



Women's Disability Studies – Sources and Chosen Aspects of Discourse

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The article presents the genesis of women's disability studies as an academic and social activity of women with disabilities who pointed out that their experiences were ignored both in general disability studies and in the feminist discourse. The contemporary aspects of women's disability studies are presented on the example of discourses on the body, violence against women with disabilities and their economic situation. The aim of the article is to present women's disability studies in a context that goes beyond the analyses focused on Europe or the United States of America and broadens the area of interest to include the experiences of women with disabilities in the countries of the Global South.

KEY WORDS: femininity, feminism, disability, women's studies, disability studies

Sources of women's disability studies¹

The emergence of a discourse on the situation and experiences of women with disabilities in the field of disability studies was a natural consequence of perceiving the limitations of analyses characterised by a male perspective on the one hand and those aspects of feminism which in their essence were contrary to the experience of disability, on the other hand. The initial assumption of the theory and research on women with disabilities was the ascertainment of "double discrimination" – by gender and level of able-bodiedness.² The specificity of the disadvantageous position of women with disabilities is therefore revealed both in comparison with men with disabilities and women without disabilities. In Colin Barnes and Geof Mercer's³ short presentation on gender and disability intersection, the sources of this intersection have been clearly identified, i.e. in addition to the general consequences of disability, also those factors which relate femininity not only to socially and economically dominant masculinity, but also to a feminist vision of

¹ The article is devoted, among other things, to recalling the relationship between the feminist movement and the separate discourse within disability studies (scientific, journalistic, artistic), which was and is communicated primarily by women with disabilities. For this reason, the adjective "feminine/women's" rather than "feminist" disability studies was intentionally used to express the more general dimension of this specific discourse, which has contributed (as before, in the case of racial studies) to the intersectional transformation of feminism. Therefore I also propose the notion "disability studies" rather than "studies about disability" which corresponds to the English term *disability studies* and is devoid of the subtext of dominance not only over the phenomenon, but also over people whose experiences and identities are closely linked to the phenomenon (more extensive justification can be found in: N. Pamuła, M. Szarota, M. Usienkiewicz, "Nic o nas bez nas", "Studia de Cultura" 2018, no 10(1), pp. 4-12; J. Rzeźnicka-Krupa, *Spoleczne ontologie niepełnosprawności. Ciało. Tożsamość. Performatywność*, "Impuls", Kraków 2019, pp. 12-13.

² Cf. M. Fine, A. Asch (Eds.), *Women with disabilities: Essays in psychology, culture, and politics*, Temple University Press, Philadelphia 1988.

³ C. Barnes, G. Mercer, *Niepełnosprawność*, transl. by P. Morawski. Wyd. Sic! Warszawa 2008, pp. 73-74.

femininity based on cause, independence and overcoming the rigidity of gender-related social roles.

Meanwhile, the spheres of life in which women with disabilities encounter additional difficulties were already defined at the turn of the 1970s and 1980s in the work of Jo Campling⁴, an attorney and a person without disabilities, one of the first people to become an active and professional ally and advocate of people with disabilities.⁵ In the first of these publications, Campling presented key aspects of the daily lives of women with disabilities, pointing out the difficulties, limitations and obstacles that also result from the social perception of female disability. According to Campling, the areas of life which significantly shape the experience of women with disabilities are: interpersonal relationships, sexuality and self-image, menstruation and menopause, contraception, pregnancy and motherhood, the economic situation, clothes, home life, education and employment. In the context of the ambiguous relations between women's studies on disability and feminism, it is worth noting that this publication, which was initiatory for this trend, was published by the Virago Publishing House, which has been continuously promoting "women's texts for all" since 1973, and in Jo Campling's "Better Lives for Disabled Women" from 1979 it included the following note: "It is only when women start to organize in large numbers that we , become a political force, and begin to move to-

⁴ J. Campling, *Better Lives for Disabled Women*, Virago, London 1979; J. Campling, *Images of Ourselves: Women with Disabilities Talking*, Routledge and Kegan Paul, London 1981.

⁵ The dedication included in this publication results from Campling's personal, albeit indirect, experience of disability as a daughter whose mother was a person with a disability from the age of three. The child-parent relationship and vice versa are important contexts for the development of advocacy attitudes towards the rights and issues of people with disabilities, often accompanied by extensive scientific reflection and an original concept of disability. This trend includes the works of e.g. Lennard J. Davis, a child of deaf parents, a key representative of cultural studies on disability, or the publications of Elżbieta Zakrzewska-Manerys, the mother of a person with Down syndrome and a precursor of Polish qualitative, sociological studies on disability.

wards the possibility of a truly democratic society in which every human being can be brave, responsible, thinking and diligent in the struggle to live at once freely and unselfishly".⁶ The readers of this publication are introduced to the context of detailed analyses of the situation of women with disabilities by a statement by Mary Greaves, a disabled British economist, activist for comprehensive social security of people with disabilities and their presence on the labour market, author of a work published in 1969, entitled "Work and Disability"⁷: "I was just an ordinary little girl with fair curly hair wearing pretty dresses made by my mother until suddenly, one day in November, when I was three-and-a-half years old I ceased being a little girl and became a 'polio'. Just a few hours and I was 'neutered' -a sexless little creature".⁸ The above mentioned statement outlines two important aspects of the then-created women's disability studies - the first one is an unambiguous entry into the process of awareness and socio-political changes, which linked the postulate "nothing about us without us" with the participatory model of everyday life and social activity of people with disabilities⁹, the second one - the importance of the age aspect (the situation of little girls and girls with disabilities) as an important intersection in women's disability studies.

Giving a voice to women with disabilities, who talk about their experiences, is a basic methodological direction adopted by disability studies from the very beginning, expressed by Jo Campling in her second publication, under a clearly "narrative" title: "Images of Ourselves: Women with Disabilities Talking". The book contains transcriptions of the statements of 24 women of different ages and with different types of disabilities, constituting a collection of texts

⁶ J. Campling, *Better Lives for Disabled Women*, Virago, London 1979, p. 4.

⁷ M. Greaves, *Work and disability: some aspects of the employment of disabled persons in Great Britain*, British Council for Rehabilitation of the Disabled, London 1969.

⁸ J. Campling, *Better Lives for Disabled Women*, Virago, London 1979, p. 5.

⁹ Zob. J.I. Charlton, *Nothing About Us Without Us. Disability Oppression and Empowerment*, University of California Press, Oakland 2000; N. Pamuła, M. Szarota, M. Usienkiewicz, "Nic o nas bez nas", "Studia de Cultura" 2018, no 10(1), pp. 4-12.

that are more like reportage rather than scientific texts, but which thus fulfil the basic postulate of direct reference in disability studies to the experiences expressed in autobiographical narratives. In any of the life stories of women with disabilities presented in the Campling study, we find key issues both from 40 years ago, when the stories were written, and today, when issues such as sexuality and motherhood, personal freedom and decision-making autonomy, medical care and social support are the spheres that still reduce a woman with a disability to a person who has incomplete rights, who is limited rather by ablistic principles and social formations than her state of health and physical fitness. It is therefore worthwhile, for example, to compare data from the Polish report of 2019 entitled "When a woman comes to the doctor. Accessibility of gynaecological services for women with disabilities - report from the study"¹⁰ with one of many similar statements made by Campling in 1981:

"How could you do it?' was a question which had many nuances and was put to me by many people, during and after my pregnancy. The GP wondered how I could have had intercourse in my 'predicament' (as a good friend invariably describes my situation). The gynaecologist wondered how it was socially possible for me to bring up a child, and social services merely stood on the side-lines, not offering any practical help but making me feel they were wondering how I would maintain myself and my child in the community, waiting for the first opportunity to take my child away from me. I went so far as to ban the social worker from the house after my baby was born because they had been so unhelpful to me during my pregnancy and I did not wish to support their professional voyeurism. You see, not only was it immoral to be an unmarried mother but it was doubly immoral to be an unmarried

¹⁰ *Przychodzi baba do lekarza. Dostępność usług ginekologicznych dla kobiet z niepełnosprawnościami - raport z badania* [When a woman comes to the doctor. Availability of gynaecological services for women with disabilities - research report], Kulawa Warszawa Foundation, available at: [file:///C:/Users/konfe/Downloads/Fundacja_Kulawa_Warszawa_dost%C4%99pno%C5%9B%C4%87_gabinet%C3%B3w_gineko logicznych.pdf](file:///C:/Users/konfe/Downloads/Fundacja_Kulawa_Warszawa_dost%C4%99pno%C5%9B%C4%87_gabinet%C3%B3w_gineko%20logicznych.pdf) [27.08.2020].

mother AND a severely disabled person daring to produce a child – a normal, healthy, beautiful child”.¹¹

The “Report” of the “Kulawa Warszawa” Foundation, prepared in accordance with the assumptions of intersectional feminism, presents data from 18 interviews with women with different types of disabilities. As a result, a complex, fairly cross-sectional picture of experiences was obtained, authorising the authors of the study to draw conclusions and formulate recommendations. The first conclusion is actually an expression of the permanence of the sources of women’s disability studies, as it states that “in medical care, there are problems specific to the group of women with disabilities that are not encountered by men and women without disabilities”.¹² The inaccessibility of medical services for women with disabilities is linked both to the physical inadequacy of space, transport difficulties and the spectrum of social barriers – from communication difficulties, through limited access to information, to overt reluctance, objectification and influencing personal choices and decisions.

I asked him [the doctor] about the possibility of getting pregnant, what it would be like, asked him to assess the real chances and so on. He said that I was crazy and in general, that in my case it is absurd that I should want to be pregnant, have a baby, because I am in a wheelchair, and you have to do ultrasound tests all the time and he basically yelled at me. He behaved a bit non-humanely and did not act like a doctor worthy of a woman’s visit. After this visit, I immediately looked for another gynaecologist.¹³

¹¹ J. Campling, *Images of Ourselves: Women with Disabilities Talking*, Routledge and Kegan Paul, London 1981, pp. 62–63.

¹² *Przychodzi baba do lekarza. Dostępność usług ginekologicznych dla kobiet z niepełnosprawnościami – raport z badania* [When a woman comes to the doctor. Availability of gynaecological services for women with disabilities – research report], Kulawa Warszawa Foundation, available at: file:///C:/Users/konfe/Downloads/Fundacja_Kulawa_Warszawa_dost%C4%99pno%C5%9B%C4%87_gabinet%C3%B3w_ginekologicznych.pdf [27.08.2020], p. 46.

¹³ *Przychodzi baba do lekarza. Dostępność usług ginekologicznych dla kobiet z niepełnosprawnościami – raport z badania* [When a woman comes to the doctor. Availability

The aim of studies presenting the experiences of women with disabilities has not changed over the decades between the first works of this type and contemporary reports – it is to combine the identification of sources and mechanisms of oppression (on the basis of gender, able-bodiedness or age) with a critical analysis of reality and the formulation of demands to the relevant entities, having real references to the needs of women with disabilities. The aforementioned report enabled, among other things, an in-depth analysis of the concept of “accessible gynaecological service”, which – according to the recommendation – should be defined taking into account the mechanisms of prevention of barriers revealed in the study, i.e. architectural barriers, in terms of accessibility to information, communication, resulting from a lack of support and application of real improvements, awareness and resulting from a lack of knowledge.¹⁴

The body, violence and economics – permanent aspects of women's disability studies

Within the framework of women's disability studies, there has been a specific strengthening of the category of corporeality, which, according to the initial assumption of this discourse, was formulated differently both by men with disabilities and women without disabilities. The radical separation of biological bodily impairment and disability, understood as the effect of social barriers, has un-

of gynaecological services for women with disabilities – research report], Kulawa Warszawa Foundation, available at: file:///C:/Users/konfe/Downloads/Fundacja_Kulawa_Warszawa_dost%C4%99pno%C5%9B%C4%87_gabinet%C3%B3w_ginekologicznych.pdf [27.08.2020], p. 33.

¹⁴ *Przychodzi baba do lekarza. Dostępność usług ginekologicznych dla kobiet z niepełnosprawnościami – raport z badania* [When a woman comes to the doctor. Availability of gynaecological services for women with disabilities – research report], Kulawa Warszawa Foundation, available at: file:///C:/Users/konfe/Downloads/Fundacja_Kulawa_Warszawa_dost%C4%99pno%C5%9B%C4%87_gabinet%C3%B3w_ginekologicznych.pdf [27.08.2020], pp. 50–52.

doubtedly contributed to the (initially fully justified) importance and popularity of the social model of disability, but it was women with disabilities that most fully expressed their reservations about the “Cartesian division”, which gave a reductionist character especially to the early social model.¹⁵ Bodily impairment is to be considered as a real state of corporeality, which means, in more recent versions of the ‘sociology of impairment’ that it is as important and complex as disability, hence “impairment is not simply a personal, apolitical experience; it is shaped by inequalities and is therefore always deeply entangled in politics”.¹⁶ This thesis finds its credibility in the statements of women with disabilities who, like Liz Crow, a British artist and activist, declare that “most of us cannot simply pretend that the impairment is irrelevant because it affects every aspect of our lives”.¹⁷ The same author also writes about the experience of corporeality in connection with impairment, which was not discussed in the reduced version of the social model: “The experience of impairment is not always irrelevant, neutral or positive. How can it be when it is the very reason used to justify the oppression we are battling against? How can it be when pain, fatigue, depression and chronic illness are constant facts of life for many of us?”¹⁸

The approach to corporeality in women’s disability studies bears the hallmarks of eclecticism, which “combines the subjective experience or phenomenology of carnality with the power of social discourse in constructing the body”.¹⁹ This discourse therefore forms part of the post-constructive transformation of the social model of disability, the main dimension of which is to move away

¹⁵ Cf. B. Hughes, K. Paterson, *The social model of disability and disappearing body: towards sociology of impairment*, “Disability and Society” 1997, no. 12(3), pp. 325–340.

¹⁶ M. Sherry, *A sociology of impairment*, “Disability and Society” 2016, DOI: 10.1080/09687599.2016.1203290, p. 1.

¹⁷ L. Crow, *Renewing the social model of disability*, [in:] J. Morris (ed.), *Encounters with strangers: Feminism and disability*, Routledge, London 1996, p. 7.

¹⁸ L. Crow, *Renewing the social model of disability*, [in:] J. Morris (ed.), *Encounters with strangers: Feminism and disability*, Routledge, London 1996, p. 4.

¹⁹ C. Barnes, G. Mercer, *Niepełnosprawność*, transl. by P. Morawski. Wyd. Sic! Warszawa 2008, p. 104.

from a generalisation of the categories of experience of corporeality and impairment towards a more differentiated treatment of the effects of lack of mobility or reduced mobility. This approach also makes it possible to effectively incorporate new threads into analyses of the situation and experiences of women with disabilities. Violence against women with disabilities or their economic situation, which will be outlined for further consideration, are not, of course, new phenomena in a chronological sense, but are examples of further social issues marginalised both in general disability studies and in feminist studies. It is also important to stress that the appropriate empowerment of these issues is correlated with a significant change in general studies on disability, which has been associated with a move away from analyses focused solely on the experiences of people with disabilities from the countries of the rich North (Europe and the United States) and the recognition of the completely different specificity of the problems of this group of people in the countries of the global South.²⁰

The texts of researchers and activists with disabilities, such as Anita Ghai, representing Indian or, more broadly, South Asian disability studies, should therefore be analyzed in a completely new light. Once again, the discourse on the situation of women with disabilities has been placed at the intersection of their exclusion from both feminist discourse and male-dominated disability studies. Ghai is fully aware that the rich and liberal countries of the West and the North have already reached the stage of "recognising the problem" and are struggling with different types of disadvantages, than the part of the world which, culturally and economically, shapes the experience of women with disabilities completely differently. Patriarchalism, castration and classism of the Indian society affect not only the everyday situation of women with disabilities, but also characterise the movement of people with disabilities in India, which further excludes women with disabilities from more active forms of fighting for their rights. Anita Ghai illustrates

²⁰ Cf. D. Goodley, *Dis/ability studies. Theorising ablist and disablism*, Routledge, London 2014.

the repeated stigmatization of women with disabilities in India by the meaning of the Hindi literal translation of the English phrase *woman with disability*, which is best reflected by the phrase: “not only a woman, but also a disabled person”.²¹

The situation of women in India is an international phenomenon, which is also reflected in the Polish media²², although the cause of media interest are most often brutal rapes, triggering waves of protest not only against specific cases of violence, but also against the constantly worsening position of women in a society that combines progressiveness and modernity with ultra-conservative attitudes. For this reason, feminist activity in India repeats the pattern of the particular activity of educated and economically independent women, who are also victims of violence, but who are able to oppose negative phenomena and develop campaigns in defence of their rights. Ghai refers to this pattern, highlighting the extremely bad position of women with disabilities, who are the “worst caste” in the social structure of India, also overlooked in feminist discourse – “in a culture where being a daughter is a curse, being a disabled daughter is worse than death”.²³

In the report for the Latin American and Caribbean area of 2019 on violence against women and girls with disabilities²⁴, the quantification of specific types of violence (sexual, physical, psychological, economic) is accompanied by the identification of equally specific lack in services and services related to the prevention of violence against women and girls. The institutions providing assistance to women experiencing violence in the countries surveyed are inacces-

²¹ A. Ghai, *Disabled Women: An Excluded Agenda of Indian Feminism*, “Hypatia” 2002, vol. 17, no. 3, p. 53.

²² Cf. P. Wilk, *Ofiary selekcji*, „Polityka” 2018, no 10 (3151), pp. 45–46.

²³ A. Ghai, *Disabled Women: An Excluded Agenda of Indian Feminism*, “Hypatia” 2002, vol. 17, no. 3, p. 53.

²⁴ L. Marques et al., *Violence against Women and Girls with Disabilities: Latin America and the Caribbean*. Gender and Diversity Division, Social Sector, Inter-American Development Bank 2019, available at: file:///C:/Users/konfe/OneDrive/Pulpit/Kobiec%C5%9B%C4%87/Violence_against_Women_and_Girls_with_Disabilities_Latin_America_and_the_Caribbean_en_en.pdf [3.09.2020].

sible to women with disabilities due to architectural barriers, lack of information in Braille language or a sign language interpreter. The staff of these institutions usually do not have any competence to respond to the specifics of people with disabilities (especially intellectual disabilities). In the case of institutional care, there are no clear procedures for preventing and reporting violence, and according to numerous studies, the perpetrator is most often an immediate family member or an employee of the care institution.²⁵ This situation, in turn, translates into a lack of adequate response from the police and the justice system, as cases of violence against women are not reported at all or the information is subject to a family or institutional filter. The list of negligence and omissions concludes the point on the lack of adequate care and support for the sexual and reproductive health of women and girls with disabilities.²⁶ Selected issues from the report concerning e.g. countries such as Uruguay, Costa Rica, Mexico and Argentina, should be compared with the aforementioned Polish report of the “Kulawa Warszawa” Foundation, in order to better understand that the lack of accessibility to specific services due to disability may be treated as a violent experience.

The economic aspect of women's disability studies reflects the diversity of problems of developed and underdeveloped countries. The general assumption of disability studies is that “in rich countries, people with disabilities are economically threatened by the expansion of the free market, population growth, the scale and professionalisation of social and educational services, and the growing need for intellectual and physical capacity to work”.²⁷ Shedding

²⁵ Cf. M. Sherry, *Disability Hate Crimes: Does Anyone Really Hate Disabled People?*, Ashgate, Surrey 2010.

²⁶ L. Marques et al., *Violence against Women and Girls with Disabilities: Latin America and the Caribbean*. Gender and Diversity Division, Social Sector, Inter-American Development Bank 2019, available at: file:///C:/Users/konfe/OneDrive/Pulpit/Kobiec%C5%9B%C4%87/Violence_against_Women_and_Girls_with_Disabilities_Latin_America_and_the_Caribbean_en_en.pdf [3.09.2020].

²⁷ D. Goodley, *Disability Studies: An Interdisciplinary Introduction*, Sage Publications Ltd., London 2011, p. 2.

light on the real experiences of women with disabilities in the Indian culture corresponds, in Anita Ghai's texts, to economic themes which are part of the broader context of reflection on the situation of people with disabilities in third world countries. Ghai sees poverty as "the most dangerous and common threat to people with disabilities"²⁸, and it is precisely the prevalence of this phenomenon that makes it disappear, becoming a permanent feature of the description of disability.

Economic figures leave no doubt that the situation of women varies according to where they live. The World Economic Forum 2020 report on the global approach to gender gaps ("Global Gender Gap"),²⁹ states that in the economic area, the gap between men and women, known as the wage gap, will be eliminated in 257 years' time. Iceland, Norway and Finland are at the top of the ranking of countries with the smallest inequalities in this area (with issues of political participation, access to education and health care added to the economic area), while the countries of the East Asia-Pacific region have the worst situation, and it will take at least 163 years for them to equalise the position of women in society.³⁰

A commentary to the information presented, as well as a summary of the problems outlined in this text, is a statement by Rosemarie Garland-Thomson, who, in defining her own aspects of feminist disability studies, i.e. representation, body, identity and activism, wrote in the context of the former: "Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both 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".³¹ The inevitable conse-

²⁸ A. Ghai, *Marginalization and Disability: Experiences from the Third World*, [in:] M. Priestley (ed.), *Disability and the life course*, Cambridge University Press, Cambridge 2001, pp. 26–37.

²⁹ *Global Gender Gap. Report 2020*, World Economic Forum, Geneva 2020.

³⁰ *Global Gender Gap. Report 2020*, World Economic Forum, Geneva 2020, p. 6.

³¹ R. Garland-Thomson, *Re-shaping, Re-thinking, Re-defining: Feminist Disability Studies*, Center for Women Policy Studies, Washington, DC 2001, p. 7.

quence of such a definition and positioning of the female body and/or the body with disabilities has been to confront women's disability studies with economic neoliberalism³² as a doctrine that strengthens the objectification and marketability of bodies, accompanied by interdependent processes of aestheticisation and cyborgisation of disability. These issues are undoubtedly an important part of contemporary studies on human corporeality, in which women's disability studies play a significant part.

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³² Cf. A. Lipski, *Problem osób niepełnosprawnych w warunkach dyskursu ekonomii neoliberalnej*, "Problemy Edukacji, Rehabilitacji i Socjalizacji Osób Niepełnosprawnych" 2018, Vol. 27, no 2, pp. 29–59.

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