



Intersection between a Social Gender and Disability: A Self-concept of Women with Disabilities in the Post-feminist Context

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Intersection between a Social Gender and Disability: A Self-concept of Women with Disabilities in the Post-feminist Context

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Abstract

The goal of this article is to analyse the intersection between a social gender and disability, and identify differences between both the perceived and attached identities of women with disabilities.

Two qualitative research studies on women with disabilities in Lithuania reveal ambiguity in the relationship of women with disabilities, towards factors that form their identities. Disability here is realised on a deeper level: it structures respondents' self-perception and self-reflection. The research also points to the fact that this part of an individual's identity is straightforwardly perceived in their society and more profoundly ruminated by the women themselves. The 'invisibility' of the womanhood here suggests that this part of an identity is perceived as a 'natural', unquestionable aspect, which is beyond criticism. Such an attitude absorbs rather than transforms normative provisions and hinders the development of practices directed at subordination of gendering structures.

From the perspective of a normative subject, disability and womanhood have equal weights, since both these aspects of identity represent deviation from the 'norm', as well as other differences and subordination. However, both these aspects have different meanings in the self-perception of women with disabilities. The social model of disability acknowledges various obstacles in the environment, which hinder personal independence or create disability. Gender on the other hand, is often naturalized, and a systemic gender-based discrimination remains unmentioned. Hence, discriminatory structures related to disability are targeted, but gender subordination remains unchallenged.

Keywords: gender, disability, post-feminism, identity

Introduction

Intersection between disability and gender as two discriminatory components reinforcing each other and creating negative synergy is analysed in this paper. Women with disabilities are more likely to be discriminated against than other women; additionally, being female, they are automatically more vulnerable than men with disabilities. According to Garland and Waxman Fidducia (1999 p.i), women and girls with disabilities face double discrimination and thus "live at the corner of disability and womanhood: with two 'minority' identities, a double dose of discrimination and stereotyping". Due to the intersection of two grounds of discrimination, women with disabilities have to put in even greater effort in order to overcome physical and social obstacles, maintain their dignity and realize their full potential.

According to the WHO (2013), disability is more common among women than men, and women with disabilities tend to have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than women without disabilities.

Prior to the intersectional approach having achieved its full recognition, women's studies did not pay enough attention to disability specifically. At the same time, disability studies were unacquainted with feminist perspectives. On the contrary, there existed an antithesis between both movements regarding certain specific questions. For example, feminists spoke for all women's right to abortion, whereas disability activists fought against the eugenic programmes. Generally, representatives of disability studies did not recognise their own field of research as a part of identity studies. This was similar to the feminist theories refusing to recognise disability among the identities that inflect the category of woman (Garland – Thomson, 2002, p. 1-2).

Only in recent decades have women's movements started to recognize disability as a possible component of female identity. Additionally, disability advocates became aware of different experiences had by women and men with disabilities.

One of the most prominent feminist disability researchers (Garland - Thomson, 2001, p.4-5), claims that feminist disability studies bring the two movements together. This is to argue that cultural expectations,

perceived attitudes, social institutions and their attendant material conditions create a situation, in which persons that are categorized as both 'female' and 'disabled', experience double marginalization. Feminist disability theory addresses broad feminist concerns, such as the unity of the category 'woman', politics of appearance, medicalization of the body, privilege of normalcy, multiculturalism, sexuality, social construction of identity, and the commitment to social integration (Garland - Thomson, 2011, p.16).

Women with disabilities are a particularly vulnerable group of society, who are distinguished in various reports by international organizations and legislation, as follows:

The World Programme of Action concerning Disabled Persons states that the consequences of deficiencies and disablement are particularly serious for women. The Standard Rules on the Equalization of Opportunities for Persons with Disabilities recall the provisions in the Convention on the Elimination of all Forms of Discrimination against Women to ensure the rights of girls and women with disabilities, and includes references to women and girls with disabilities.

The Convention on the Rights of the Persons with Disabilities recognizes that women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation. To address this concern, the Convention on the Rights of the Persons with Disabilities has also taken a two track approach to promoting gender equality and the empowerment of women with disabilities. Additionally, in its two recent resolutions on Realising the Millennium Development Goals for persons with disabilities, the General Assembly called for the incorporation of a gender perspective. The Beijing Platform for Action (1995), recognise that women with disabilities face additional barriers to achieving gender equality, and call for action at all levels to address and take into consideration their concern (United Nations Enable, 2010, para 4-9).

Recognition of the need for a specific institutional investigation, into achieving a better quality of life for women with disabilities, is growing globally. Unfortunately, however, these trends very often are minor and underdeveloped in Lithuania, on levels of implementation, identification and formulation of the problem. For instance fundamental human rights of women with disabilities are guaranteed in Lithuanian legislation. However, this is according to the principle of *inter alia*, which means that they are not distinguished as a specific social group in need of protection. Most often their rights are based either on the principle of

equality; or they can claim protection on the specific basis of either gender, or disability (Sumskiene, et al., 2014).

The non-governmental and public sectors, media, and general society in Lithuania are only just starting to accept the concept of multiple discrimination. Non-governmental organisations representing different vulnerable groups are just beginning to collaborate, build coalitions and implement joint projects. Nevertheless, these new trends are influenced from the outside, i.e. by the international context and pressure to offer consolidated support. However, these are episodic fragmented practices that do not represent the integrated approach nor response to inequality. The paradigm of identity politics, where a group identity is based solely on one aspect of that identity, and then on this basis the political response is consolidated, stimulates and supports the atmosphere of permanent competition. Thus different social groups are forced to compete for limited resources, political influence and societal attention.

The fear that women's issues will dominate over the disability problems or vice versa, and that increased attention to persons with disabilities will undermine the existing gender equality instruments and politics, augments obstacles to ever eliminate discrimination experienced by those confined in the intersection of different identities (Sumskiene, et al., 2014).

The aim of this article is to analyse the intersection between a social gender and disability, and identify differences between perceived¹ and attached² identities of women with disabilities in Lithuania.

The Republic of Lithuania lies on the eastern coast of the Baltic Sea. The neighbouring countries are Latvia, Russia, Poland and Belarus. Its geographical size is approximately 65.3 thousand sq.km. The population of the country was estimated to be 2.9 million in 2015. The predominant religion in Lithuania is Christianity, with the largest confession being Roman Catholicism. Lithuania is a constitutional, multiparty, parliamentary democracy. The legislative authority resides in the parliament (Seimas). The president oversees foreign and security policy, addresses political problems of foreign and domestic affairs.

¹ Self-attribution to a certain group(s)

² Dominating societal perception of which group(s) an individual belongs to

The Supreme Council of the Republic of Lithuania adopted an Act on the Restoration of the Independent State of Lithuania on 11th March 1990, following the five decades of occupation by the Soviet Union. In 2004 Lithuania joined the European Union and NATO. Over the quarter of a century of its independence Lithuania has been implementing basic political, economic and social reforms, while transiting towards a democratic, human rights and western values dominated country.

Interplay between Identities

Homogenous attitudes towards both women and men hinder a precise evaluation of the differences in experience arising from aspects of a person's identity: race, social class, age, sexual orientation, ethnicity, health status and other complex diversity facets (Anthias, Yuval-Davis, 1989; Harris, 1991; Lorde, 1984; Nussbaum 2000). Hence, it is essential to abandon restrictive binary logics or opposites-based analysis (e.g. female experience vs. male experience). It is important to assess and evaluate the interplay between various aspects of a person and his/her identity. Kimberly Williams Crenshaw (1989) discusses the specific vulnerability of women, who find themselves in the intersection of 'race' and 'gender'. She uses the term 'intersectionality' when writing about the obstacles encountered by black women in the field of employment. This indicated that a situation where the category 'women' was mainly identified with being 'white' and a 'black' identity was associated only with men; in legal terms black women became invisible and suffered from double marginalisation and social exclusion.

When investigating situations with an intersection of two or more basis for vulnerability ('race' and 'gender' in the given case), the focus should not be put on only one of them in isolation. For example, in cases of developing women's programs the ethnic background of women and related needs may be overlooked, since being female is considered the key aspect. Also, in programs that target immigration issues, measures are designed without regard to the 'gender' aspect and related peculiarities, due to the whole focus being placed on their citizenship status. As an alternative, Crenshaw (1989) proposes the analysis of interplay of various grounds for inequality, which shows how the different components of the intersection transform their content or change the understanding and perception of the different aspects of identity.

A person is not a basic sum of the definitions of himself/herself. Age, sexual orientation, ethnicity, disability and other differences form qualitatively different expressions of femininity and diverse sex or gender experiences by groups that are defined by ethnicity, sexuality and other categories. This integrated, mutually (trans) formative impact is aptly defined by the Complexity Theory developed by Sylvia Walby. She notes that every system uses other surrounding systems, and consequently changes under their influence (Walby, 2007). It is therefore inaccurate to assume that a system as a whole is formed simply by a sum of the individual components. Whilst speaking about the processes taking place in society, she stressed that

the situation in each of the social areas (in economy, politics, systems of violence or civil society) changes due to the changes in other areas, and these changes also result in respective content changes. The same is true in terms of formation of a personal identity (such as gender), the content of which varies in interaction with other aspects (such as physical disabilities).

However, being aware of the cultural context as a part of the systems participating in complex interactions, it has to be admitted that due to the inequalities within the dynamics of power on the institutional level, various identities and bases for vulnerability receive unequal attention, treatment and state security (Verloo, 2006). According to Hancock (2007), this creates preconditions for the 'oppression Olympics', i.e. a competition in pursuit of the nomination of the most disadvantaged to achieve political attention, without the changing of existing systems or practices. In individual contexts this promotes revision of the components of an identity, aiming to emphasize one aspect and reduce the importance of the other aspects.

Mieke Verloo (2006) notes that the origin of categories of gender, race, ethnicity and class is perceived in several different ways in society. For some, the argument of 'nature' is invoked, while others are regarded as the consequences of social practices. For example, differences between people, arising on the basis of their social class, are stereotypically associated with the economic and social processes. Whereas, 'race' is seen as resulting from biology or nature, also being closely associated with 'ethnicity', which tends to be perceived as a result of educational, cultural and geopolitical factors.

Gender, as Verloo specifies, is commonly seen as a phenomena of having two positions at once that are perceived as originating in nature, as well as in biology. Although the perception of a biological origin is contested, and gender is often defined as a socially constructed set of interpretations, norms, symbols, behaviours, institutions and identities, only the post-modern gender theory includes biology in the social construction of this concept. Such understanding is hardly ever a part of gender equality policies nor is it integrated into addressing the demands of feminist organizations.(Verloo, 2006).

The concept of disability is not unambiguous either. A close link between this 'condition' and the body's (dys)function on the basic level promotes the interpretation of disability as a 'natural'/ 'nature related' phenomenon, especially in the case of congenital disability, or a 'deviation' from the general 'norm'. The

legitimising identities view impairment as 'abnormality' and it may be viewed as the most significant part of a person's identity. The subsequent social exclusion and segregation involve issues of isolation and lack of community support. Such approaches to identity have led to various different models of disability to develop.

In light of achievements in the field of medical science, the concept of a 'healthy' person and one who is 'disabled' (which promotes culturally and socially constructed interpretations of disability), is becoming more and more problematic. Back in the 1970s, the social model of disability emerged challenging the then predominant bio-medical model, within which the impairment or health condition had been seen as the main problem, thus focusing on 'fixing' or 'curing' the individual. However, according to the new approach, a disability was viewed as a social state, rather than as a bio-medical condition. This has led to the emphasis being put on the people's rights to services and promotion of laws to end discrimination. The social model uprising in reaction by people with disabilities to their experience of social exclusion caused by social responses to impairment. It promotes citizenship, rights, inclusivity, mainstreaming and self-representation rather than domination of clinical expertise.

This intermediary position that acknowledges both the naturally occurring aspects of the human condition, as well as the influence of socially constructed norms, may be applied to the assessment and categorisation of 'gender' and 'disability' in a similar direction. On the one hand both these categories are seen as 'natural' factors, fundamentally related to the nature of a human being and peculiarities of a human body, which strongly affect the direction of a person's functioning within society. On the other hand, this direction is also under the major influence of external social, cultural, political and economic interventions.

However, with regards to their social significance, categories of 'gender' and 'disability' are not seen as being equally the same and tend to affect the reality of individuals differently. The 'gender' category, similar to those of social class and 'race', is one of the fundamental foundations of social order across societies. The common perception tends to determine it as a strictly fixed and a very specific construct based on binary opposition (female vs. male). The traditional approach to boundaries of the 'gender' concept essentially has no permeability. When a child is born, it is automatically designated as either male or female; hence the existing order is inevitable.

Compared to the average lifespan of a person, changes within the gender system are significantly slow. In the meantime, the disability category is commonly understood more as a spectrum or a scale, rather than a strict opposition. It is generally viewed as a nuanced shift, moving from one extreme ('perfect health') to the other ('major disability'). Research shows that in most cases, which amounts to approximately 83%, disability is a condition that develops during the course of a lifetime, rather than something that a person is born with (NHS, 2014). Therefore, in many cases a person who had thought of him/herself as 'healthy' has to construct their personal identity anew (Swain and French, 2000). Here the contraposition of the concepts of 'healthy' and 'disabled' can be questioned and challenged. The concept of 'temporarily able bodied', instead of 'healthy' is thus proposed (Marks, 1999; Rae, 1989, Garland – Thomson, 2001).

Differently from gender, disability may not be defined as a collection of visually and socially accepted, predictable attributes. Rather, disability is treated as a deviation from the existing physical or mental health standards within society and its culture. According to Garland-Thomson (2011), the notion of disability combines heterogeneous group of individuals, whose sole attribute they have in common is a 'deviation' from accepted 'norms' in society.

There is no known society where a person could expect to avoid the categorisation by sex or gender. The possibilities of changing one's ascribed category of sex following birth is complicated significantly. In Lithuania, individuals who are determined to achieve this face complex legal, medical and social barriers. Hence, sex or gender is the most numerous social category.

From the global perspective, the status of disability is linked to a relatively smaller number of individuals. There is no unified monitoring system that would make it possible to evaluate the total proportion of people with disabilities in society (WHO, 2014). Moreover, there is no universal legal definition of disability. Nevertheless, researchers state that "persons who have disabilities are the largest minority group in the anyway overcrowded act of multiculturalism" (Davis, 1995 cited in Goodley, 2010 p.2). This social group may be called the invisible, even though it is the largest, minority. This is due to the fact that their opportunities to express themselves in the cultural, political and economic life of society are limited by the inaccessibility of the environment and social stigma, as well as unmet health and individual needs.

One of the most prominent disability researchers, Shakespeare (1996), has determined the analogy between the origins of the terms gender (a 'social sex') and disability. The notion of gender was brought up as a counterweight to a female or male body, deeming masculinity and femininity to be socially constructed roles. The concept of disability sprung as an opposition to terminology such as 'functional disorder' or 'impairment'. Such concepts emphasize physical, mental or sensory limitations, whereas the term 'disability' encompasses the availability of opportunities to participate equally in society, and loss or constriction of such possibilities, due to existing physical or social barriers. This change in paradigm has shifted focus from the body as a defining attribute, to social relations that determine personal subordination, in both feminist and disability movements (Shakespeare and Watson, 1996). In order to better understand how women with disabilities construct their own identities, which in its turn influences their self-consciousness, we need to find out how contemporary society represents and forms concepts of femininity and disability.

Post-feminist Approach to a Woman

It is noted in academic literature that the way media and mass culture represents women recently has changed significantly: instead of being portrayed as passive objects designed to please the male's eye, especially young women are presented as active, independent and having a sexual power (Ringrose, 2013). These changes in the representation may be seen to be related to the 'post-feminist turn'. According to Rosalind Gill, the term 'post-feminism' has become overloaded with various different meanings: "*In recent years, debates about everything from the history and exclusions of feminism to the gender consciousness (or otherwise) of young women and the ideological nature of contemporary media, have crystallised in disagreements about post-feminism*". However, she proposes a new understanding of post-feminism, which can be used to analyse the contemporary cultural products. Gill argues that post-feminism is best thought of as a sensibility that characterizes increasing numbers of related films, television shows, advertisements and other media products (2007a). In her opinion, post-feminism is best regarded as an understanding or an approach, which represents the interlacement of contradictory feminist and anti-feminist themes.

The researcher distinguishes between several relevantly consistent features that describe the post-feminist understanding. Firstly, it is characterized by transition from *objectification* of women to *subjectification*. Secondly, self-monitoring, self-control and self-discipline are emphasized. Additionally, the

focus is directed at individualism, choice and empowerment, as well as against predominance of the 'beautification' paradigm. Moreover, the idea of natural differences between different gender groups is restored, whilst the sexualisation of mainstream culture is emerging and consumerism is highlighted. Finally, the connection is made between the concept of femininity and peculiarities of a female body, which is especially relevant and important to the topic addressed by this article (Gill, 2007a).

Rosalind Gill (2007b) indicates that one of the most staggering aspects of the contemporary media culture is the overemphasised obsession with a human (female) body. Femininity is represented not as a social, structural or psychological quality but mostly as an attribute of a body. Correlations are made between femininity and possession of a 'sexy body', rather than such characteristics as affection, care or maternity, which were predominant in former eras (Rotundo, 1993). The 'sexy body' is seen as the main, if not the only, attribute of a femininity. On the one hand a sexual body is rendered as a female source of power, however, at the same time it is seen as something that has to be subjected to external control, care and discipline, as well as change (e.g. through consumerism and expenditure), in order to meet the ever growing demand for rigid and limited standards of female attractiveness. According to Rosalind Gill (Gill, 2007a), reporting on women's bodies constitutes one of the largest parts of all content covered by media of various genres. Bodies are constructed as a 'window into the inner life' of a woman and are examined, as well as critically reflected upon by both men and women themselves.

The higher attention paid to the female body as a determining factor for her feminine essence is related to the overpublicised sexualizing of contemporary culture, and normalisation of pornographic images in the mainstream media, with its ever younger target groups. These trends should be critically reflected upon, although not in order to support the 'anti-sex' groups, but aiming to draw attention to the consequences of such representations in society, where sexual violence against women is rampant (EWL Barometer on Rape – Report of European Women's Lobby, 2013). Moreover, such criticism seeks to reveal the discriminatory nature of related practices that foster social exclusion. According to Rosalind Gill (2007a), only a certain 'type' of women is constructed to be seen as active, sexual desire-driven subjects. Such women are portrayed as the ones who desire sexual relationships with men; they are preferably young in age, thin and pretty. In addition to this, Myra Macdonald states, that women who are of an older age, higher body weight, have wrinkles, etc., are never assigned a sexual 'subject-hood' and instead often remain a

subject to offensive and sometimes even vicious representations. Indeed, the figure of an 'unattractive' woman, who is actively seeking a sexual partner, remains one of the most vilified characters in a range of popular cultural forms as referenced by Rosalind Gill (2007a).

Disability Perception

In previous decades, the image of the body in disability studies has differed from its manifestations in the post-feminist discourse. Hughes and Paterson (1997 pp.326-7) notice that sociologists 'discovered' the body in the 1990s, and at a similar time disability studies moved it into somewhat 'discursive shadows'.

Orientation towards the body, pathology and defectiveness of the anatomy, or the bio-medical model of disability, dominated for most of the 20th century. In this model disability was perceived as a bodily defect, which affects the personal tragedy of an individual. Society, relatives and professionals could provide only sympathy, treatment and support. The social model of disability emerged in 1976 when the Union of the Physically Impaired against Segregation³ (UPIAS) publicised *The Fundamental Principles of Disability*, where they stated that:

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1976 p.14).

This approach opposes the bio-medical model and maintains that disability is a social construct, created by the physical, social and other barriers, evident in a world adapted solely for persons without disabilities (Stone, 1984, Finkelstein, 1993, Oliver, 1993, Hughes and Paterson, 1997). Removal of these obstacles rather than elimination of medical defects would allow more successful functioning of individuals with disabilities in society. In the bio-medical or individual model of disability, which is highly prevalent in society, the impaired person is seen either as a problem or as the cause of a problem. Such an approach to disability leads to absolute discrimination and contravention of human rights. On the contrary, the social model of disability is a holistic approach to disability developed by activists who had disabilities themselves, and it explains the restrictions and exclusion experienced by persons with disabilities, as a result of social-structural, attitudinal and environmental barriers (Pierson and Thomas, 2002 p.440).

³ An organisation of persons with disabilities, established by residents of a social care institution in the UK. They established and presented a completely new concept of disability, and tackled it in a more comprehensive and global way (Hunt, 2001) <http://www.labournet.net/other/0107/upias1.html>

Current and past trends in disability studies and disability activism aim to shift focus from the body towards social factors. Nevertheless, the perception of disability by society is mainly based on bodily and behavioural differences, rather than external obstacles. The ideology of treatment dominates over the disability studies' discourse: money for medical procedures is collected through charity campaigns, and professionals tend to correct and regulate 'deviant' bodies and minds. As Garland (2002 p.15) notices, these attempts to 'normalise' bodily variety often happen at the cost of otherwise potentially adjusting environment and changing attitudes.

According to Garland (2002 p.5), "disability is a broad term within which cluster ideological categories as varied as sick, deformed, crazy, ugly, old, maimed, afflicted, mad, abnormal, or debilitated – all of which disadvantage people by devaluing the bodies that do not conform to cultural standards". Disability researchers maintain that these degrading stereotypes are predominant cultural narratives, which are communicated to individuals through the traditional socialisation channels such as schools and mass media (Rappaport, 2000).

In the post-feminist approach, as it is defined by Gill, women are closely associated with their bodies. This association augments cultural narratives of disability, thus women who have disabilities are perceived as helpless, asexual, unsuitable for maternity and pushed away from traditional female roles as wives, housewives, or mothers, in the predominant discourse (McDonald, Keiz, Balcazar, 2007, Fine and Asch, 1988; Morris, 1993). Nevertheless, researchers notice that people are not passive observers of public discourses. They are able to interpret information received from the media, therefore they are often called the 'active audience' (Fiske, 1989). Later in this article, the following question will be analysed; are women with disabilities an active audience, able to transform the traditional perception of gender and disability, and form their own self-perception. This will be done through a presentation and analysis of two empirical studies.

The Research

Data from two qualitative research studies form the empirical base for this article. The first one took place in December 2013 – January 2014. A group of researchers completed a study that was requested by the Equal Opportunities Ombudsman's Office under the name of "Quality of Life of Women with Disabilities in Lithuania". The target group of this study were working age women with sensory, physical, psychosocial and intellectual disabilities. Twenty women with various disabilities and socio-demographic characteristics participated in the research. Semi-structured interviews were used as the data collection method (Sumskiene, Jonutyte, Augutiene, Sumskas, 2014 p.7). The aim was to analyse the quality of life of women with disabilities, with the main focus being on intersection between the two grounds for discrimination: gender and disability. This study provided an in-depth analysis of personal experiences related to health, family, housing, education, labour, income, civic and political participation, security and other aspects of the lives of women who have disabilities.

The second research study was completed by NGO Mental Health Perspectives in September – October 2014. Its goal was to analyse the development of societal attitudes to vulnerable groups in 2009 – 2014, in order to identify the main reasons for discrimination and provide recommendations. In this study, disability was identified as one of the grounds for discrimination. This piece of research employs data gathered during focus group discussions by persons with disabilities. A total of 12 individuals shared both personal experience of having a disability, and being a member of a disability NGO (Sumskiene, Jankauskaite, Levickaite, 2014 p.34).

Both semi-structured interviews and focus group discussions were based on questionnaires that contained inquiries concerning: personal experiences of living with a disability, being a women and mother, experiencing discrimination and exclusion on both grounds of discrimination, and having survival strategies developed to cope with related daily challenges.

The analysis of interviews was supported by the qualitative data analysing software NVivo8. It was pursued using the six steps approach: transcription, paraphrasing, development of captions, theme comparison, sociological conceptualization and theoretical generalization (Meuser and Nagel, 1989).

This article presents results of the empirical generalization: similarities and differences of participants' experiences are named, as well as their knowledge structures are generalized. The analysis is illustrated with quotations by the participants, which is presented in the form of a translation of the authentic language.

Interview Analysis

A data analysis reveals ambiguous relationship between various aspects that influence the forming of an identity. The interviews and focus groups that were a part of a study called "Analysis of a Situation of Women with Disabilities" show that disability is the factor, which consciously structures the women's self-awareness and self-reflection, more so than that of gender. The greater emphasis placed on experiences dealing with disabilities, rather than gender, can be explained by the nature of the survey conducted, i.e. the respondents were directly asked what effect their disability has on the quality of their lives. However, cases being especially rare (exclusive rather than typical) of the respondents' reflection on their experiences as *women*, suggests that the aspects related to disability and gender are given very different meanings within the structure of an identity. Disability is a component which is more notable and reflected upon. In this sense the self-awareness of the respondents is more often based on the 'active approach strategies, i.e. the predominant critical approach to disability, which describes the person with a disability as a 'deviation from the norm' and allows space for challenging of the perception of the normative subject.

The 'invisibility' of the gender aspect of an identity suggests that it is seen more as a 'natural', unquestioned and fundamentally unchallenged factor. This circumstance significantly decreases the opportunities for 'active approach'. It becomes more of an absorbent rather than a transformational normative that hinders any development of a subordinated structure changing predominant gender practices.

Disability Issues: "But I am a Person!"

The 'perfect' (normative) member of society in our culture is constructed as someone with a healthy body, according to which politics of a social state are also being formed. Special programmes are being created in order to 'meet' the needs of persons with disabilities. Hence, integration strategies for the 'largest minority group of society' are often not even suggested. Such a political practice forms a public discourse which is based on contraposition between 'us and them', where a person with disabilities is labelled as 'different' or 'the other'. However, the 'active approach' allows women with disabilities to reject this dichotomous approach, and not to feel social exclusion, under an inclusive and non-discriminatory atmosphere: "I probably have not been identifying myself as a disabled person in general" (Vilma).

In the 'active approach', the opposition between the 'healthy'/ 'normal' and 'disabled'/ 'deviated from the norm' is rejected whilst emphasizing the need to change public attitudes towards people with disabilities: "to value the person, not to feel sorry for him/ her" (Aldona). It is suggested for the person's quality of life and not the body condition to be the main reference criterion. In turn, a better quality of life is mostly associated with 'spiritual', rather than physical or material aspects. Respondents do mention the spirit, the soul, which they say must remain strong whilst their body's powers are weakening: "your soul, your spirit will see you through it. You will continue to do everything that you used to do when you were 'healthy'." (Audra). The concept of a quality of life is also related to the level of autonomy, i.e. the ability to manage your life at your own discretion, meet own physical, social and spiritual needs.

The aim to achieve more independence, depending on the individual health condition, is an especially vivid leitmotif amongst the respondents. It is revealed through their efforts to adapt their living environment to their needs, which is often done through investment of personal time and money, not waiting for or trusting the institutional care or support. Additionally their striving for more independence is visible in the women's formation of social networks (families, relatives and friends), which provide an opportunity to have targeted support and assistance, and at the same time preserve independence. Here the life of a 'loner' is seen more as a sign of independence rather than that of loneliness; in a way it is a proof of independence to self and others.

Respondents indicate that living together even with the closest people (a friend, sister or parents) is somewhat disruptive to the set usual day-to-day life and order: "they come and put all cookware on the top shelves..." (Audra). However, the alignment with ordinary families, where adult children live independently and separately from their parents, as well as their desire to maintain autonomy, is noted here. The respondents find the reverse ratio more acceptable, where they live not with 'personal assistants' to them but where they are able to provide support to others themselves. Women with disabilities capable of working at home and dealing independently with their daily lives become the centre of attraction for their relatives and loved ones. They are proud of their necessity and give meaning to themselves as the asylum providers for their relatives. Although such residents sometimes prevent them from "enjoying freedom", women with disabilities find the status of being a carer attractive, because it dismantles the traditional model of power, in which the superiority of the 'healthy' prevails. The ability to help provides the opportunity for self-empowerment. Moreover, a number of the respondents said they support homeless people. This symbolic gesture also has influence on empowering them: "they told me, they respected me" (member of a focus group).

External support is appreciated but care and 'privileges' are avoided, since those are seen as promoting the status of being 'different': "Overall, not many people know what I can or cannot do because I try not to make it visible" (Rasa). On the other hand, women with disabilities happily accept the support that is unrelated to their disability, i.e. such help that highlights men's help and support as something done to assist them as women, not as 'the disabled'. This point will be discussed further in the section *'Genderless Living Beings': Establishment of One's Own Identity* later in this article.

The revelation of one's insecurities and vulnerabilities often makes the person feel 'weaker' and opens up an opportunity for bullying to occur in society towards people with disabilities. Humiliation and devaluation severely affects any person's dignity. It exists as a form of emotional abuse that de-humanises the 'other' individual. This model of behaviour is by now acknowledged by society and understood as a violation of a politically correct approach to equality and diversity: the declared discourse of tolerance teaches the 'stronger' ones not to harm the 'weaker' persons. However, the experiences of the respondents in this research reveal that contempt is still prevalent towards persons with disabilities. It still exists as an integral part of the socialization process for them, where curious children take after their parents and inherit

negative attitudes or hyperbolic caution towards individuals with disabilities: "do not look that way child, let's go, let's go..." (member of a focus group).

The respondents shared that another very straightforward gesture of protection against the alleged 'evil' is making the sign of the cross over persons with disabilities by others on the streets. The respondents see this as a humiliating discriminatory practice based on alleged sympathy: "I say: "And why are you making that sign of the cross over me?", and she says: "You are so young, and [poor] you are in a wheelchair..." (Aldona). Society tends to struggle to understand subordination practices that are based on exaltation of those who 'have the power'. The misbalance of power within the action of 'tolerance' is often not even challenged. In the day-to-day practices this manifests itself as frequent provision of 'generous patronizing pity', which in turn becomes a symbolic gesture of marking and promoting social exclusion.

The social model of disability is vivid in the attitudes of the respondents: "Of course the fact that the environment is not adapted makes a physical disability more profound" (Audra). Hence, barriers to fully-fledged existence of a human being are challenged by such institutional ways as approaching the media, joining disability forums and movements, as well as local communities. Whilst considering this you can hear perseverance, self-discipline, determination and motives of new initiatives in their voices: "I will fight for my rights and I will continue proving my point, and if I need to I will go public, but I will not give up. Because otherwise there is no life." (Aldona).

Rethinking the effect their health condition has on their lives and formation of their own identity, women with disabilities tend to identify with the normative subject and claim their right to the full recognition: "I am a *person*, even though in a wheelchair, I am still a *person!*" (Aldona). Using a general category 'a person' gives the women the opportunity to reject the opposition between 'the norm' and 'deviation from the norm', and instead to form a positive self-image and an active civil position removing discrimination or simply overcoming the daily encounters of physical and social barriers in their environment. The fight for their fundamental rights, determination, self-discipline, persistence and aspiration for individual autonomy gain a positive sense in this context. However, from the perspective of gender equality, these attributes are seen as those of a 'real man', which in itself gives meaning to the normative subject. It is being constructed not only through the opposition between a 'healthy' and 'disabled' body but also through

that of 'femininity' and 'masculinity', which in a way leaves women with disabilities with a dilemma: to be a *person* or to be a *woman*..?

Gender Issues: "You are all just the same as the other women"

Identification of beauty with femininity in the Western culture is deeply rooted. Numerous examples of this 'requirement' can easily be identified in daily routines of female socialization. However, in the post-modernist culture this imperative is significantly adjusted. The contemporary cultural requirement for beauty encourages all-inclusive care and control of behaviours, actions and daily practices, as well as disciplining of the body; constantly aiming to achieve greater effects towards the creation of individual sexuality (Gill, 2007b). Whilst analysing the effect of this culture on adolescents' self-conceptualisation via social media, Jessica Ringrose (2013) notes that certain sexualised discourses and images determine girls as sexual objects and shape the core of their subjective sexual performance. The discourse on sexualised topics is not avoided by women with disabilities either, but the response to these topics in that sense becomes much more complex than the trajectories described by Jessica Ringrose.

In this context some of the culturally formed aspects of femininity are adopted, others are either ignored or strictly rejected. From the perspective of women with disabilities, the internalization of the predominant attitudes of society becomes a barrier in itself. For example, women who have various health conditions are unable to meet the socially constructed requirements for 'ideal femininity', such as to be young, pretty, thin and healthy. Hence, from the perspective of the normative subject, they feel like they cannot be seen neither as a man, nor a woman. As a result, the experience quoted by several respondents is that of becoming a 'gender-less child', the object of pity and sympathy: "oh dear child, it is so bad for you, will you live poor thing..? Hey but everything will be alright, don't you worry..." (member of a focus group). On the other hand, the lack of alternatives within the public discourse lessens the women's possibilities to use the 'active approach' and oppose the proposed 'norm'.

Women with disabilities experience double discrimination in the gender system. Being female they experience deviation from the 'norm' associated with masculinity, at the same time their disability leads to deviation from the socially constructed ideals of femininity. Being present together at the same time the aspects of disability and gender hinder the person's positive self-concept significantly. However, the subordinating effect of the two concepts is absorbed differently and this affects formation of self-concept differently in different individuals. On the contrary to the situation of the case of disability, the social model does not work from the perspective of gender. This is due to the lack of opportunities to meet the set

criteria for adhering to the normative requirements of femininity, being more clearly defined, i.e. to be pretty, lovely or to start a family and have children. As a result women become frustrated and sad, and start defending themselves through alternative methods such as sarcastic remarks. But on the whole the 'norm' of femininity and especially the order of gender remains unchallenged: "And would you imagine, a beautiful, wonderful, great woman all of a sudden becomes disabled..." (Audra).

Disability turns self-concept based on gender into something that could be described as a metaphor of a 'dotted line'. For example, some practices that symbolise femininity are reproduced: "If I'm going out, I do still want to put make up on and dress up nicely" (Marija); others are perceived as barriers: "You can always change something, because I wouldn't live in a tent, maybe I could try but I am a lady so... Somehow I find it awkward to go into this adventure" (Dana).

However, the respondents perceive both positive and negative aspects of 'being a woman' as a given fact. For example, the attitudes to gender or experiences caused by the existing social order of gender go unnoticed more commonly, contrary to those related to disability. Discrimination on the grounds of disability is noted, challenged and rejected, whereas the institutional blindness with regards to gender aspects is mostly not even noticed. This is especially vivid in the experience described by Audra, where rehabilitation procedures in a respective institution that degrade female dignity are first of all described as related to the environment not being adapted to the potential needs of persons with disabilities, rather than ignorance with regards to the gender aspect, e.g. the unavailability of a hoist. The discomfort felt by women who have to take their clothes off in front of strange men is only mentioned in fragments: "There is a hired man. He arrives to lift you whilst you are naked, it's so 'fun'... Lifts you in naked – lifts you out naked... You are like a robot, you see..." (Audra).

The opportunity for women with disabilities to form emancipated sexual identity, is particularly hindered by the cultural norm of femininity being deeply sexualised, i.e. the glorification of young and thin, idealised bodies, rather than a more representative commonly had human experiences. All practices, including the sexual and sexualised ones, are turned into objects of continuous self-control and discipline that is ensured by the public discourse in the post-feminist context. It sends out ambiguous messages, presenting the active sexual expression as an imperative of contemporary femininity (i.e. a 'true woman' has to be sexy) but also as a social deviation from the 'norm' (i.e. the epithets demeaning women often refer to

an active but commonly unacceptable sexual behaviour). Hence, women, including those who have disabilities, are in the middle of an imprisoning dilemma of whether to be sexy or not. Nevertheless, whichever strategy they choose, (to celebrate their sexuality or to suppress it), it does not help them avoid the main socially constructed requirements for expression of femininity. Related dilemmas are experienced especially profoundly when it comes to making decisions about having children, and discussing reproductive health issues with doctors.

Medical doctors are representatives of the profession, who accommodate discussions about the most intimate aspects of one's health. They are amongst those who understand diagnosis best, along with the daily barriers and consequences of it. However, research shows that medical doctors tend to ignore the strengths of their patients, along with the opportunities and wishes of women with disabilities to live independently in the community. Representatives of this profession are amongst the first ones who tend to reject femininity of women with disabilities, especially when it comes to gynaecological issues, pregnancy or birth giving. Experiences of the respondents demonstrate that within the medical sector, only the disability aspect is recognised: they are almost perceived as 'genderless living beings' (member of a focus group). Medical practitioners are often surprised by the questions of women with disabilities in relation to sexual life: "Oh, so you have a boyfriend? Really? Wow, that is something surreal" (member of a focus group); and by questions related to gynaecological complaints: "So you should be happy that your periods have stopped" (Sandra); and towards a will to have children: "When I take my child to hospital, everyone looks at me instead of attending to my child: as if to say how is that possible..?" (member of a focus group).

Some of the respondents did look for and eventually find gynaecologists and other professionals who attended to their reproductive health adequately, supervised them during pregnancy and helped them to have children. Others had experiences, where medical doctors showed respect to their femininity: "You are all just the same as the other women, do you hear me?" (Audra). However, some respondents recalled experiences where respective professionals were usually rude and disrespectful towards women with disabilities: "A nurse called the doctor through an open door, and he responded by shouting back to her that he is attending to a 'neurological invalid'" (Audra).

Disability does make it more difficult for women to resist dehumanization. And culturally associating femininity to a youthful, sexy, perfect body, hampers the achievement of a positive gender based self-

image, which ultimately would provide individuals with more space for practices that could transform the predominant social 'norms'.

Genderless Living Beings”: Establishment of One’s Own Identity

Women with disabilities face various reactions from others that emphasise their differences and subordination. A part of such reactions is based on the understatement of vulnerable individuals, (while others are based on exaggeration of those in power). Nevertheless, their common denominator is disability being the only dominating part of their identity. In most cases this also leads to ignorance and derogation of their femininity and autonomy. Women with disabilities face both contradicting constructs, they are neither able to unambiguously position themselves as women, nor deny the narrow disability identity. Therefore, women with disabilities become active moulders of their own identities.

The research reveals two pronounced components of the identity of women with disabilities: self-sufficiency and femininity. Their self-sufficiency, emphasises a strength, motivation and ability to overcome barriers for functioning in every step of their lives. The research participants managed to adjust their living environment, feel safe and comfortable in their homes and find and keep a job; achieving respect and appreciation by their colleagues and managers. Further proof of self-sufficiency is the capacity to actively participate in the social and cultural life of society, which is traditionally highly inaccessible for individuals with disabilities. Self-sufficiency in most cases means a persistence to achieve their goals, the ability to use their own ingenuity or the social capital: “I managed to slip into the gallery through an emergency door” (Albina); “Anyhow I went to the concert... I found three men and they took me upstairs. Even so I managed” (Asta).

Also the research revealed more complicated manifestations of self-sufficiency in problematic situations. For example, women with disabilities are generally more vulnerable to violence or abuse. Nevertheless, research respondents expressed their feeling of psychological safety because of their disability, due to their own belonging to a socially vulnerable group: “Sometimes I think that, if they attacked some lady, they wouldn’t assault someone in a wheelchair. I suppose that they would see a soul mate in those wheels.” (Agne).

Women with disabilities find ways of maintaining self-sufficiency even in degrading situations, fraught with demean of their femininity. For example, sanatoriums are not equipped with adjusted lifts, therefore women with disabilities must seek help to get into the baths: “You go to the corridor, ask some men to get

you all naked into the bath. Fun, isn't it?" (Asta). Women are deprived of their dignity during these humiliating procedures, nevertheless, they try to keep at least their financial self-sufficiency paying for these services: "You pay for everything. You hire people... Five, ten litas. And it makes you puke when you leave following all this abjection" (Asta).

On the other hand, support provided by men in other parts of life have positive connotations. The collected data shows that women with disabilities appreciate men's help to overcome obstacles: "I used to find three men and they would help me upstairs" (Asta); "There was a staircase... I suddenly felt that my wheels were up in the air and some four men on each side of me..." (Sofija).

The respondents perceive men as helping, reasoning and offering their help not only in the fields, which traditionally require 'man's' power. Their help is more acceptable to women with disabilities because they tend to perceive it as a disability-neutral man's help to a woman instead of services by 'healthy' members of society to individuals with a disability. The positive colour of these experiences lets us assume that women with disabilities tend to reduce their self-nurtured self-sufficiency, if help provided to them can be attributed to a man's help to a woman. In other words, in certain situations their self-sufficiency is easily downgraded to a quasi-helpless image of femininity: "...and everyone laughs saying: "you are beautiful, that's why they carry you"." (Sofija).

There are cases of manipulation involving this quasi-helplessness and a more traditional cliché of the gender roles, where men have been reminded of their duty to 'take care' of a woman. The traditional hierarchy of women being subordinated by men is overthrown when quasi-helplessness is invoked, especially when supplemented with some female attractiveness. This story has been told by a participant of the focus group, a very young and beautiful young lady, who is a wheelchair user: "There was a bet... We were crossing the street, there were those men standing. I was dressed quite normally, no suggestions of being poor, or something. Quite normal, ordinary, properly dressed. I told: men, I need money, I live poor, I lack money. Would you give me some? And that man took out of the pocket, like, almost three hundred litas⁴". (Participant of the focus group).

⁴ Equivalent to 85 euro

Nonetheless, doubts remain as to whether such a reverse of gender-power relations would be still possible if the 'provocateur' would not correspond to culturally accepted codes of female attractiveness.

The situation with regards to women without disabilities is more complicated, and, according to the respondents, has a stronger negative load. For example, mothers prohibit their children staring; older women make the sign of the cross over them. In public spaces women criticise display of female identities, for example, wearing make-up: "...why don't you wear less make up!" (Samanta), or even smile: "An *invalid* smiles, laughs over here!" (Sofija).

When forming their female identity in their daily routine, some women with disabilities rise to the challenge despite the dominating trend to desexualize them: "I do it vice versa. If someone takes me out with a wheelchair, I keep laughing. I feel the way they look at me, that's why I want to show: I'm fine, I'm happy" (Sofija). Others reject the notion of sexual practices: "Afterwards [during the process of rehabilitation - authors] a sexologist storms in and starts explaining about sexual relations and so on... come on, stop these jokes! One should recover first, not now..." (Audra). In both cases, sexual self-reflection is disclosed via opposition or even confrontation of representatives of the normative femininity.

Conclusion

It is important to take the intersectional approach, when analysing experiences of women with disabilities. Within this approach the interaction between the consequences of various aspects of an individual identity, is viewed as an empirical question that reveals their meaning to specific individuals or groups of people. From the perspective of the normative subject, having a disability and being a woman have similar meaning, i.e. both aspects of an identity symbolise subordination, deviation from the 'norm' and being 'different'. Nevertheless, the two aspects of disability and gender gain a very different meaning and weight in the self-consciousness of women with disabilities. Disability is viewed from the perspective of the social model, hence, recognising that disability is either created or made more profound by external environment, social, economic and cultural barriers. Whereas gender bias is being neutralised, thus, systemic barriers that arise due to gender issues, are often imperceptible. As a result, disability discrimination promoting structures are being challenged, whereas gender based order remains essentially unquestioned. Partly such dynamics of self-perception may be explained by looking at it from two different perspectives: that of disability and the one of gender. Opportunities to question such dichotomy between power and subordination are not equal for women who have health issues or disabilities. In the case of having a disability, a certain barrier of opposition has to be overcome, namely the deviation from having a 'normal healthy' body, thus, boundaries of this particular factor are more fearlessly challenged, widened and diminished. Due to the peculiarities of the gender system, a woman with disabilities experiences double discrimination: as a female she is opposed to a man, and having a disability she becomes seen as deviation from the 'norm' whereas a 'healthy' woman is the 'ideal'. However, subordination from the perspective of gender is often not noticed due to the full attention being focused on removal of social exclusion on the basis of disability, even though a woman who has a disability is a woman first, who enjoys laughing, putting make-up on and may desire male attention.

All of the above restricts opportunities for emancipation of women with disabilities; even though awareness of the social aspects of disability promotes positive relation to one's own identity and aspirations to strive for fully-fledged recognition. However, the gender aspect becomes an assumption of a double 'detention'. This is because the essentialist rather than social understanding of gender hinders development of a critical approach to the patriarchal order of gender, which would neutralise female subordination to males. Additionally, it defines the concept of femininity as especially narrow, and in sexualised and de-

humanising ways, which do not allow women to positively cherish their relationship with their own femininity. Whilst concentrating their efforts to be acknowledged as 'true women', the respondents who have disabilities lose the opportunity to object to the subordinated order of gender, hence, gender to them becomes more of a 'fate' than disability.

As indicated in the report *Tackling Multiple Discrimination: Practices, Policies and Laws*, drafted by the European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, "to address the needs and represent the interests of intersectional groups, the European Commission should develop funding sources for multiple-ground NGOs" (2007 p.7). Such an integrated holistic approach has a potential to solve complex issues of inequality more effectively. Additionally, it would help reduce tension amongst various NGOs, who are often left to compete for very limited resources, political influence and attention from society. Organisations that advocate for women's rights should focus more on the fact that women who are representatives of various different vulnerable groups, perceive, experience and express their femininity differently. Therefore, measures that are directed at emancipation of women, cannot be offered according to only one single approach. It has to become common awareness that there might always be internal (i.e. within the certain group of women) objections. At the same time, disability studies should pay more attention to how the dimension of gender may affect emancipation strategies for persons who have disabilities, through either complicating or positively encouraging the individual and group situations.

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