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IL PROGETTO SUL CORPO DELLE PERSONE IN CONDIZIONE DI DISABILITÀ FISICA TRA IDENTITÀ, EMBODIMENT SESSUALE E SPORT

PROJECT ON THE BODY OF PEOPLE WITH PHYSICAL DISABILITIES BETWEEN IDENTITY, SEXUAL EMBODIMENT AND SPORT

Valentina Paola Cesarano
Università degli Studi di Napoli Federico II
University of Naples Federico II

Antonio Ascione
Università degli Studi di Bari “Aldo Moro”
University of Bari “Aldo Moro”

Abstract[1]

If the sexuality of disabled people, in its complexity of embodiment, is considered a cultural taboo, a mere physiological problem in medicine, and has not been the subject of much attention from the social sciences, it should be noted that even the disability policies themselves have only recently begun to recognize their myopia with respect to sexuality. The concept of sexual citizenship has offered a promising way forward, aiming to relate the sexual self and the social self, thus framing sexuality in a perspective that integrates desires and rights, intimacy and civil recognition, sexual bodies and legislative bodies. A further focus on the corporeity/disability binomial can be found by deepening the educational value of sports practice for the disabled person, and the social and cultural phenomenon of the Paralympic Games. The pedagogical-special field, is actually increasingly expanding today - in line with the recent “UN Convention on the Rights of Persons with Disabilities” - to the problems that emerge in relation to work integration, the right to leisure and recreation, and basically to the search for an adult identity for the disabled person. Accordingly, it is in this broadened horizon of perspective of the Special Pedagogy studies that we can integrate and investigate the formative value of the corporeal dimension, the educational and social value of sport for the disabled people.

Se la sessualità delle persone in condizione di disabilità, nella sua complessità in termini di embodiment, è considerata un tabù culturale, un mero problema fisiologico in medicina, e non è stata oggetto di molta attenzione da parte delle scienze sociali, va notato che anche le stesse politiche sulla disabilità hanno iniziato solo di recente a riconoscere la loro miopia rispetto a tale questione. Il concetto di cittadinanza sessuale ha offerto una strada promettente, mirando a mettere in relazione il sé sessuale e il sé sociale, inquadrando così la sessualità in una prospettiva che integra desideri e diritti, intimità e riconoscimento civile, corpi sessuali e corpi legislativi. Un ulteriore focus sul binomio corporeità / disabilità può essere trovato approfondendo il valore educativo della pratica sportiva per la persona in condizione di disabilità, e il fenomeno sociale e culturale dei Giochi Paralimpici. Il campo della Pedagogia Speciale che tradizionalmente ha indagato principalmente bambini in età scolare e disabili, si sta attualmente orientando sempre più - in linea con la recente “Convenzione ONU sui diritti delle persone con disabilità” – verso i problemi che emergono in relazione all’inserimento lavorativo, il diritto allo svago e fondamentalmente alla ricerca di un’identità adulta per la persona disabile. Di conseguenza, è in questo orizzonte allargato di prospettiva degli studi nell’ ambito della Pedagogia Speciale che possiamo integrare e indagare il valore formativo della dimensione corporea, il valore educativo e sociale dello sport per le persone in condizione di disabilità.

Keywords

body, physical disability, identity, embodiment, sport

corpo, disabilità fisica, identità, embodiment, sport

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[1] Il presente contributo è stato congiuntamente progettato dagli autori. Tuttavia, al fine di distinguere l’attribuzione dei singoli paragrafi a Valentina Paola Cesarano sono attribuiti i paragrafi 2, 4 e 5 e a Antonio Ascione i paragrafi 1 e 3

1. Are the bodies of disabled people regarded as worthless?

Seeing disability as an embodied identity allows us to see the body as a localized agent in a socio-cultural framework; the body is disciplined and shaped, but at the same time it is a meaning-producer within a network of powers. Sexuality is then a privileged crossroads as it represents one of the social places where the body becomes the main actor (Plummer 1995). As Foucault (2008) recalled, the body is generally taken for granted as the "zero point" of the world; objects, relationships, desires and power surround it, and it is therefore always "elsewhere", always overshadowed by the relationships of which it represents the center. On the contrary, according to Foucault, sexuality (together with mirror and death) is that place where the body is aware of itself, beyond utopia, and is finally "here" (Foucault 2008). Due to the social perception of impairment, disabled people are considered deviant from bodily normative standards. These standards concern both the morphology of the body and the combination of its functions, and represent a bodily capital indispensable for entering the world of sexuality and for gaining gender identity. The disabled body holds this capital to a limited extent, due to a social process of de-sexualization. If sexuality is socially constructed, the barriers that hinder access to sexuality are also a consequence of the social perception of bodies, and not of the bodies in and of themselves. Both sexuality and disability have long been immune to a sociological investigation that could identify this social perception of disabled bodies as bodies that - in the sexual sphere - do not matter. On the one hand, there is a firm belief that the origin of disability is the body, and - on the other - as Steve Seidman (1996: 2) noted: "Sexuality is perhaps the last human dimension that many of us refuse to grant is socially created, historically variable, and therefore deeply political". In our reflection, however, both disability and sexuality are seen as two social constructions. The body is not a neutral instrument at the complete disposal of the almighty will of the subject who " lives" in it, and sexuality is not a sphere of action regulated exclusively by the free desire of the subjects who practice it.

2. Sexual embodiment in physical disabilities

The way in which sexuality, as a positive power, materializes the bodies acts differently depending on the morphology on which it operates; gender difference is a material diversity that has been widely discussed, while the morphological diversity of disabled bodies, and the consequent construction of the non-disabled/disabled combination is a figure that most often remains in the background, in a non-problematic way. The denial of the sexuality of the disabled is considered almost a natural fact, while its attempted recognition generates confusion, disgust, and disapproval. Margrit Shildrick (2004) indicated some of the tensions raised by the attempt to conceive disability and sexuality together. These tensions and discursive resistances are deeply rooted as they affect not only the idea of sexuality as behavior or activity, but also the concept of "normal" subject, of autonomy, control, identity, in short terms the parameters for defining the human being. The disabled body is structured as insufficient, missing of something, unfinished, and therefore unsuitable to play the role of the object of desire. The disabled body evokes an idea of dependence and vulnerability bringing it closer to the child, and in fact, the sexuality of the disabled is denied even through mechanisms of infantilization. These mechanisms weigh more on young people with disabilities, who are usually more dependent on their families. Care work regulates the bodies. Docile bodies are more easily disciplined, and docility here also means de-sexualization. In most cases, de-sexualization affects the potential of the body, the construction of actions that it is lawful or illicit to embody. But in the case of the "Ashley Treatment", a controversial therapeutic intervention attempted for the first time on a young American disabled girl, de-sexualization was achieved by a series of surgical interventions, thus acting directly on the material body. Ashley is a child with a serious congenital and irreversible brain pathology; if not assisted, she is unable to move independently, manipulate objects, speak or eat. Although reacting to external stimuli, she is unable to process communication in linguistic terms since her cognitive age has been declared comparable to that of a three-month-old infant. At the age of six and a half she began to enter puberty, and her parents decided to adopt a series of interventions that should have improved Ashley's quality of life, especially in anticipation of the future. The baby's uterus and breast were removed and she underwent hormone therapy that stopped her growth; it is estimated that her growth in terms of weight was attenuated by 20%, and in terms of height by 40%. The motivations that led Ashley's parents to subject their daughter to this treatment are above all of practical nature; a small and light body is easier to move and, together with the absence of the breast, reduces the risk of bedsores in a patient with no mobility at all. The removal of the uterus eliminates the side effects of the hormonal treatment, as well as the problem of managing the menstrual cycle and the possible pain associated with it. Having uterus and breasts - according to her parents - would be a pointless burden because, in any case, Ashley will never have children and will never be breast-feeding. The "Ashley Treatment" is presented not only as an extraordinary measure, but also as a possible treatment protocol, and has been strongly criticized on many fronts, especially in the area of disabled activism. It has been stated that this treatment has the advantage of bringing the cognitive self closer to the bodily self. But who does the possible inconsistency cause discomfort to? These measures were taken so that parents could continue to take care of their daughter at home, without having her assisted in a facility, an accommodation considered unhappy and indignant. The activists pointed out that if the child does not have a sense of dignity, then she would never suffer in living in a special facility or in receiving care from people other than her parents. The fact that preventing a child from becoming a woman has to do with sexuality and not just with the routine of body care is still admitted by the child's parents themselves; in this way, as they argue, Ashley will be less vulnerable to sexual abuse by those who will take care of her when her parents are gone. Scholars (particularly Fine and Asch 1986) have shown that, in many cases, the so-called measures to prevent sexual abuse of disabled girls and women (such as sterilization) can be equally effective in hiding the signs left by the abuse itself, especially when signs of discomfort that eventually emerge are interpreted as a consequence of disability and not as a possible abuse. More generally, the criticisms and concerns addressed to this treatment have underlined the danger of re-proposing a medical/individualist model of disability that conceives the disabled person as an individual to be fixed, manipulated, adjusted to the needs of society and the non-disabled individuals that surround him/her, and have instead reiterated the need to think about responses to disability that involve everyone, and society in general, in a transformative way; this because disability is an issue that concerns not only disabled individuals, and therefore cannot be solved only by their normalization, segregation, and neutralization.

3. Sexuality, body control and subject unity.

Medicalization is a particularly radical and invasive form of control - especially when exercised directly by medical institutions as in Ashley's case - but in general, sexuality is always highly regulated by forces of society as it represents a risky ground for the autonomy of the subject; in sexuality, bodies relate to each other, modify each other, penetrate each other, produce and exchange bodily fluids, the boundaries that delimit them become thinner, and substantially, they lose control. The idea of the Western subject is based instead on a series of dualisms - body, machine man, self - which a disabled body puts in crisis and that are also threatened by sexuality; here is the operational link between the regulation of sexuality and the de-sexualization of the disabled subject. Both are mechanisms that monitor the boundaries of the subject, and protect him/her from the danger of disintegration, loss of control, autonomy and differentiation; a danger that both disability and sexuality evoke. The lack of control over one's own body and its functions, in some disabilities, can be a constant embodied experience (for example, in cases of spasticity, incontinence, and so on) that, during a sexual activity with another person, becomes even more difficult to manage. Shakespeare and Watson (1995) noted that these conditions often lead people with disabilities to dissociate themselves from their bodies, making them a problematic object from which to distance themselves or an object which others take care of, thus losing actually the sovereignty over their embodiment. Similarly, Shildrick noted that the sexuality of the disabled subject throws in crisis a characteristic considered essential within the sexual sphere, namely the management of instability and fragility of the body. The attempt to limit instability - i.e. the control of one's own body - and to deny fragility - through a performance of strength and autonomy - are difficult mechanisms to support when the body is disabled, which is thus built as a symbolic place of instability and fragility, and therefore unsuitable for a sexual action.

4. Sexual citizenship

If the sexuality of disabled people, in its complexity of embodiment, is considered a cultural taboo, a mere physiological problem in medicine, and has not been the subject of much attention from the social sciences, it should be noted that even the disability policies themselves have only recently begun to recognize their myopia with respect to sexuality. Since disabled activism has become detached from medical paternalism, the sphere of intervention of the policies has been linked to the society by the individual; due to the fact that it is wrongly believed that sexuality is an individual and private dimension, rather than a cultural and social one, the political campaigns of disabled people have been fought for work, education, accessibility of transport, and in general for those civil rights that are exercised in the public sphere. In order to pay attention to these expressions of discomfort, more recently, disability studies have proposed (Shakespeare & Watson, 1995) to analyze the sexuality of disabled people in its social dimension; in order not to restore the area of sexuality to medicine, or to the private conscience of individuals (both individualistic perspectives), the concept of sexual citizenship has offered a promising way forward, aiming to relate the sexual self and the social self, thus framing sexuality in a perspective that integrates desires and rights, intimacy and civil recognition, sexual bodies and legislative bodies.

Intuitively, the sexual citizenship of the disabled is not a question of identity. In fact, disability is not a sexual identity, but the social construction of an embodiment that has unpredictable consequences on sexuality. On the contrary, in the case of homosexuality, the right to the realization of sexuality is directly linked to the sexual identity of those who identify themselves as homosexual. Identity, however, also comes into play overwhelmingly in disability with regard to gender identity; in fact, the de-sexualization of disabled bodies also goes through de-muscularization and defeminization, to the point that the status of disability becomes an identity variable preceding the gender, while in non-disabled individuals, this variable immediately comes after that of the "human being". In a constructivist framework, materiality means always materialization, and therefore sex - like sexuality - is not a mark left at birth in bodies, but a hermeneutical operation that assigns a sex (just one of the two) unequivocally and definitively to bodies. However, this is a social activity even when - as in the case of the disabled - it is not fully recognized. In this sense, if we want to conceive disabled people as sexual citizens, first of all it is necessary to provide them with the conditions to define, express and realize their gender identity. The social cancellation of the gender identity of disabled people is crystallized in the well-known symbol of the person (a man? or a woman?) in wheelchairs indicating toilets for disabled people; if conclusions were to be drawn from the arrangement of toilets, it would have to be said that there are three sexual genders: men, women, and disabled people. When the toilet for the disabled is merged with one of the two already existing, it is usually designed together with the women's bathroom, thus materializing the de-sexualization of disabled bodies, particularly those of men who - by virtue of their condition - are allowed to cross freely a space otherwise highly guarded and segregated with respect to the gender. It is no coincidence that the only other male bodies that can cross the toilets of women are those of children, and similarly the de-sexualization of disabled people goes through infantilization.

5. The body as a fundamental dimension of the life project: the importance of motor activity

The bodily dimension in disability is a dimension that diachronically sees an evolution from the exclusion, marginalization and concealment in antiquity, to the affirmation as an inescapable dimension in the contemporary development of the self, in the formation of identity and in the formative and relational processes of the disabled person (Zappaterra, 2010). This evolution of the affirmation of the body perfectly matches with the evolution of the imaginary of disability, which has only recently freed itself from negative images of limits, difficulties and suffering. Mythology, classical literature, medieval iconography, the philosophical reflection of the seventeenth and eighteenth centuries show a denied, devalued, hidden image of the body of the disabled, because the body is sick, weak, deformed and therefore stigmatized, and placed ex limine with respect to the ideological-cultural space of the city (Foucault 1976). In spite of this, over time, the role of the body in the development of the potential and in the formative processes of the disabled person has come to a forefront, an important role testified by studies in the field (also thanks to the autobiographical methodology) by disabled people who narrate the priority role of the body in the process of acceptation of a diversity which is no longer felt as stigma, but accepted and shown as one of the essential characteristics of the self (Trisciuzzi et al. 2006). The body is the starting point for the process of identity building, as the intrapsychic and inwardly socialized self-image of disabled people today is nourished by a perception of the self that goes through a body which is no longer the object of negative stigmatization, as evidenced by the trends of a recent "culture" of disability. In the evolution that the corporeity/disability binomial has gone through during the twentieth century (and which is still going through today), we have chosen to introduce here two focuses. The first is the role played by the body, starting - almost paradoxically - from studies on the type of disability that mostly affects the body and compromises movement, i.e. cerebral palsy in children or cerebropathies. In this fundamental field we can find Adriano Milani Comparetti's contribution (brother of the more famous Don Milani), a figure of excellence in the field of cerebral palsy in children; the scholar-physician-pedagogist revealed the more social and socializing aspect of movement and motor habilitation practice. He coined the expression "social rehabilitation" to refer to the positive aspects of the movement itself, carried out even outside the clinic, in every sphere of life of the disabled person (Milani Comaparetti 1982). Thus the motor activity of the person with brain injury will not only benefit from the habilitation/rehabilitation technical intervention tout court, but will also have an impact on the more general structuring of the subject's personality in a holistic approach to the person, which made Milani Comparetti a forerunner of the reflections on the inclusion of disability typical of the Nineties of the twentieth century, although he operated between the fifties and the eighties (Trisciuzzi 2005). A further focus on the corporeity/disability binomial can be found by deepening the educational value of sports practice for the disabled person, and the social and cultural phenomenon of the Paralympic Games. The pedagogical-special field, which has traditionally investigated mainly school and disabled children, is actually increasingly expanding today - in line with the recent "UN Convention on the Rights of Persons with Disabilities" - to the problems that emerge in relation to work integration, the right to leisure and recreation, and basically to the search for an adult identity for the disabled person. Accordingly, it is in this broadened horizon of perspective of the Special Pedagogy studies that we can integrate and investigate the formative value of the corporeal dimension, the educational and social value of sport for the disabled, and the raison d'être of the Paralympic Movement as a social and educational phenomenon. We can rightfully say that these events are only a part of the history of social inclusion of the disabled, it is their "sports page"; a history marked by the contribution of extraordinary personalities that in a pioneering way, but with an indelible mark, have paved the way for new dimensions to disability starting from the body (Zappaterra, 2010). Curious is the analogy that can be noted in this regard between Sir Ludwig Guttmann' s figure and work, President of the International Stoke Mandeville Games Federation and Father of the Paralympics, and Antonio Maglio, father of the Italian Paralympism, thanks to whom in 1960 the annual Stoke

Mandeville Games were moved to Rome on the occasion of the XVII Olympic Games. Guttmann and Maglio share a belief in the therapeutic value of sport, or better, in "sports therapy" as the most natural form of re-education, because it can improve the performance of concentration, motor coordination, muscle weakness and spasticity; above all, in the disciplined use of sports practice, both have caught the emergence of that playful and competitive dimension enlivening the will of the disabled person, going beyond the traditional methods of physiotherapy and exercising those moral and volitional resources that disability has often humiliated (Guttmann 1977a, Arrigoni 2008). Not surprisingly, *Spirit in motion* would later become the motto of the Paralympic Movement. In this respect, we know how much Guttmann insisted on the importance of sport as a social reintegration, and on the need for a deeper understanding between typically-developing people and disabled people in society and culture (Guttmann 1977b). The corporeity of the disabled in sport offers positive images of full integration, dynamism and social participation, such as those provided by Oscar Pistorius or Natalie Du Toit. These positive images, where the bodily dimension is in the foreground, could be said to be in the limelight also as a result of mediatization; they can help produce a new imagery about disability, thus they can help develop the understanding that disability transcends singularity, because diversity, even in the body, intrinsically and transversally characterizes the human being (Zappaterra 2008). As Cannavò wrote: "I did not even dare to imagine [...] that the Paralympics would gain so much momentum as to represent today the leading edge of a cultural growth in the world" (Arrigoni 2008).

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