodotte dai corpi abili ed è escluso dal progetto condiviso di un mondo-insieme-con-gli-altri. La riflessione fenomenologica appare, in questo senso, in grado di ripensare e sostenere la partecipazione sociale delle persone con disabilità fisica.

Keywords: Phenomenology; Disability; Physical Disability; Non-Normate Body; Dis-Appearance.

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1. Introduction

Socrates: Then is life worth living with a wretched and corrupt body?

Crito: Not at all.

(Plato, *Crito*)

In order to understand how phenomenology may contribute to the debate about disability, it is of primary importance to define and understand the social impact and consequences of a construct called ableism (Smith, Foley & Chaney, 2008; Campbell, 2009). By ableism, we mean the set of practices and attitudes which devalue and limit the potential of people with disabilities (Kattari, Olzman, & Hanna, 2018). Ableism is a form of discriminatory thinking characterized by the belief that people with disabilities are defective, “need to be repaired” or cannot function like the other members of the society (Castañeda & Peters, 2000). Ableism goes along with disablism, an operative paradigm, conscious or unconscious, which promotes differential and unequal, sometimes unfair and unethical, treatment of people with (real or presumed) disabilities. The term “disability” in everyday use refers to characteristics of the “whole” identity of the people defined as disabled. In this context, disability is a metonymy as it replaces the indication of a precise and particular disadvantage with the whole person’s deficit. Besides, the term “body” here is used almost exclusively in its meaning of bearer of a handicap (Paterson and Hughes, 1999).

People who do not have a disability, who have not experienced a temporary one or who have never been close with individuals with disabilities, may not understand to what extent the social world is built around able people, how ableism and disablism affect everyone’s daily life. Turner (1992) defines ours, a “somatic society”: while the images of bodies have pervaded public and media space (beautiful bodies, healthy bodies, able bodies mostly), one’s body is the field political and cultural activity. The dominant social norms and interpersonal practices lead to exclude the bodies of people with disabilities from the mainstream of contemporary society or relegating them to “special” areas and places (Paterson & Hughes, 1999).

In this context, gaining disability among the topics of phenomenological attention is urgent and politically necessary action. The relationship between pedagogy and phenomenology is not only of a social and philosophical nature but defines possible future change (Bertolini, 2003). The application of this type of reasoning is an educational and, at the same time, political activity capable of unravelling the prejudiced thinking about the disability-related phenomena and fully understanding their structures (see Lascioli, 2011). Moreover, according to Reynolds (2017a; 2017b), too long disability has been omitted from this philosophical tradition, due to the ableistic conflation of disability with pain, suffering and disadvantage. According to this author, the conflation consists of the following:

1. disability is a lack or deprivation;
2. deprivation of potential goods is damage;
3. the damage causes or is a form of pain and suffering.
4. given points 1, 2 and 3, the disability is coextensive with (in the weak version) or causes (in the strong version) pain and suffering.

Merging disability with lack and deprivation means jeopardizing a phenomenology of disability (Martiny, 2015), levelling it with the rhetorical paternalism of the norm-gifted subjects. If the gnoseological starting point is experience and, particularly, the body (Merleau-Ponty, 2005; Toombs, 1995; Paterson & Hughes, 1999), the ableistic conflation appears to be wrong and far-fetched. This view turns out to be not only in stark contrast to the liberal and historicist conceptions of disability (Hughes & Paterson, 1997; Abrams, 2016) but also a criticism of an abstract and not anchored to the world-of-life (*Lebenswelt*) phenomenological enquiry. Moreover, as claimed by Lascioli (2016), disabilities refer much more to people’s biographies than to their biologies. The reasons on which disabilities depend on, beyond the limits imposed by specific health conditions, include people’s life stories, their specific ways of functioning in real life contexts, when obstacles or barriers are present, or skills are not sufficiently supported.

2. The compromised lived body

Each body is more than a set of anatomical and physical structures: just as it is impossible to grasp the sense of a gesture starting from the sum of muscle movements, it is not possible to appreciate the existential scope of the ‘being-body’ by analysing the sum of functions and abilities (Merleau-Ponty, 2005) exclusively. The body is a unity of meaning, an active producer of meaning in contexts (Reynolds, 2017b). This statement is in profound contrast with the so-called “Cartesian” approach, that is, with strictly materialistic interpretations of disability that ignore the crucial aspects of embodied existence. The models of empirical and medical thought reduce the body to its objective status and disability to the body’s damage (Abrams, 2016). The ontological implications of the “body as fact” are tragic: the experiences of the body (*Leib*) are eliminated, and only the symptoms of the body exist (*Körper*) (Bendelow & Williams, 1995). This trend entails the danger of objectification of the body as a thing without intentionality and intersubjectivity (Csordas, 1994; Wehrle, 2019) and makes us miss “the opportunity to add sentience and sensibility to our notions of self and person, and to insert an added dimension of materiality to our notions of culture and history” (Csordas, 1994, p. 4). The body has its primacy (Merleau-Ponty, 2005; Wehrle, 2019), as through it, people have access to the world (Lyon & Barbalet, 1994). Our perception of everyday reality depends on a “lived body” (Bendelow & Williams, 1995; Iori, 2006), that is, a body that simultaneously experiences and signifies the world (Merleau-Ponty, 2005).

The story of Professor Toombs opens to a vivid understanding of what means disability (in this case, an acquired one) for the lived body. The Toombs’ interest in the phenomenology of disability (1995) started from experiencing the disease-related consequences: she was diagnosed with multiple sclerosis at the age of 30. Multiple sclerosis is a disease that progressively disables the central nervous system, erodes typical functionings, sometimes temporarily, sometimes definitively. She declares:

As an embodied subject, I do not experience my body primarily as an object among other objects of the world. Rather than being an object for me-as subject, my body as I live it represents my particular point of view on the world. I am embodied not in the sense that I have a body — as I have an automobile, a house, or a pet — but in the sense that I exist or live my body (Toombs, 1992). In this respect the lived body is not the objective, physiological body that can be seen by others (or examined by means of various medical technologies) but, rather, the body that is the vehicle for seeing. Furthermore, the lived body is the basic scheme of orientation, the center of one’s system of coordinates. I experience myself as the Here over against which everything else is There. As orientational locus in the world, my body both orients me to the world around by means of my senses and positions the world in accord with my bodily placement and actions (Toombs, 1995, pp. 10–11).

The body guides people in the world, through the senses, and makes it the centre of the existential possibilities: in fact, objects present themselves as invitations to actions. Moreover, the spaces are not only neutral but rather mark the range of possible intentions and feasible activities. Toombs (1995) explains this concept by analysing how her body thematized the “restrictive potentiality” of space while losing mobility due to the disease: reaching a place, for example, by experiencing motor disorders, generates a profound disturbance in the lived body. If for the able people, moving opens the space to the body, not so for those with a disability.

Permanent loss of function represents a modification of the existential possibilities inherent in the lived body. The lived body manifests one’s being-in-the-world not only as orientational and intentional locus but in the sense that distinct bodily patterns (walking, talking, gesturing) express a unique corporeal style, a certain bodily bearing that identifies the lived body as peculiarly me. Motor disorders transform corporeal style. New patterns of movement are experienced as unfamiliar, unrecognizable. (Toombs, 1995, p. 16)

For people with physical disabilities, common objects may become incredibly resistant (Toombs, 1995; Wehrle, 2019). In the case of acquired physical disability, as body functionings change, it is necessary to develop novel or alternative ways of interacting with objects. In this sense, the participation in the world is tiring and may generate a sense of exhaustion which Toombs calls “existential fatigue”

(Toombs, 1995). Implementing (personal, professional, social) purposes requires not only physical abilities but, above all, an exercise of will. When a constant effort is needed to perform the simplest tasks (getting out of bed, getting dressed, taking a shower, taking a trip), there is a strong urge to withdraw, to cease doing what is required. Consequently, physical disability exerts a centripetal force towards social isolation: the person with disabilities is strongly tempted to reduce commitments in and for the world. Toombs (1995) claimed to have reached this awareness:

whenever I attend stand-up gatherings such as receptions. In my wheelchair I am approximately three and a half feet tall and the conversation takes place above my head. When speaking to a standing person, I must look up at them and they down to me. This gives me the ridiculous sense of being a child again surrounded by very tall adults (Toombs, 1995, p. 17).

In a culture that certainly does not contemplate the physical difference and dependence of people but, on the contrary, applauds normality and autonomy, according to Toombs (1995), the shame (Sartre, 2014) of not being “normate” like the others (Goffman, 1963; Murphy 1987; Toombs, 1995; Wehrle, 2018) emerges. A further autobiographical example of another phenomenologist is in Paterson and Hughes (1999). One of the articles’ authors has cerebral palsy. He tells:

A delivery person arrived with a package and said (when I opened the door) ‘Oh, is your mum not in.’ She obviously thought that I wasn’t a ‘responsible adult’ and, therefore, not eligible to participate in the partnership required to complete her task. It is highly unlikely that she would have arrived at such a conclusion had I been a non-disabled person in their late twenties (Paterson & Hughes, 1999, p. 606).

This shame connotes the existence of non-normate bodies, not only in terms of lived space and identity but also as regards the individual relationship with time (Toombs, 1990; 1995; Wehrle, 2019). As the objects of the world are materials for the personal identity purposes and space is an invitation to actions and a *movement towards*, so time is made of promises (de Warren, 2017) as it is typically experienced as a “gearing towards the future” (Toombs, 1995, p. 19). We usually act in the present in light of anticipations of what will come, with objectives relating to future possibilities. Those who live in a compromised body experience an interruption of time-future.

[...] temporal experiencing changes in the sense that the sheer physical demands of impaired embodiment ground one in the present moment, requiring a disproportionate attention to the *here* and *now*. One is forced to concentrate on the present moment and the present activity rather than focusing on the next moment. Mundane tasks take much longer than they did prior to the change in abilities. For instance, when habitual movements are disrupted, the most ordinary activities such as getting out of bed, rising from a chair, getting in and out of the shower, knotting a tie, undoing a button, demand unusual exertion, intense concentration, and an untoward amount of time. (Think, for example, of the difference between the time and effort required to tie one’s shoelaces using one, as opposed to both, hands — especially if one is right-handed and only able to use the left hand to perform the task.) In this respect persons with disabilities find themselves “out of synch” with those whose physical capacities have not changed. This temporal disparity is not insignificant in terms of relations with others (Toombs, 1995, pp. 19–20).

This change in the relationship with the time-future influences the ways of giving meaning to one’s identity: in particular, the sense of what is possible in one’s life changes (Toombs, 1995).

3. Intersubjectivity for non-normate bodies

According to a phenomenological approach, therefore, the loss of mobility changes one’s experience of space, alters the taken-for-granted awareness of (and interaction with) objects, compromises body identity, influences relationships with others and generates a change in experiencing time. In this context,

phenomenological studies underline a second aspect of the embodied dimension of disability: social influence (Hughes & Paterson, 1997; Paterson & Hughes 1999; Turner 1992). Merleau-Ponty (2005) argues that consciousness can never be objectified as an ill or disable one. So if the person with disabilities complains or is aware of her/his disability, this is possible only through comparison with others (with the world of the able persons, with their spatial, bodily and cultural norms), or when they adopt a statistical-objective vision of themselves (Reynolds, 2017b). Abrams (2016), conducting a critical and interdisciplinary project around disability, called “disabled phenomenology,” defines the person with a disability as “organized” from a cultural point of view: a structural intercorporeity inscribed the body (Martiny, 2015).

The majority of the available literature on disability addresses the body within an interactionist perspective. Such an approach does not offer phenomenologically-oriented descriptions of the discrimination experienced by disabled bodies compared to the able ones (Abberley, 1987; Paterson & Hughes, 1999). Phenomenological research should address, in this context, how society structurally disables people with disabilities rather than studying the effects of social action on individuals since there is a risk of representing the compromised body as a passive recipient of social forces (Abberley, 1987). According to Turner (2001) and Abrams (2016), the bio-psycho-social model itself, promoted by the World Health Organization (WHO, 2001), would involve the distinctions between biological/social, impairment/disability, body/society, medicine/politics, theory/emancipation, pain/oppression, typical of a neo-Cartesian thought (Abrams, 2016). If the dichotomies are useful for didactic and communicative reasons, using them as a decisional, ethical, educational and political basis, risks misleading the recognition of the real experience of compromised bodies (Martiny, 2015).

In “*Disability studies and phenomenology. The carnal politics of everyday life*” Paterson and Hughes (1999) emphasize that the body is agency and activity. This perspective is the phenomenological basis for understanding, beyond all interactionism, the structure of social disabling (and oppression) of compromised bodies. It is in the links of the impossibility of being protagonists of the self in the social world that Paterson and Hughes (1999) foresee forms of bodily, carnal oppression (Abrams, 2016).

Accordingly, Leder’s concept of “body dys-appearance” (1990) is quite explicative. It refers not only to the non-appearance or disappearance of the body but also the impossibility of the bodily appearing for structural reasons (Leder, 1990). Leder claims that the body disappears behind any daily routine. Paterson and Hughes, applying this concept to the daily life of bodies with disabilities, reflect how, within the interplay with able bodies, they are physically present and absent at the same time (Kattari, Olzman, & Hanna, 2018). For example, concerning norms of communication, which are socially defined by the able bodies, people with language impairment tend to avoid participation in all those daily interactions of the *Lebenswelt*: the body with disability disappears, both in functional and aesthetic terms (Paterson & Hughes, 1999). In Paterson and Hughes (1999), an episode (one of the two authors, as mentioned, due to cerebral palsy experiences a language disability) is reported in the first person concerning a rather ordinary communicative practice.

The following story is a good example of how carnally informed orders of time work to exclude me from opportunities to communicate. I was in a lift with a stranger when she began asking questions about university. It was an impossible situation because I realised that I would have no time to speak before one of us would reach our destination and have to exit the lift. The opportunity to communicate was constrained not only by the traveling time of the lift, but because the duration norm of this particular communication was not commensurate with my carnal needs. I did not enter the conversation because it would be cut short or result in one or both of us missing our floor, or worse still, the communication may have ended in the ignominious situation in which the doors have to be kept open by manual means, thus eliciting the petulant disapproval of other users for whom the lift is a vehicle which operates within a very strict and mechanical time-frame. Such outcomes would stray outside the conventions of communication and so I am policed by these conventions into an unsatisfactory interaction. My options are reduced to a smile or a nod of the head, and I am ‘reminded’ of my body (Paterson & Hughes, 1999, p. 606).

Disability as dis-appearance, therefore, is not an intracorporeal phenomenon, but an inter-corporeal

one, as it is related to forms of relationship with others. This “out-of-the-norm” existence leads to self-representation as presence-as-alien-being-in-the-world (Paterson & Hughes, 1999). The compromised body disappears in the context of intercorporeity and intersubjectivity because it is not recognized as an active agent within the physical, cultural and social world (Kattari, Olzman, & Hanna, 2018; Wehrle, 2017).

From a phenomenological point of view, the world is embodied because it is our purposes and “projects” that make the world what it is (Hughes & Paterson, 1997; Paterson & Hughes, 1999). Every person who is excluded and cannot make a contribution to the creation of the social world cannot find a meaningful place in it. The first social oppression is, therefore, the exclusion from the shared project of a world-together-with-others. Here the compromised body “disappears” (Leder, 1990) because able bodies dominate the information that animates the world (Paterson & Hughes, 1999). As in the experience of Toombs (1995), a person with a motor disability encounters disabling obstacles because the material data of non-able bodies have not been taken into account in materially creating the world. “Exclusion is everywhere, and each time it is experienced, it is experienced in the form of carnal self-recognition or ‘dys-appearance’” (Paterson & Hughes, 1999, p. 604, t.d.a.). The events told previously show that there are, therefore, implicit structural rules emerging from inter-corporeal interactions as a product of the embodied needs of able people.

These daily “codes of conduct” (Paterson & Hughes, 1999), while favouring the existential project of able bodies, open the field to the oppression for people with disabilities. As discussed above, the compromised body perceives and knows time and space in a different way and objects become particularly resistant to personal projects. Moreover, oppression and prejudice are embodied in relationships with others and become part of the daily life experience. According to Paterson and Hughes (1999), oppression is not to be understood as an abstract structure. It is sensed by the flesh, whenever the body “disappears.”

In their autobiographical accounts, Toombs (1995), Paterson and Hughes (1999) reveal an essential element of the intersubjective experience of disability: the daily reality of condescension which is part of the social “dys-appearance” structure. Because the compromised body is considered dependent and perceived as having deficit and diversity, people with physical disabilities are often excluded from social responsibilities: “they are a palpable denial of ‘social competence’ based on a knee-jerk aesthetic judgement” (Paterson & Hughes, 1999, p. 606). This judgement relies on reactions to the compromised, non-normate body. In particular, condescension results in perceiving compromised bodies such as those of eternal children. This form of prejudice, one of the most common among others that can be highlighted (Lascioli, 2016), impacts the educational relationship, as it depends on the intention of the educator.

As ethical beliefs have become frequently aestheticized in the postmodern world (Maffesoli, 1996) ‘the tyrannies of perfection’ (Paterson & Hughes, 1999, p. 607) play a central role in shaping intercorporeal encounters. Besides, social competence is conferred on those bodies that have a performance according to standard rules. Social competence of people with disabilities disappears not only because their body is compromised but also because the norms that declare a socially competent person are defined on the basis of what able bodies can do.

Limiting the exclusion of people with disabilities from sociality involves rethinking their participation in the *Lebenswelt*. Expecting that people with disabilities normalize to the standard means excluding their possible contribution to society and making the *Lebenswelt* increasingly alien to them. Phenomenology seeks, in this context, to problematize these “normed” dynamics (Wehrle, 2018) which provide the base for the ableistic prejudices (Kattari, Olzman, & Hanna, 2018). It is crucial to reverse the hegemony of normate bodies by raising awareness about disability issues. Consequently, alternative ways of thinking about non-normate bodies may make information to create a shared world emerge (Davis, 1995).

4. Concluding remarks

This article shows how disability shapes the bodily experience (space, time, relationship with the self, with others and with things) and the compromised and non-normate body should be considered the

intentional locus from which to start a phenomenological understanding of disability. Disability is not a problem of medicine and rehabilitation exclusively. It is an identity issue and consequently, an educational and political problem (Paterson & Hughes, 1999). According to Leder (1990), the environment produces a vivid, but unwanted, awareness of one's compromised body. The body undergoes "disappearance" which is not biological but social and political. According to Paterson and Hughes (1999), when prejudices are encountered in the behaviour or attitudes of others, the compromised body "disappears," just as it disappears in the face of embodied (and socially produced) norms for able bodies. The exclusion and interruption of communication, in the case shown, are therefore not referable to the inability (or deficit) of a person with disabilities but should be credited to the norms of "normal" communication, which are a priori hostile to non-normate forms of physicality. Just as, compared to the changed character of motor skills of Toombs (1995), it is essential to recognize that those people who "negotiate" space in a wheelchair live in a world that is designed for those who can stand (Toombs, 1995). These forms of lived body are therefore doubly compromised: compromised because they are not-normate and compromised because they disappear.

Phenomenology brings out oppression and disadvantage as "ostracism from opportunities to participate in the everyday, mundane, sensate minutiae of the lifeworld" (Paterson & Hughes, 1999, p. 605) and questions how the body is socially ordered in the "somatic society" (Turner, 1992). Mind and body are not valid categories for describing the matter of embodied human existence (Abrams, 2016). Making reflection on disability dependent on these Cartesian categories ignores the fact that somatic society has eliminated the modernist separation of the body from politics. The body is not a passive component in politics but the place of exclusion, and therefore of factual oppression (Paterson & Hughes, 1999). Supporting the desire to be active citizens of people with physical disabilities means creating a world in which their bodies do not "disappear."

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