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Re-gendering or de-gendering disability? Living with disabilities in contemporary societies

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Editorial

1. Introduction[1]

During the 1980s, disability studies took on a specific academic identity. Developed initially mainly by male activists and academics living with one or more disabilities, and following a change in perspective thanks to female activists and academics who underlined the importance of reconsidering initially overlooked aspects, disability studies is now an interdisciplinary research field with historical, cultural, social, medical, economic and political perspectives.

Considering disability means considering the human condition in general. Age, unexpected life events, accidents at work, environment, diet and many other factors – not all of them predictable – may change a person's physical, sensory and cognitive condition, placing them permanently or temporarily in the category of people living with one or more disabilities. Defining how and by whom human *normalcy* is constructed and incorporated symbolically in the most disparate times, spaces and places is a generalisation, and one which may fail to identify stable criteria. It is more plausible to observe how discrimination has evolved, that is, the type of marginalisation affecting people who do not fit with a temporary and situated model of *normalcy* in a given time and place. In a world where the fluidity of the human condition is increasingly evident, talking about disability involves updating our own viewpoint and identifying issues for closer analysis, thereby avoiding the traditional binary macro-categories: congenital/acquired, physical/sensory, mental/cognitive, chronic/degenerative.

While disabled people[2] have the right to define their individual needs, including where, how and with whom they would like to live or work, and to share their desires and viewpoints, there is an increasing understanding that all these aspects intersect with other fluid characteristics – such as age, the course of debilitating conditions, new treatments and

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[1] The essay, in its entirety, is the result of the authors' shared and prolonged reflections over the years. Nonetheless, for authorship, the drafting of the different parts of this text can be divided as follows: paragraphs 1, 2, 3, and 5 are attributed to Rita Bencivenga; and paragraph 4 to Darja Zaviršek.

[2] Since the text refers to the social model of disability developed in the UK, we have chosen to use the expression "disabled people" instead of the equally common "people with disabilities" used more widely in the US. Initially, using the term "disabled" was designed to underline how society itself "disables" people who could otherwise live full, satisfying lives based on their own, independently-established criteria.

cures which may change once definitive outcomes – and, naturally, with gender. Ability and disability, physical integrity and disfunction are relative concepts that are culturally and socially situated. The variety of bodies, and cultural and social environments makes us all part of a complex *continuum* of normalcy, just as the variety of our individual self-perception challenges gender stereotypes.

2. Disability studies meets feminism and gender studies.

In the 1970s the social model of disability (from now on the “social model), developed in the UK by people with disability (Hasler 1993; Oliver 1987; Shakespeare 2010) ”) reframed the view of disability, shifting it from a personal attribute to a social question, one of many forms of social oppression. It is therefore the response of the social context to people’s physical, sensory and cognitive conditions that creates disadvantages and limitations: the social model therefore subverts previous perspectives. However, some female activists soon showed that the original version of the social model did not give sufficient visibility or interpretation to their experiences as women. A number of activists with disabilities such as Liz Crow (1996), Jenny Morris (2006) and Elena Pečarič (2002) were among the first to negate the division between public and private, underlining how important it is to apply the feminist motto “personal is political” to the field of disability. Female academics with disabilities soon joined the activists, making disability the subject of their research and including the feminist perspective in their studies. This meant that the experiences of disabled women could be included in the theories and research programmes undertaken by the various feminist movements. For reasons of space, just some examples are given here.

Susan Wendell wrote about her experience of chronic illness, analysing what can be considered a disability and what cannot, as well as the difficulty of identifying as disabled – with a disability that is invisible to others – and who *counts* formally and officially as disabled (Wendell 1996).

Rosemarie Garland-Thomson explored the construct of the disabled body in a particular cultural context, discussing the role of medical, political, cultural and literary narratives in considering some bodies as inferior. In *Extraordinary Bodies: Figuring Physical*

Disability in American Culture and Literature (1997), Garland-Thomson plays on the ambivalence of the word *Extraordinary*, intended as both extraordinary and *as* out of the ordinary, that is superior or inferior to the ordinary. She observes the parallel between disabled bodies and women's bodies:

> "[m]any parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both the female and the disabled body are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority" (Garland-Thomson 1997, 19).

Carol Thomas coined the expression *psycho-emotional dimensions of disablism* (1999, 46), affirming that neither an impairment nor its effects can be reduced to purely biological aspects, because "the bio-material always intersects the socio-cultural" (2007, 137). It is also thanks to these academics that feminism and gender studies interacted with disability studies, opening up new perspectives.

Disability studies in the post-structuralist tradition have recognised the need to consider the material body. As part of Critical Disability Studies (Meekosha and Shuttleworth 2009; Vehmas and Watson 2014), post-structuralist theories have made it possible to challenge what was seen as an essentialist understanding of the human race. This made it possible to dispute the classification of human beings as *normal* or *impaired* based on a huge, constantly expanding range of corporeal and cognitive traits. The concepts of gender and disability are therefore deconstructed; they become fluid categories, inspiring further reflection on how the two conditions intersect (Feely 2016) and on the possibilities opened up when disability and queerness meet crip theory, thereby recognising that *another world is possible*, to use Robert McRuer's apt definition (2003 and 2006).

We are now beginning to see that our current concept of *normalcy* may or should be readapted for a not too distant future when space travel will require *new normalcies* (Federici 2020). Many aspects of our lives will be de-materialised, and cloning, genetic editing and gene transfers, already tested on animals, will perhaps become significant and viable options for all humanity.

For some years now, research has been moving towards an intersectional analysis of a series of *isms*: ableism, sexism, speciesism and racism, to name the most commonly researched.

While Carol J. Adams (1991 and 2010) had already studied the links between animalism and feminism back in the 1990s, breathing new life into ecofeminism after it had waned for some years (Adams and Gruen 2014), a book and two articles published more recently by Sunaura Taylor (Taylor 2011, 2013a and 2013b) connect the struggle for animal rights with the struggle for disabled people's rights.

The term *ableism* refers to stereotypes, prejudices, discrimination and social oppression towards disabled people (Bogart and Dunn 2019; Campbell 2001; Monceri 2014). While two terms can sometimes be used in different contexts, ableism when referring to social oppression and *dis*ablism when talking about individual discriminations (Jun 2018), in other cases (McLean 2011) the emphasis falls on the viewpoint of whoever is discriminating. It is ableist to maintain that being *able* is the *normal* and therefore superior human condition. In this second case, discourse and relations appear more nuanced; critical behaviour or language is not used, but one part of humanity is still seen as superior to another. The many nuances taken on by ableism in academic contexts are explored in a recent book by Nicole Brown and Jennifer Leigh (2020). It reveals how disability is still seen in academic circles as a problem that needs to be solved, rather than a different way of working and being (Brown *et al.* 2018). This approach makes it difficult for many people to openly talk about their own needs (Brown and Leigh 2018).

Critical Disability Studies has been described by Margrit Shildrick (2012) as a post-conventional approach to disability. Grouping together ideas from feminism, post-colonial studies and queer theory, Shildrick challenges the categories of *disabled* and *non-disabled,* maintaining that conventional binary thinking must be rejected. In future, disability studies should deconstruct the categories that define disabled people as different from others who may be considered non-disabled, at least as defined by legislation or medicine based on specific times and places. Shildrick suggests that the differences are neither practicable nor sustainable; only by deconstructing them can we foster the position of disabled people and ensure they are included and can participate fully in society. A recent book by Katie Ellis, Rosemarie Garland-Thomson, Mike Kent and Rachel Robertson, *Interdisciplinary Approaches to Disability. Looking Towards the Future* (2019), offers interdisciplinary research paths covering a wide range of themes and establishes a benchmark for the development of Critical Disability Studies in the future.

According to Dan Goodley (2013), disability is interwoven with other forms of oppression and subsequent rebellious reactions. Considering disability inevitably leads to an understanding and deconstruction of racist, sexist and heterosexist ideologies as well as the revolutionary responses they evoke. Creating ways of being and working in which similarities and differences coexist is considered the main outcome when disabled and non-disabled people collaborate on research projects. Claire Tregaskis and Goodley (2005) open up many reflections on possible partnerships in the research sector, supporting the idea of trusting relationships that enable everyone’s feelings and problems can be shared.

3. Doing research, being the object or subject of research.

The issue of how disabled and non-disabled people interact in research pathways recurs frequently in disability studies. The danger of research *exploiting* its subject matter has highlighted the importance for researchers to explicitly state their position and situation, to *write themselves into their work* and provide intellectual biographies and interpretive paradigms so that readers can easily situate and contextualise their analysis. Researchers must therefore take responsibility for their opinions and what they write, and to do this they must be aware of their position in relation to other people. They must understand that their knowledge is conditioned by a myriad of factors that shape their personal story and perception.

In our different individual stories, factors such as ‘race’, nationality, age, social class, gender identity and sexual orientation, our existential pathway, physical, sensory or cognitive level of ability, cultural background and the period of history all intersect. All this enables us to think certain things while precluding others. We can see some phenomena, but others are hidden to us.

In the 1990s, the disabled people's Movement began to suggest that the participatory research method should be prioritised in disability studies, enabling researchers and their subjects to work in partnership. The participatory research tradition, initially inspired by Kurt Kewin's study of action research, had been explored in the UK education sector as early as the 1960s (including at London's Tavistock Institute), and was formalized by Cunningham (1976). The goal of this kind of research is not just to gather new knowledge, but to bring about change in the social context. In participatory research, members of the group work together in the initial stages to establish the results they want to achieve. They may be actively involved in observation, interviews or delivering questionnaires. In this model, the researchers draw on their expertise, sharing experience of planning research and data analysis to help the subjects of the study reach commonly defined goals. Knowledge is therefore transformative as well as active and participatory. The proposal by the disabled people's Movement was an important step forward, enabling research topics to be put forward by people experiencing problems related to their physical, sensory or cognitive conditions, as well as people who do not see the limitations or disadvantages traditionally associated with them by the *able-bodied*.

The emancipatory paradigm, subject of a special edition of *Disability, Handicap and Society* in 1992, highlights the social, political and economic factors excluding disabled people and calls for a new kind of relationship between researchers and the subjects of their research. The ultimate aim of research must be to improve the services and policies offered to disabled people and give them a better quality of life.

Post-structuralist and deconstructionist theories have also criticised the view of researchers as expert, objective, neutral people who interpret realities without representation, realities which can be investigated with the appropriate instruments without actively involving the subjects of their research. Deconstructionism considers the person who knows as another object of knowledge: the Subject. This challenges the role of the researchers and their perspective.

In 1996 Emma Stone and Mark Priestley identified six principles needed for emancipatory research. Two of them appear to be closely linked to their time and are now outdated: choosing a different perspective to the medical one, which views disability as a personal tragedy, and the preference for qualitative rather than quantitative research methods. The remaining four principles are:

- "the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for selfemancipation;
- the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabledpeople and/or the removal of disabling barriers;
- the evolution of control over research production to ensure full accountability to disabled people and their organizations;
- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences" (Stone and Priestley 1996, 10-11).

James McDonald (2013) has reflected on the fluidity of the dynamics of power, articulating a queer reflexivity lens, which entails engaging in a reflexive questioning of the categories used to identify people and recognising the shifting nature of researcher and participant identities over the course of the research process. He has taken up the ongoing debate on the role of disability researchers who are not living with disabilities, or do not see themselves as disabled people. The identities of participants in scientific research into the dynamics of power change, awareness grows, but it would be disingenuous to think that the pathway to awareness only applies to the subject of the research. The identity of researchers changes too, and their awareness of their own power is increasing.

> "For instance, are white researchers in a position to study people of color? Are men able to study women and women's issues? Can "straight"-identified researchers study the Lesbian, Gay, Bisexual, Transgender and Queer community? I argue that the question of whether or not to "match" for categories of difference in research studies is complicated by the fluid, shifting nature of identities that queer theory highlights. (2013, 127)

While no researcher can fully understand the experiences of a group unless he or she belongs to it, concluding that one can only study groups to which we belong seems to negate one of the basic premises of scientific research.

The relationship between impairment (a physical state) and disability is being analysed increasingly through new lenses, and it is now considered neither fixed nor permanent but potentially fluid and unpredictable. This new perspective has impacted the way in which disability is measured and the self-definition of disability, and it also involves more cultural and social aspects. Social policies play a vital role in determining if and when an impairment becomes disabling. Those familiar with the degrees of impairment qualifying people for percentages of disability, for pension purposes by way of example, are well aware that there is no clear distinction between being disabled and non-disabled. A person may have a partial disability, or be *not disabled enough* (Altman and Barnartt 2000)

In the research field, considering disability in terms of fluidity rather than permanence enables us to analyse the changing role of cultural differences in what constitutes disability, and how social processes and institutions create or negate the status of a disabled person (Barnartt and Altman 2010). Adopting this perspective might provide a new starting point for non-disabled researchers looking to undertake research involving disabled people. It is time for a new standpoint in which we are all in a permanent state of fluidity, to varying degrees. This does not mean denying the very real difficulties experienced by the population as a result of changes to their bodies or because of social and cultural obstacles, but it enables interactions based on a new understanding that any situation we may experience is potentially fluid.

The way we learn, analyse and interpret models of exclusion also depends on the interaction between our personal life experiences and education inside and outside of academia (Allan and Slee 2010). If our individual background shapes the way we perceive and interpret the world, an awareness that our condition is fluid can only help us reflect on inclusion, exclusion, discrimination and empowerment.

4. A brief overview of the articles in this issue.

In the editorial to the first issue of *About Gender* in 2012, Emanuela Abbatecola, Isabél Fanlo Cortes and Luisa Stagi wrote that one of the main challenges for the journal was to fill in certain gaps in Italian academia. The aim was to overcome a delay in three areas: the widespread unease towards feminism felt by the new generations; the then-recent introduction of Men's studies; and an overdue and still tentative acknowledgement of LGBQTI+ studies, seen as marginal, social, conceptual and narrative at the time. Eight years later, with an issue covering an area not yet widely explored by Italian academics – the gender approach to disability – it is interesting to see articles by women researchers embarking on their careers: one exploring how masculinity intersects with acquired disability, and one suggesting interaction and integration between feminism, queer-crip theories and disability studies.

Disability research is still not common in Italian academia, with notable exceptions such as the *Minority Reports. Cultural Disability Studies* periodical published by Suor Orsola Benincasa University, Naples. An issue covering the gender approach to disability is therefore an important opportunity to examine the state of research in these areas. Contributions from researchers at the start of their academic careers gives us great hope for the future, especially if they are able to pursue their interest in coming years and inspire other colleagues and their departments. This will enable them to explore lesser-known research avenues and become part of a thriving international community.

The increasing number of researchers living with a chronic illness, disability or neurodiversity who choose it as the formal subject of their studies is another aspect worth highlighting, and explored by another article in this issue. It is particularly important for disabled people to take part in scientific research today, in the face of an ever-expanding neoliberal viewpoint that prioritises productivity and efficiency. This has an impact on people whose primary activity is scientific research, particularly those facing the challenges of disability on a daily basis. When they are not formally classified as disabled, the challenges of the workplace are even more difficult to overcome. The ableism found in many universities is confirmed by the fact that people with disabilities, chronic illnesses, invisible conditions such as chronic fatigue or fibromyalgia and various forms of neurodiversity (Brown and Leigh 2018) are underrepresented in academia. Not wishing to adopt a medical view of disability, we are keen to point out that these conditions can enrich diversity in research pathways. They fill in unexplored gaps, particularly when it comes to the advantages and positive aspects of individual diversities, as we have shown in the previous pages, revealing the wealth of interpretations on these issues that are brought by people living with one or more forms of impairments.

Theoretical perspectives and individual and group reflection lead many of us to choose research topics that suit our interests and mirror our situation, making them observable and analysable in concrete pathways. The central theme of this issue of *About Gender* is the gender perspective in disability studies, and the articles included explore different avenues. While leaving the choice of topics open, the call invited reflections on how we can re-gender or de-gender disability by analysing what it means to live with one or more impairments or disabilities in contemporary society. The call asked for theoretical and empirical articles, with no limitations on the scope of observation and analysis, in the hope of revealing what currently interests researchers in the field. The result is a series of articles exploring many disability-related issues from the viewpoint of gender: maternity; the role of services in furthering or combatting discrimination; legislation and its impact on the lives of disabled women; reinterpreting masculinity in view of acquired disabilities; sexuality; violence; intersections with LGBTQI+ issues. Each of these topics would require a separate issue for it to be explored in depth.

Written by Claire Fleet and Ian Clara, the first article looks at social workers' complex working environment and reveals inconsistencies in the services offered to disabled women. The analysis shows the importance of social workers' skills as well as their willingness to work around the government's social policies. Fleet and Clara's final suggestion is that government policies and legislation should be balanced to provide better support and funding for services helping disabled women who are physically abused by their partners.

Ester Micalizzi's article provides theoretical insight on how physically disabled women experience maternity in Italy, concentrating on toxic discourse and the stereotypical view that maternity and disability are incompatible. Referring to new, unregulated familiarities that transcend the boundaries of the private, Micalizzi supports the idea of analysing how being able intersects with heterosexism, classism and racism and how all this may be internalised by disabled women.

Chiara Montalti frames disability advocacy through the concept of cyborg politics and in particular two conceptual terms, affinity and avidity, as proposed by Donna J. Haraway. Montalti affirms that a mobile politics, based on affinity and avidity, may have positive impacts for disability advocacy. In particular, affinity and avidity are seen as sources of trouble, but a productive one, worth of being pursued.

Costanza Agnella's analysis of gender and disability reports on an Italian legal ruling that enables female prisoners – but not male prisoners – with severely disabled children to serve out their sentence at home. Agnella examines the representations of maternity and paternity set out in the ruling, underlining how women are relegated to care-giving roles. She also observes how the legislators' decision reinforces the idea that female prisoners are doubly guilty: for having committed a crime and for failing in their parental role as *good mothers*.

Raffaella Ferrero Camoletto and Valentina Ferritti look at how sport makes it possible to (re)build a socially acceptable form of masculinity, looking at turning points in men's lives following an acquired impairment. Ferrero Camoletto and Ferritti's analytical perspective straddles two fields of research, Disability Studies and Men's Studies, which developed independently and have only recently intersected through renewed interest in bodied and gendered aspects of disability. By analysing three life stories, the authors show how the interviewees' attitudes towards their masculinity fit within the neutralisation of the disabling effects of their impairments and their attempts to optimise aspects of their bodily and emotive experiences which partially replicate dominant models of masculinity.

Alessandra Maria Straniero traces the history of debate on violence towards disabled women in Italy, revealing how political and legislative dynamics and public attitudes intersect with the voices of women activists in disabled people's movements. First-hand accounts and descriptions of projects run by and for disabled people (underlining the scope of the problem) provide useful data on a dimension that is still difficult to frame.

In her article, Chiara Paglialonga describes the intersection between sexuality, gender and disability. Extensive interviews with disabled people and workers in the health and social care sectors enabled Paglialonga to examine the rationale behind the submission and incorporation of sexual and gender norms, while gathering possible strategies for owning, negotiating and redefining sexuality as enacted by the disabled people interviewed.

In her article, Soledad Arnau Ripollés, academic, activist, Independent Living person, offers an intersectional analysis of approaches to disabled women and LGTBQI + people, examining the multiple forms of discrimination they face. The quasi-neologism used in her article, *functional diversity*, is used in Spanish academic circles (Romanach and Lobato 2005) to replace the terms special needs, disability, impairment. By intersecting with the viewpoint of functional diversity, feminism and queer-crip theories might become important reference points in dismantling multiple discriminations.

5. Conclusions.

Overall, this issue on gender and disability underlines the importance of the intersection between these and other possible perspectives. The topics covered in the articles are diverse – violence, sexuality, parenthood – and the people who feature in the authors' documentary and empirical research include those with personal experience of disability as well as family members, social and health care workers, legislators and activists working in NGOs run by and for disabled people. This extensive group might benefit from reflections on solid theories, with possible legislative, social and cultural implications. Gender studies and feminist/queer activism play a first-hand role in developing gender policy, and one can hope that the viewpoints of feminist disability studies and crip studies – and of disabled activists – will be included more and more frequently, creating an intersection between disability studies and queer theory.

In conclusion, this issue is without doubt an important milestone in gender and disability studies in Italy. In 2000 Thomas Gerschick reflected on the profound effect disability has on the concrete and symbolic experience of gender, highlighting the lack of theories capable of understanding the relations between these two areas, and asking questions which have not yet been answered in full. We draw this editorial to a close by posing some of the same questions he asked twenty years ago, confident that this issue of *About Gender* is a real step towards understanding them better:

> "How does disability affect the gendering process? How does it affect the experience of gender? How does having a disability affect women's and men's abilities to enact gender? […] How and under what conditions do social characteristics such as race, class, age, and sexual orientation further mediate the relationship between gender and disability? How does gender affect the experience of disability? […] How might the stigmatization and marginalization that women and men with disabilities face contribute to the creation of alternative gender identities?" (Press 2010, 1263 and 1267).

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