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Breaking the silence: Disability and sexuality in contemporary Bulgaria

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Abstract

This paper explores the silence surrounding disabled people's sexuality in contemporary, postsocialist Bulgaria. The related desexualisation of disabled people is regarded as an instance of disablism that is sustained through medicalisation, patriarchal stereotypes and negative understandings of the bodily difference of 'impairment'. The analysis draws on disability studies and phenomenology in order to elicit the workings of these mechanisms in everyday discourse as represented by an autobiographical essay and an internet discussion. A number of strategies for challenging disablist desexualisation are also highlighted whose point of departure is breaking the silence on the topic of disabled people's sexuality.

Background

Since the fall of the state socialist regime in 1989, Bulgaria has experienced a turbulent 'transition' from centrally planned towards free market economy and from one-party rule towards parliamentary democracy. This transformation has been accompanied by a number of significant social and cultural changes, but also by a number of continuities. The new order ostensibly undermined all kinds of boundaries – national, ideological, cultural. Travelling abroad became easier and people gained unprecedented access to previously scarce or explicitly forbidden cultural resources, a process that has been greatly enhanced by the internet since the mid-1990s. Nevertheless – or probably precisely as a reaction to such disorienting openness – negative attitudes towards *difference* along major socio-cultural axes like ethnicity, gender, sexual orientation and disability have remained relatively stable. Public discussion on such issues was largely silenced during the state socialist period, when the problems of difference were expected to automatically wither away with the abolition of class exploitation. They did not disappear,[1] but neither did they dissolve with the development of the free market and parliamentary democracy after 1989. The results of recent sociological studies strongly suggest that 'at the moment in Bulgaria (and to a different but approximating degree in all postsocialist countries) many real problems exist in relation to the perception and approach towards difference' (Tomova, 2009: 120).

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[1] This is testified by the persistence of gender inequalities during state socialism despite the high inclusion of women in non-domestic labour activities (Tomova, 2009). Also revealing in this respect are the attempts at solving the problems of difference through violence, as reflected in the forceful assimilation of Bulgarian Turks at the end of the Todor Zhivkov's rule (Curtis, 1992).

The interplay between change and continuity over the last two decades of transition is especially pronounced with regard to issues of disability, although Bulgarian sociologists rarely consider this form of difference in their analyses. Two examples will clarify the point. As might be expected, individualism has quickly become the dominant way of structuring relationships with others and the self in the new, aspiringly neoliberal order (cf. Outhwaite, 2011). Nevertheless, disabled people continue to be denied individual agency. This is particularly evident when one considers the ongoing hegemony of paternalistic personal assistance schemes (CIL, 2009). They were first introduced by the government in 2002 and since then have proved time and again incredibly resistant to reforms along the lines of the Independent Living philosophy and practice (CIL, 2009; Mladenov, 2004). The other example is related to lexicon. In 2005, a major legislative change finally substituted the problematic label 'invalid' (*invalid*) with the more appealing 'person with disability' (*chovek s uvrezhdane*).[2] The substitution was promoted by progressive disabled people's organisations, reflecting the self-perception of the majority of disabled people in Bulgaria, particularly those of working age, as suggested by a nationally representative survey conducted in 2001 (CIL, 2002: 15). Yet everyday use, supported by the media, continues to obstinately resist this linguistic transformation – for a great number of Bulgarians, as for most of Bulgarian journalists, disabled people are still 'invalids'.

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[2] Applied to a person, the word *invalid* has the same negative connotations in Bulgarian as in English. Bulgarians usually use the word *uvrezhdane* to refer to the bodily difference denoted by British social model theorists as 'impairment' (Oliver, 1996). In this sense, *uvrezhdane* is also used interchangeably with the word *nedag*. Following the social model of disability (ibid.), I translate *uvrezhdane*, as well as *nedag*, as 'impairment'. Yet in the instances of more ambiguous usage I translate *uvrezhdane* as 'disability' in order to preserve the allusion to the social aspects of the phenomenon implied in the original utterance. My translation is then simultaneously an interpretation informed by the social model of disability.

Illuminating such historical patterns makes it easier to trace the dynamics of *disablism* in Bulgaria. The term is introduced and widely used by British disability scholars as analogous to concepts like sexism, racism and homophobia (Thomas, 2004: 578-579). Accordingly, disablism can be defined as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Goodley and Runswick-Cole, 2011: 604, drawing on Thomas, 2007: 73). This definition follows the insights of the social model of disability (Oliver, 1996) which makes a sharp distinction between the social phenomenon of 'disability' and the bodily phenomenon of 'impairment'. From this perspective, people with physical, sensory and/or mental impairments are disabled by society and it is this particular kind of oppression that is identified as 'disablism'. Since the 1980s, the social model has been very influential politically and conceptually, not only in Britain, but all over the world, including Bulgaria. Nevertheless, it has been criticised by disability scholars for taking the naturalness and negativity of impairment for granted (e.g., Michalko, 2002; Schillmeier, 2010). Such critiques suggest that it is imperative to consider as an essential aspect of disablism the belief that impairment 'is inherently negative and should the opportunity present itself, be ameliorated, cured or indeed eliminated' (Campbell, 2009: 5).

Reports highlighting the inequality, segregation and oppression experienced by disabled Bulgarians have been mounting over the last decade, mainly due to the efforts of grassroots organisations of disabled people. These have included: nationwide studies criticising Bulgarian disability policy as a whole (CIL, 2002; 2003; 2004); critical analyses of

disability legislation (Panayotova and Todorov, 2007); accounts of the inaccessible built environment, of which many recent examples can be found in the media; cases of discrimination adjudicated by the Bulgarian Commission for Protection against Discrimination (www.kzd-nondiscrimination.com); and, reports on the degrading and inhuman conditions within residential institutions (Angelova, 2008; CIL, 2004; BHC, 2011). In sum, the restrictions of activity and the undermining of the psycho-emotional well-being of disabled Bulgarians have been well documented by Bulgarian human rights advocates, with occasional support from the media. The genealogy of this pervasive disablism refers back to state socialist responses to disability (Mladenov, 2011: 479) but, more importantly, it has survived the demise of the regime. In 2007, an international comparative study covering fourteen European countries put Bulgaria on one of the last places (twelfth) in terms of the overall inclusion of disabled people in the country (International Disability Network, 2007). All this raises questions about the underlying features of the present Bulgarian context that sustain and/or facilitate disablism. Several such features can be outlined that might not be specifically Bulgarian when considered individually, but constitute a more or less distinctive physiognomy of the structure underlying disablism when taken together.

Firstly, disability-related regulations, concepts and practices in Bulgaria have been heavily medicalised (International Disability Network, 2007: 64-66; Mladenov, 2004). Historically speaking, such medicalisation[3] can be traced back to the influence of the Soviet approach

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[3] My understanding of the term is very similar to the one outlined by Holm (2009). Drawing on Peter Conrad, Holm (2009: 33) defines medicalisation as 'the process that occurs when a given area of human activity is defined socially as falling under the proper purview of medicine', including 'any state that such a process might lead to'. Thus medicalisation 'involves allowing the medical profession sole or pre-eminent power to

of *defectology* (Grigorenko, 1998) during state socialist times (on the Soviet medicalisation of disability see Iarskaia-Smirnova, 2011: 120). At present, it is most conspicuous in the standard method for certifying disability status – the 'Medical expert assessment of the ability to work' that exerts significant material and symbolic power over all structures and processes concerning disability (Panayotova and Todorov, 2007; Mladenov, 2011). And, as will be argued in the second part of this study, the medicalisation of disability permeates everyday discourse too. Secondly, Bulgarian disability policy-making is dominated by the so-called 'nationally representative organisations of and for disabled people' as defined in the Bulgarian *Law for the Integration of People with Disabilities* of 2005. These large membership-based umbrella structures have been criticised for reproducing and sustaining paternalistic and charity-focused approaches to disability (CIL, 2002; 2003; 2004; Mladenov, 2009).[4] Yet they have retained their exclusive position as the government's 'legitimate partner' when disability policy is concerned, enjoying annual government subsidies (Panov and Genchev, 2011). Thirdly, disability-related thought and action in accord with the social model of disability and the Independent Living philosophy is confined to a few grassroots civil society entities. At present, these groups are small in size, financially fragile and often excluded from local and/or national policy-making.[5] So far,

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define a given issue, decide whether or not it is a problem, and define the appropriate (therapeutic) solution to the problem' (ibid.). Holm also highlights the intrinsic relationship between medicalisation and social control: 'the process of medicalization allows the medical profession to take control of an area of life that other parties, often ordinary people previously controlled' (ibid.).

[4] The genealogy of these organisations is far from straightforward. Some, like the Union of the Deaf (www.sgbbg.com) or the Union of the Blind (ssb-bg.net), came into existence well before 1944, albeit under different names. Others, like the National Consumer Cooperative of the Blind (www.npksb.com), emerged during state socialist times. Yet others, like the Union of the Invalids (www.disability-bg.org) or the Bulgarian Association for Persons with Intellectual Disabilities (bapid.com), were founded after the fall of the regime in 1989. The extent to which the state socialist ideology and practice influenced the values, ideas and activities of these organisations is not immediately obvious and requires a separate analysis.

[5] This frailty of grassroots organisations is an aspect of a more general phenomenon: 'The weakness of civil society, in the sense of associational life, remains a striking feature of the postcommunist world.' (Outhwaite, 2011: 8) Outhwaite cites Howard (2003: 13-14), who has pointed out that '[a]lthough the breakdown or

disability has not been pursued as a legitimate and valuable field of study by Bulgarian social and political scientists, nor by those working in the field of humanities.

This list of features is far from exhaustive but it nevertheless provides some clues for imagining the present physiognomy of what underlies disablism in Bulgaria. In addition to these 'macro-level' features though, disablism is also deployed – and challenged – on the plane of the everyday. One needs to look at this micro-level in order to understand the constitution and reproduction of social order and meaning. Common, everyday understandings of disability revolve around people's views about their own and others' *bodies*, and particularly around bodily differences identified as 'impairments'. There is much to learn from this 'carnal politics of everyday life', as Paterson and Hughes (1999) have put it. Proceeding from this presumption, in what follows I will explore how Bulgarians discuss disability in non-expert, public contexts. The conjunction of the topics of sexuality and disability in an autobiographical essay and an internet discussion will serve as a 'magnifying glass' that exposes the ways in which disablism is sustained and/or challenged in everyday discourse.

As far as my own conception of the body is concerned, it is informed by phenomenology, where human body is seen as (i) a vehicle of meaning that is (ii) itself always already invested with meaning. This understanding of the body is captured by the phenomenological notion of living or *lived body*, in German – *Leib* (Heidegger, 2001;

survival of democracy may not be at stake, the *quality* of post-communist democracy suffers as a result of the weakness of civil society, as post-communist citizens become increasingly alienated from the political process, while simultaneously lacking the institutional leverage that organizations might provide'.

Merleau-Ponty, 2002). From such a perspective, *pure* physicality is an abstraction – an objectifying detachment from the meaning-engendering context or what phenomenologists call 'world' (Heidegger, 1962: 91-94). As Merleau-Ponty (2002: 131) puts it, '[t]o be a body, is to be tied to a certain world'. This phenomenological understanding of human corporeality is implicit in most of what follows. It allows me to suspend or 'bracket' the taken-for-granted negativity of impairment without disembodying the human being – an approach that has also been promoted by Paterson and Hughes (1999; for a more recent discussion see Scully, 2009). I will explicitly revisit these points in the conclusion. Now, I will return to the 'macro level' once more in order to introduce the specific topic of discourses on disability and sexuality that will be analysed in the second part of the paper.

Disability and sexuality

State socialism was reluctant to talk about sex. As Phillips (2010: 176) points out in relation to the former Soviet Union, 'questions of gender and especially sex were a closed book throughout much of Soviet history'. This reluctance characterised the Soviet Bloc as a whole, where silence was imposed on public discussion of these issues and even on the open admission of sexuality (Tomova, 2009: 146). Such silencing was even more pronounced in Bulgaria than in East Germany or Hungary, for example, because of the relatively greater degree to which the country was closed off from western cultural influences. After 1989, discourses on sex and sexuality were quickly and effectively normalised and liberalised. Nevertheless, disabled people have remained excluded from

such liberalisation, as if continuing to live under the state socialist taboo.[6] Of course, the cultural desexualisation of disabled people is by no means a specifically state-socialist or specifically Bulgarian phenomenon. It is characteristic of western modernity in general, where disabled people have consistently been regarded as 'sexless beings' – 'aesthetically neutered objects of benevolence and assistance' (Hahn, 1990: 314). Yet the Bulgarian case can furnish important insights into the mechanisms of rendering disabled people 'sexless', especially given the physiognomy underlying Bulgarian disablism outlined in the previous section. In such an analysis, differences from western countries may be easier to spot (cf. Shakespeare et al., 1996) than those from the countries of the former Soviet Bloc, where similarities seem to prevail, although the available information is scarce (Phillips, 2010: 182-183; see also Iarskaia-Smirnova, 2002).

By speaking publicly about disabled people's sexuality, Bulgarians break an important cultural taboo that, although genealogically traceable to state socialist 'puritanism', transcends its boundaries. This is the tacit prohibition on associating issues related to sex with issues related to disability. Western modernity has exempted certain groups from this interdiction, but their membership has almost exclusively been confined to experts in the 'helping' domain: 'There is quite an industry producing work around the issue of sexuality and disability, but it is an industry controlled by professionals from medical and psychological and sexological backgrounds' (Shakespeare et al., 1996: 3). Hughes (2000:

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[6] This situation suggestively parallels the one concerning homosexuality: 'The prohibition of discrimination on the basis of sexual orientation is incorporated in a numbed of normative acts, and particularly in the Law for Protection against Discrimination. At the same time, in the country there is actually no public debate on the problems of homosexuals as problems of power relations in a society that is dominated by hierarchical sexist attitudes' (Tomova, 2009: 147).

564) also points out that, apart from popular prejudice, the 'sexual invalidation of disabled people is mediated by medical knowledge'. The corollary is that discourses related to disabled people's sexuality have been heavily individualised, professionalised and/or pathologised. A 'regime of truth' (Foucault, 1980: 131) has been constituted, regulating *what* can legitimately be said and *who* can legitimately say it. This regime regulates Bulgarian public discourse too, perhaps to a greater extent than in most other European countries, including some of the Eastern European ones.[7] Consequently, the mere bringing of the topic of disability and sexuality in a non-expert public context is already a subversive act, a challenge of dominant mechanisms of truth production (cf. Hahn, 1990: 312-313). Such an act becomes even more subversive when the person speaking is himself or herself (self-identified as) disabled, for it then becomes an instance of *reclaiming the voice* (Milner, 2011) – a cornerstone of individual and collective empowerment and emancipation.

What is needed to make such subversive and empowering acts possible? Spaces for alternative public deliberation are an important foundation because they provide discursive 'clearings' (I am borrowing the term from Heidegger, 1962: 171 and 401-402) where disability issues can be addressed in non-expert – and, accordingly, non-pathologised and/or non-paternalistic – ways. Few such 'clearings' have existed in the twenty odd years of the Bulgarian transition. Among them were the periodicals edited and published by the Center for Independent Living – Sofia, a Bulgarian non-profit, non-governmental organisation of disabled people founded in the mid-1990s with the mission 'to provide

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[7] For a comparative analysis of disability-related policies and practices in fourteen European countries see International Disability Network (2007).

disabled people with the support they need to achieve independent and complete human living' ([cil.bg/en](cil.bg/en)). The Center's periodicals included the monthly newsletter *Independent Living*, of which 52 issues were published in 1999-2004; the magazine *Integral*, of which nine issues were published in 2001-2004; and the monthly magazine *Independent Living*, intended to succeed the previous two, of which six issues were published in the second half of 2004. This prolific publishing endeavour came to a halt in December 2004.[8]

All of the Center's periodicals contained a special section entitled 'Taboo'. It was explicitly designated for discussing openly and publicly disability-related issues that usually remained silenced, including issues related to disabled people's sexuality. I will take as my example an autobiographical essay that first appeared in the *Integral* magazine in 2002 and was subsequently reprinted in the *Independent Living* newsletter in 2003. The four-page essay, entitled 'I, my impairment and sex' (*Az, moeto uvrezhdane i seksat*), was written by Nina Zhisheva and appeared in the 'Taboo' section of both periodicals. This piece deserves to be read not only as a text, but also as an event. It was a venture not simply into uncharted territory, but also into one which has for a long time been dominated by expert knowledge and power. The rich and multi-layered essay is thus an instance of the aforementioned

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[8] I have collaborated with the organisation throughout the first decade of the new millennium, although I have not been directly involved in its publishing programme. All the periodicals of the Center were supported by foreign donors through programmes for civil society development in Bulgaria – none enjoyed any financial support from the Bulgarian state. Consequently, when the foreign programmes ended, the Center's periodicals disappeared, for they could not sustain themselves through free market mechanisms. As in other cases related to cultural and social policy issues, the market proved to be a problematic regulator. For as far as the 'public good' was concerned, the Center's publications had an important and pioneering function – to open up a public space for the articulation of subjugated knowledges. In a similar fashion to state socialist taboos or outright repressions – and similarly to the 'regime of truth' of medicalisation – the market can also silence voices.

'reclaiming the voice'. Below, I reference the text with page numbers only; the translation from Bulgarian is mine.

'I, my impairment and sex'

Zhisheva (2002) identifies from the outset the two interrelated issues that I have already singled out – the desexualisation of disabled people and silence on the topic of disabled people's sexuality:

> Interestingly, has it ever occurred to you that disabled people need sex too? No? According to many they are so 'impaired' and the sex is so 'normal' and natural that it is as if they are mutually exclusive. What is more, for disabled people themselves sex is almost always Taboo Number One. I have a severe physical impairment myself and I know it, alas, from my own experience. I know many people like myself and I admit in anguish that I have rarely heard these people speak frankly among themselves on the topic of sex. (p. 6)

These two issues of desexualisation and silencing are aspects of the same existential-ontological problem. Zhisheva regards sexuality as an essential dimension of full human being – 'sex really incorporates the beauty of everything human' (p. 6). She thus hints at the mechanism for denying the status of subjects (Shakespeare et al., 1996: 3), or, more generally, the 'ontological invalidation' (Goodley and Runswick-Cole, 2011: 608) of disabled people that is put in operation by the denial of sexuality. The violence of disablism (ibid.) which is related to this ontological invalidation is not targeted at a specific feature

of the individual, but at his/her very being. Such violence is experienced by the person who comes to inhabit a world where there is 'no place' for her/him – an uncanny or unhomely dwelling. 'Exclusion, even oppression is a kind of homelessness. It implies a world of bodily discomfort, of being left out in the cold', write Paterson and Hughes (1999: 604). Zhisheva's point is that a profound existential-ontological crisis develops when an essential aspect of one's being is denied a place through desexualisation: 'The woman in me had to fall asleep in order for me to live. (…) Do you understand what I was doing? Allegedly in order to live, I was slowly killing myself' (p. 8).

Where does this desexualisation of disabled people come from? What causes it? Zhisheva suggests that it comes from culture and not from nature – disabled people are not naturally a-sexual. This is the main thrust of her argument and it is rearticulated at several points throughout the essay:

> …with time I also found out something that perhaps will seem preposterous or intolerable [*nelepo i nedopustimo*]… or grotesque. I found out that I, a woman with impairment, think, desire, seek and have a need – a real and completely normal need – for sex. (p. 7) …I was a normal person and needed sex just as much as I needed food when I was hungry or medical assistance when in pain. I needed sex just as much as everyone else (p. 8).

The desexualisation of disabled people is a question of 'upbringing', 'attitudes', 'societal perception' (p. 6). It is made, not given. Zhisheva also identifies the particular cultural construct that is responsible for desexualisation – the perception of impairment as inherently negative, as 'something ugly that, with its very essence [*sas samata si*

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sashtnost], kills the desire for beauty' (p. 6). 'I was ugly. I was crippled. I was prejudged as being no good. I was not entitled to sex.' (p. 8) This negative understanding is tied to a stifling charity attitude: 'Just about that time – as if from the Salvation Army… – good relatives and friends visited and laboured to convince me that one can live without sex' (p. 8). But most importantly, this negative understanding is solidified through internalisation: 'I was slowly killing myself, day after day going down, deeper and deeper into the sticky swamp of self-pity' (p. 8). If one is not able to disregard the part of one's self that is invested with negativity, this negativity tends to take over one's whole being. Silence becomes self-imposed, negativity transforms into self-hatred and oppression is internalised:

> I resented life, fate, God, the physicians who injected me with the live vaccine against polio. I resented my doom, my ugliness, myself, nature for creating male and female persons, my natural desires. (…) I came to hate my breasts that disobediently continued to react as an erogenous zone whenever unwittingly touched. I wanted to vanish from this world, not to be there, to have never existed. (…) My God, I came to be ashamed of myself – I was deformed, incomplete, useless! I was so convinced of this ugliness and uselessness of mine that even if someone told me he had feelings about me, I just did not believe him – I thought that he did it solely out of courtesy, because he realized how much it would hurt me if he disregarded me too. (pp. 7-8)

The self-hatred related to 'internalised oppression' (Mason, 1990) comes with cynicism and is self-perpetuating – one tends to unwittingly treat others in such a way that they will react negatively: 'I became evil and cruel and people did not like me' (p. 8; see also p. 9).

What is the way out of this vicious self-negating trap? Zhisheva's text suggests that the solution is to recognize its imposed or constructed character and thus to restore the externality of this negativity – in other words, to denaturalise the existential-ontological negation. In disability studies, this has been aided by pointing out the disabling features of the built environment that people with impairments inhabit (e.g., Finkelstein, 1980: 25-26). Some poststructuralist disability scholars have also highlighted the disabling features of knowledge/power constructs, including those concerning 'impairment' (Tremain, 2002). Another option, suggested by the feminist strand of disability studies, has been to locate negativity in the objectifying 'male gaze' (Thomson, 1997: 26). This last possibility is actually hinted at by Zhisheva when she refers bitterly to 'those who did not see the woman in me but noticed only my deformed bottom and the apparatuses' (p. 8) – '[b]ecause men judge whether a woman is "good" by the size of her breasts, the length of the legs and the behind' (p. 7). But Zhisheva does not elaborate this critique of sexual objectification and its relation to disability. Instead, she chooses to focus on the technical aids – the orthopaedic leg braces – she utilises in order to get about:

> I found out that in order to have sex, I have to take off my iron apparatuses… and they are ugly. They have never been part of me, yet they are my physical independence – I can move from here to there only with them. I came to hate them and I have hated them to date. (…) I hated these iron things, I regarded them as fetters, they enveloped [*obvivaha*] not only my body, but also my soul. Yes, I felt pain in my apparatuses [*moite aparati me bolyaha*]. (p. 7)

This attitude towards the leg braces is ambivalent. On the one hand, they provide independence, on the other hand, they are 'fetters.' Zhisheva asserts that they are not part of her, but they still 'envelope' her body and her soul to the point where she can feel pain in them. The reason for this ambivalence is that, while technical aids enable a person to exercise agency on one level, on another level they also 'help to disable by working to reproduce the conditions for the making of difference and disability in the first instance' (Moser, 2006: 388-389). Similarly to the everyday environment, assistive technology embodies a corporeal norm. Consequently, it can cause the bodily difference of 'impairment' to seem *problematic* or, in other words, to *dys*-appear by *appearing as* dys-functional (Paterson and Hughes, 1999: 602-604). Indeed, it is not simply that the 'iron apparatuses' are themselves 'ugly', the problem is that they make the person who uses them 'ugly': 'In the beginning I tried to hide them by all means, but I was never successful – they always meanly exposed themselves and betrayed my incompleteness, my difference. They made me ugly.' (p. 7) Yet, being *detachable*, in both material *and* cultural sense, mobility aids can also disburden the person and her body form self-hatred; they can translate self-directed hatred into object-directed discontent. More generally, as something made, as something constructed, technology testifies that the 'ugliness' of the impaired body is itself not given.

The turning point comes with an encounter. A young man approaches Zhisheva in a disco club and asks her whether she dances. Still trapped in the self-perpetuating pattern of internalised oppression, she immediately assumes that he is mocking at her and retorts: 'I do not dance. Don't you see that I am an invalid' (p. 9). Yet it turns out that he is not

interested in her body, but in her soul: 'I did not ask about your body. I asked about your soul. I cannot dance either, and I am not an invalid. No, believe me, beautiful music can make my soul really dance.' (p. 9) At that, the man looks at Zhisheva in a special way – his eyes are 'childishly sincere' and he does not detach them from her eyes while speaking to her (p. 9). It is this non-objectifying look, coupled with the unexpected reply that sets Zhisheva free from self-negation. She is able, for the first time, to detach her self from the negativity carried by her orthopaedic devices: 'Then, in this infinitely short moment, I understood – I loved through my soul and not through my legs, ugly as they were in the iron apparatuses.' (p. 9)

Notwithstanding the personal transformation, it seems that this new, emancipated self is still radically disembodied. Furthermore, the detachment of the soul from the body seems to reproduce the very pattern of desexualisation that Zhisheva has criticised at the outset. Consequently, existential-ontological invalidation returns through the proverbial back door – the disablist negation of corporeal difference is reinscribed at the very moment of its alleged overcoming. This problem predates every attempt at disability emancipation through privileging *personhood* – or what has been criticised in the disability studies literature as the '"person first" ideology'. As Michalko (2002: 10-11) has argued, '[c]hoosing personhood over disability emphasises both the strength of personhood and its separation from the body'. The corollary is that:

> Inclusion on the basis of privileging personhood over disability is thus never inclusionary. The difference-of-disability is always excluded in this version of inclusion. Social change is never part of such an inclusion. (ibid.: 155)

There are two considerations that at least complicate such a reading of Zhisheva's text. The first is that Zhisheva does not actually distance herself from her *body* but rather from her *technical aids*: 'there are no orthopaedic apparatuses for the soul. The free soul just does not need them' (p. 9). The second consideration is related to Zhisheva's understanding of 'soul'. It seems that her use of the notion mirrors the phenomenological concept of *lived body* because Zhisheva actually proposes an *embodied* understanding of the soul: 'Yes, I had a soul – and *she was able to dance*! Yes, I had a soul and she was able to love, to make love – and to be made love to [*Da, az imah dusha i tya umeeshe da obicha, da lyubi – i da bade lyubena*].' (p. 9, emphasis in the original) It is this insight that leads to the conclusive reclaiming of positive self-identity. Importantly, this newly found identity is a sexually integrated identity, one which does not deny one's body and sexuality, but accepts and enacts them:

> Why did I allow myself to perceive myself as ugly, useless, deformed? This was absolutely not me! This was some other Nina, different from myself. I am Nina – with a fragrance of endless hot meadows, the ardent Nina, who also can burn hearts with her look, the exceptional Nina, the one and only, the unique. Nina, who can caress gently, who can whisper the sweetest words and make the loved one pulsate with happiness and desires. With the same happiness and desires that fill me. (p. 9)

Zhisheva enhances this affirmative statement with the proud assertion of her motherhood: 'Both of my children were conceived as a result of hot sexual experiences.' (p. 9) Thus she challenges another widespread stigma – that disabled persons, and particularly women,

cannot be (good) parents: 'Whereas motherhood is often seen as compulsory for women, disabled women are often denied or discouraged from the reproductive role that some feminists find oppressive.' (Thomson, 1997: 26) The relationship between disability, sexuality, femininity and motherhood will be explored in the next section. I will finish this one with Zhisheva's last sentence that rearticulates the fundamental existential importance attributed to sexuality: 'I don't know whether this is sex or joy, or love… The only thing I know is that it is something wonderful, something that makes us human, us – women and men.' (p. 9)

'We talk about sex'

Let me now turn towards a collective reflection on the topic of sexuality and disability. The discussion took place on an internet forum hosted by the Bulgarian web portal www.dir.bg. It was held under the rubric 'We talk about sex' (*Govorim za seks*). Neither the website, nor the forum, not even the rubric were specifically focused on disability-related issues – the setting was non-professional, non-specialised and as mainstream as one can get. The mere fact that disability was discussed in the context of sexuality, rather than sexuality in the context of disability, made a difference. The discussion happened in 2004 and was renewed for a short while in 2007 with some of the original participants taking part in the later exchange as well. All the discussants participated anonymously, using nicknames instead of their real names. The personal information disclosed occasionally suggests that many of them had only a marginal interest in the topic of disability while some were relatives or friends of disabled people and only few were disability professionals (service

providers). Most importantly, several participants identified themselves as disabled, thus enacting – like Zhisheva – the aforementioned 'reclaiming the voice'. Both male and female participants took part and no gender seems to have dominated the discussion, although gender-specific understandings did (as will be explained below). The number of participants can be estimated at 35, providing that nobody used more than one nickname, which seems unlikely. The number of comments exchanged in 2004 was 71, with further 25 added in 2007, or 96 in total. All this testifies that the topic attracted significant interest.[9]

There are no indications that the discussion was triggered by a specific event. It was initiated by one of the participants who formulated its subject as 'On bodily deficiencies', and its guiding question as 'How many of you would accept your partner having physical impairments without this embarrassing you?' At some point during the discussion Zhisheva's essay was posted in full by another participant (judging by the personal information shared by this participant, it seem unlikely that it was Zhisheva herself). This posting stimulated further debate and testifies that the *Integral* magazine reached the mainstream. The collective and open nature of the dir.bg forum, coupled with participants' anonymity elicited tacit yet widespread understandings of disability and sexuality. Even statements that were deliberately provocative or purposefully exaggerated drew on culturally available knowledges. Whilst it is questionable that this open, collective and anonymous discussion produced more truth on the topic, it does seem that it did – and it still can – stimulate reflexive awareness of the mechanisms that produce and sustain such

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[9] The archive can be found online at
http://clubs.dir.bg/showthreaded.php?Board=talkabout&Number=1942347955, last accessed 12 January 2012.

truths. As was the case with Zhisheva's essay, the material is too rich to be comprehensively covered within the thematic and material confines of this study. Therefore, I will restrict myself to outlining several important themes that relate directly to the foregoing analysis – silencing and desexualisation, the meaning of impairment, medicalisation, and gender. The translation of all the comments from Bulgarian is mine; they are referenced with the latinised participants' nicknames in brackets.

Silencing and desexualisation

The reflexivity hinted at in the preceding paragraph manifests itself at an early stage of the discussion. Echoing Zhisheva's essay, the silencing of discourses that bring together disability and sexuality is explicitly recognized and thematised: 'what you are talking about is one of the many taboos… And as a taboo it causes a spontaneous dread [*uzhas*] and/or denial [*otrichane*] in most people.' (*Lilit*) The dread and/or denial brought about by the topic are seen as existentially motivated. Echoing Shakespeare's (1994) reflections on disability and disavowal of frailty, it is pointed out that impairment produces uneasiness because it is a reminder of human finitude: 'physical impairments confront us with our own vulnerability and fragility' (*Lilit*). Reluctance to engage with the topic is openly expressed by another participant who regards the issue of disability as 'too serious and important', concluding: 'I do not see it as appropriate for this club [that is, the online discussion club 'We talk about sex']. People with impairments have too many problems for us to try to disentangle them here.' (*GROZNIK 1*) This statement unwittingly reproduces the already highlighted 'regime of truth' that regulates discourses on disability. It implies that 'serious

matters' should be addressed by 'serious people' (read 'experts') in 'serious settings' (a number of such *special* places have existed in Bulgaria for a long time). As such, the statement is an instance of both desexualisation and silencing – in response, the initiator of the discussion retorts: 'the unwillingness to discuss such a topic here is also a form of discrimination against people with physical problems. They too have a right to sex and they have a right to speak about it.' (*High Carbon Steel*) Accordingly, breaking the silence surrounding disabled people's sexuality is aptly regarded as a prerequisite for social change, where the very inclusion of disabled people in society is at stake:

> It is not enough to make the public transport and the public buildings accessible for them in order to integrate them [disabled people]. Social engagement is needed too. And a change of attitude, which has to do with the mind and begins with not disregarding the topic as a taboo. (*Kotkata Marta*)

This briefly sketched exchange revolves around the two issues that also served as points of departure for Zhisheva's essay: desexualisation and silencing. In addition, it hints at the ways in which these disablist patterns are reproduced on an everyday level. People maintain 'regimes of truth' by disciplining themselves and others with regard to what can be spoken, by whom and in what settings. The exchange also illuminates the possibility and importance of resistance to these everyday disciplinary pressures. Such resistance is important because it addresses existential and socio-political problems like discrimination, exclusion and the disavowal of human finitude. Last but not least, the exchange testifies to the high degree of reflexivity of the discussants, facilitated, no doubt, by the possibility of

publicly deliberating the issues of concern. Central among these issues is the meaning of impairment.

The meaning of impairment

From the outset of the discussion, impairment is regarded in negative terms, thus reproducing the hegemonic understanding of this type of bodily difference as a 'limit without possibility' (Titchkosky, 2005: 657). The subject 'On bodily deficiencies' (*Za telesnite nedostatatsi*) frames corporeal differences in terms of disadvantage or lack. The guiding question 'How many of you would accept your partner having physical impairments without this embarrassing you [*bez tova da vi smuti*]?' implies that impairments *themselves* cause distress. The negativity conveyed by such wording becomes conspicuous if one considers alternative ways of posing the question, for example: 'What are the physical characteristics of your partner that do not comply with the norm and that attract you?' One could also change the addressee of the utterance, again with significant consequences: 'What are the physical oddities of yours that attract your partner?' Questioning, in other words, has a twofold significance. On the one hand, it is indispensable for opening up discursive 'clearings' where phenomena can appear and become accessible. Yet, questioning also *confines* the discoursing parties to the local worlds thus disclosed. A symptom of such confinement is the production of tautologies like this one: 'Bodily deficiencies are misfortune for the people who have them.' (*GROZNIK 1*) Even those discussants who attempt to challenge the pre-supposed negativity of impairment tend to fall back upon it. The reason is that this negativity is

23

implied in the very terms that allow them to take part in the discussion in the first place: 'It is not so much that the people themselves are those who do not accept the bodily deficiencies of their partner, but the surrounding ones, the others' (*razbiram*). Note that it would be very difficult for me to 'accept' my bodily *difference* if it is regarded as *deficiency* in the first place.

On the other hand, the negative understanding of impairment does not – and *cannot* – hold absolute sway over participants. Even *within* the naturalised negativity of impairment a degree of uncertainty is present. For example, impairment is regarded as self-evidently problematic; it is *given* (not made) as problematic; it is conceived as problematic outside any interpretive economy, outside culture, language, understanding, meaning: 'It is as though we are something disgusting that does not deserve to exist. It [what we are] does not deserve [to exist], but nevertheless it is a fact.' (*High Carbon Steel*) And yet, *High Carbon Steel* also points out that 'to have a physical problem practically means to be marked for life'. Now, to denote impairment as a 'mark' suggests that impairment *is* actually implicated in a particular interpretive economy. From such a perspective, impairment is a *sign*. Yet again, it is a special kind of a sign – one that cannot be effaced and has a fixed meaning. Nevertheless, such rendering suggests that the problem of impairment is an *interpretive problem*, a problem of an interpretation that has gone *rigid*, an interpretation lacking plasticity or flexibility: 'my experience shows that they [disabled people] remain to a great extent confined in their own environment… mostly because other people avoid them, even if they do not want it – these are instincts' (*hose*).

Is then impairment something naturally negative or something culturally negative? Can it be one without being the other? Can it be both, without undermining the very distinction between 'natural' and 'cultural'? Such questions implicitly challenge the negativity of impairment within the very terms that take it for granted. In addition, there are discussants who challenge this negativity explicitly: 'what I cannot understand is why you decided that impairment is a misfortune' (*she the wolf*). Some come even closer to the 'affirmative model' of disability (Swain and French, 2000) by finding beauty in impairment: 'One of the men who has impressed me most is blind – the curious thing is that his eyes are incredibly beautiful, beautiful blind eyes' (*SilentEnigma*).

The negativity of impairment is also at stake in distinguishing between 'minor' and 'major' impairments, or between 'physical' and 'mental' impairments, where the former are regarded as acceptable or even as 'charming extra[s]' (*alexbg67*), while the latter – as unacceptable, particularly in the context of intimate and/or sexual relations. A number of participants make such claims, for example: 'Blindness and limping – OK. But imagine that you are in bed with a person who has chunks instead of arms; or with a woman who, instead of a breast, has a hole' (*seriozna 36*); 'The only and most dangerous [impairments] are mental and emotional deficiency; everything else makes the loved one even more unique.' (*Sex Maniac*) While as a rule such statements reproduce and reinforce disablism, they nevertheless highlight another internal instability of meaning – the *scope* of the concept of 'impairment' cannot be fixed and its boundary is subject to constant negotiations (cf. Thomson, 1997: 12-15). This is also reflected in the frequent uncertainties and disputes about what counts as 'acceptable' or 'unacceptable' impairments: 'But otherwise I also

know a family where the man has had both legs amputated at the knee. He was like that when they met. And they have lived harmoniously for many years' (*seriozna 36*); 'My mother has a serious physical impairment of the right half of her body but I am always pleased to see how my father watches her with that carried-away look.' (*SilentEnigma*)

To summarise, the online discussion incorporated numerous implicit and explicit challenges to the negative understanding of impairment – an understanding that nevertheless marks the discussion's point of departure. Implicit challenges betray the inherent instability of attempts to fix the meaning of physical difference. Explicit challenges testify to the subversive potential of collective reflection on disability and sexuality. In both cases, the mechanisms of subversion are similar to the ones mobilised by Zhisheva in her essay – they make corporeal negativity appear less private, less natural, and/or less fixed. Nevertheless, the negative understanding of impairment retains its hegemony throughout the discussion. One of the main reasons for this is the pervasive medicalisation of impairment-related discourses and practices.

Medicalisation

Drawing on their research with disabled people in the United Kingdom, Shakespeare et al. (1996: 10) point out that '[i]n the realm of sex and love, the generalised assumption that disability is a medical tragedy becomes dominant and inescapable'. The medicalisation of disability is also hegemonic in Bulgaria and is among the most consistent features of the discussions on disabled people's sexuality, even when they explicitly endeavour to

26

challenge disablism. Disabled people, their outlook, lifestyles, life chances and life choices are consistently counterposed to those of *healthy* people. Below are some examples of how medicalisation manifests itself in everyday discourse, taken from the <u>dir.bg</u> discussion:

A healthy woman, who nevertheless is marked with huge purple spots on her skin, would agree much more readily to have a relation with a blind person than someone who is impeccably beautiful (otherwise who is going to admire her beauty). (*Kurator*)

…it is not possible for a healthy person to fall in love with an impaired [*nedagav*] one, this only happens in the movies… (*GROZNIK 1*)

…the truth is that even if someone has been born completely healthy, nobody, absolutely no person is insured that she or he won't be injured some day and go over to the category 'invalid'. (*Lilit*)

…people with disabilities do not have problems… the healthy have problems with them… (*she the wolf*)

Every time [I visit the pool] I see how she swims more than all the healthy women in the pool. She has a great body, despite her problem. I admire her because of her incredible will… (*Idiotche*)

In these examples the distinction between those who are 'healthy' and those who are not is used to organise different and even mutually challenging arguments about disability and intimacy. The first comment underlines the importance of appearance, engaging in what has been identified by Hughes (2000) as the 'aesthetic invalidation' of disabled people. The argument is furthermore gendered – it is a woman who is expected to be worried about appearance, an issue that I will elaborate on below. Most importantly, the possibility for intimacy is *grounded* in deficiency. Thus not only individuals, but also their intimate relations, are seen as governed by privation. It is not that Mariyka is attracted to Ivancho, it is that a lack of beauty is attracted to a lack of sight. The second comment rearticulates this conviction in negativity-driven intimacy. Disabled people are lumped together on the basis of pure and simple privation – they are alike because they all *lack* something. The third comment is of a different sort – it highlights the universal precariousness of human condition, articulating a reminder of finitude that is supposed to enhance acceptance and understanding of difference. Similarly intended, the forth comment points towards the attitudinal barriers that create problems for disabled people. Finally, the fifth comment attempts to challenge negative perceptions of disability by rendering it in heroic terms, in terms of 'overcoming' – a strategy that nevertheless takes the negativity of impairment for granted. Notwithstanding their differences, all these statements about disabled people's bodies, identities, relationships and lives invoke the notion of 'health'. Crawford (2006: 403) has pointed out that '[i]n modern societies, the meaningful practice of health is inextricably linked to the science, practice and layered meanings of biomedicine'. The persistent recourse to 'health' is then both a manifestation and an effect of medicalisation, especially when disability-related issues are concerned.

This becomes clear in cases when medicalisation is bound up with the belief in reproduction as the ultimate purpose of life. Although pro-natalism has been in decline since the beginning of the Bulgarian transition, 74.2% of female and 67.9% of male Bulgarians, responding to the European Values Study of 2008 (www.europeanvaluesstudy.eu), still maintained that a woman needs to have children in order to fulfil herself as a person (Pamporov, 2009: 162). Some of the participants in the dir.bg discussion reproduce these values in uncompromising terms: 'the main aim of men and women getting together is to have children' (*Kradets na sartsa*). Accordingly, it is suggested that disabled people are excluded from sexual discourses and practices due to:

> our instinctive striving to 'pair' with healthy partners – in order to secure healthy genes, guaranteeing healthy offspring. True, not every physical impairment is genetic – and even if it is, it does not necessarily preclude the person from creating completely healthy children. But here we are speaking about instincts and primary reactions which for most of the people are not conscious and thought through [a]nd which serve the purpose of our survival as a biological species over the course of evolution. (*Lilit*)

In this vision, 'offspring' provides a fixed teleological point of reference for human existence. The meaning of human life is to reproduce itself on the biological level – i.e., 'to secure healthy genes, guaranteeing healthy offspring' or, more generally, to survive as a species. Notably, such an understanding wholeheartedly espouses the norm of health and it is indeed hard to imagine modern reproduction outside the purview of medical

professionals, institutions and technologies (cf. Holm, 2009). Against this background, the differences associated with impairment seem problematic. The reason is that, according to *Lilit*, impairment is instinctively equated with lack of health – a lack that is seen as transferable to offspring. Consequently, suggests *Lilit*, people with impairments tend to be automatically excluded from the reproductive equation, and with it – from discourses and practices of sexuality. In sum, the medicalised notion of health imposes a hierarchical classificatory order on human diversity through reference to a norm – 'healthy partners', 'healthy genes', 'healthy offspring' or 'healthy children'. It thereby impairs the ability to imagine intimate and/or sexual relations without constantly referring to the 'naturally given' ideal of able-bodiedness. Besides being medicalised, this ideal is also gendered, which significantly adds to its rigidity and power.

Gender

Despite inclusion of women in non-domestic labour, the state-socialist regime remained patriarchal in many important respects (Tomova, 2009: 134-136). Postsocialist societies have reasserted these patriarchal values in a process of 're-traditionalization…, where women have been ushered back into hearth and home, while men play the dominant roles in the new market economies and new political structures' (Phillips, 2010: 178). In her analysis of disability in present-day Ukraine Phillips (2010) has convincingly shown how disabled Ukrainians negotiate their identities *within* this male-centred regime of knowledge/power, especially when sexuality is concerned. Similar considerations have been put forward by Iarskaia-Smirnova (2002) with regard to disability and sexuality in

contemporary Russia. It is therefore unsurprising that many of the participants in the dir.bg discussion reproduced patriarchal understandings about the roles of men and women in society.

In a world dominated by masculinist visions and values, framing impairment in terms of 'lack' parallels how the feminine is also understood in terms of 'lack'. Thus '[b]oth 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' (Thomson, 1997: 19). Indeed, the perception of disabled people, male and female alike, as weak, incapable or *lacking* is often enhanced by feminising the bodily difference of impairment: 'What better way to exclude a legally blind boy than to feminize the biology of his eyes? What better way to exclude me from the "guys" than to castrate me – "cunt eyes".' (Michalko, 2002: 20-21) On the other hand, the *lack* associated with being a woman in a man's world is often perceived as the ultimate impairment. Take, for example, the following playful exchange, lavishly decorated with smiling and winking faces in the original: 'Well done, lass!!!' (*she the wolf*, responding to a comment by *Jolee*) – 'What lass, she has an internal impairment (of the hymen).' (*O!Sag*) – 'I love people with a sense of humour. You are right, my hymen is irreparably impaired.' (*Jolee*)

Another aspect of the male-centred culture is the association of masculinity with active agency and femininity with aesthetic appearance. Accordingly, the questions asked with regard to disabled people's sexuality tend to follow two distinct, gender-specific formulas: (i) Can disabled men be sexually *active* despite their impairments? (ii) Can disabled women

31

be sexually *attractive* despite their impairments?[10] On the one hand, disabled men's sexuality is defended with respect to potency or the ability to perform sexually: 'We are greater lovers than some of the healthy who are filled with complexes to the edges of their hair.' (*neponosim*) If the presentation of a man is important, it is so only insofar as it manifests an ability to display sexual potency, physical strength and/or economic power: 'Well, as the saying goes, "The true man is recognized even when naked", so why care about [bodily] deficiencies.' (*Sex Maniac*) On the other hand, the sexuality of disabled women is defended (or denied) with respect to aesthetic appearance, as suggested in the comment cited above about the hypothetical woman with 'huge purple spots on her skin' (*Kurator*). Feminine appearance is seen as important in order to *attract* sexual attention and action. Reproducing and embodying this pattern, the Bulgarian transition has given birth and popularity to an odd couple: a stocky man dressed in trainers and track suit with a crew-cut haircut and an obligatory golden chain around his thick neck, accompanied by a slender woman with a fancy haircut, high heels, glossy clothing and expensive makeup. Disabled Bulgarians are excluded from this embodied ideal, where the masculine power to act complements and is complemented by the feminine ability to become an object of action. Indeed, similarly to the feminine body, the impaired body is also objectified; but while the feminine body is objectified as a *sexual object* (Young, 2005: 38-44), the impaired body is objectified as an *a-sexual object* (Hahn, 1990: 315), mostly within

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[10] Phillips (2010: 176) makes the following observation, reflecting on a mobility seminar for wheelchair users in Ukraine: 'whereas most of the men at the meeting used active wheelchairs, the majority of women participants used large, so-called "room" or home wheelchairs, or lever-drive chairs operated by pumping two levers with the hands'. Thus the assignment of gendered lifestyles is mediated by assistive technology. What are these lifestyles? According to Phillips (2010: 186), '[g]oing out in public (being mobile) is seen as an important aspect of masculinity, but women seem more worried by their visible imperfections and are given more leeway to stay at home in their "traditional" setting'.

medicalised 'regimes of truth'. This kind of asexual objectification is at the heart of the already discussed desexualisation of disabled people.

Things get more complicated when familialist and reproductive expectations are added to the patriarchal mix. Familialism – the view that the nuclear family (comprising of a father, a mother and child/ren) is *the* defining element of good life – is still strong in Bulgaria. Summarising data from the European Values Study of 2008, Bulgarian sociologists point out that '[d]espite the crisis of the family institution, the family continues to be an absolute value [*bezprekoslovna tsennost*] for the Bulgarians' (Pamporov, 2009: 167; see also Tomova, 2009: 143). In such a context, women are expected to be good mothers as well as attractive sexual objects. For some discussants these two roles collide: 'It is just that I desire the woman who stays with me to be perfect, but if she is perfect, she will not be a good mother of her children… You know the saying, better an "unworthy" [*nestruvashta*] woman in your hands and in your home with the children than a beautiful, intelligent and bright one outside' (*HishtniK*). Other discussants see women's sexual appeal as a prerequisite for reproduction: 'A woman, no matter how hollow her nut is [sic], has no problems with reproducing providing she has big tits, a tight body and nice butt.' (*High Carbon Steel*) Notably, '[t]he same goes for a man, but in this case it is money which can secure him reproduction' (*High Carbon Steel*). The appearance vs. agency dichotomy is clearly expressed here. Women are sexually valuable when aesthetically attractive and men when they are economically potent. In addition, sexuality is reduced to an instrument for procreation – a position which, again, excludes disabled people, for they as a rule tend to be 'instinctively' (*Lilit*) left out of the reproductive equation.

These gendered expectations are not fixed. Sometimes, it is disabled *men*'s sexuality that is salvaged through recourse to 'beauty': 'Is a man like Andrea Bocelli not beautiful? Does the fact that he is blind make him ugly or rather different but still beautiful?' (*razbiram*) There are also those discussants who, similarly to Zhisheva, question the sexual objectification of women (but note the structural similarity with *Kurator*'s comment about 'purple spots' and blindness): 'Do you make love to a woman only because of her body? Aren't you attracted by her eyes, her radiance, her internal world, her sensibility, her principles, etc. Isn't it possible to fall in love with all these things and thus to become blind to her impairment?' (*debi*) Notwithstanding these occasional challenges, the gendered expectations of the male-centred worldview remain hegemonic throughout the discussion. Together with the taken-for-granted negativity of impairment and medicalisation, these rigid gendered expectations contribute to the desexualisation and the attendant existential-ontological invalidation of disabled people.

Concluding remarks

In this paper, I explored the conjunction of disability and sexuality, drawing on examples from postsocialist Bulgaria. I focused on the social, political and cultural aspects of this intertwining, but I also looked at it in existential and ontological terms. The overall aim was to show how disablism is perpetuated and/or challenged within common, everyday understandings of the body, and, more specifically, of the bodily difference of impairment. These understandings were elicited by looking at non-expert public discourses on disability

and sexuality. Two sources of information were used – an autobiographical essay and an internet discussion. Their analysis highlighted several general points.

Firstly, the topic of disability and sexuality is *silenced*, mainly by subjecting it to an expert-centred 'regime of truth'. This silencing is directly related to a pervasive *desexualisation* of disabled people that is existentially-ontologically invalidating. Secondly, in the rare instances when they emerge, non-expert public discourses on disability and sexuality tend to be medicalised, thus reflecting the hegemony of medical knowledge, experts, institutions, technologies and practices in the domain of disability in Bulgaria. Thirdly, the bodily difference of impairment is as a rule understood in *negative* terms – as deficiency or lack. This understanding, supported by medicalisation, adds to the perception of disabled people as asexual beings, and accordingly, to their existential-ontological invalidation. Fourthly, impairment-related discourses are gendered along *patriarchal* lines. Thus gender-specific expectations informed by a male-centred worldview regulate the construction of disabled people's identity, particularly when sexuality is concerned. All these patterns contribute to the (re)production of disablism in Bulgaria.

At the same time, various instances of resistance to disablism were also highlighted in the context and content of Zhisheva's essay and the dir.bg discussion. I underlined the crucial importance of *opening up spaces* for non-expert public reflection on disability and sexuality. The acts of disclosing and maintaining such 'clearings' themselves work to subvert disablist patterns. This subversion is greatly enhanced when those who are usually 'spoken about' – i.e., disabled people themselves – *reclaim their voices* by speaking

publicly on their own sexuality. My analysis also suggested that the negative meanings attributed to particular bodily differences are inherently unstable. Consequently, disablism is undermined by exploiting and *amplifying this instability of meaning*, particularly within discourses on sexuality where corporeal understandings are pivotal. In addition, it is also important to openly and *explicitly challenge* the taken-for-granted negativity of impairment. Such direct attacks on disablism reach to its core, but this also means that they are prone to suffer the strongest repulse. In sum, each and every one of the aforementioned mechanisms of resistance needs to be deliberately cherished in attempts at overcoming disablism.

I would like to finish this study with two methodological considerations. The first has to do with the relationship between analyses on 'micro' and 'macro' levels. Although the present study focused on the former, the critique of the everyday cannot displace structural critiques of the type outlined in the introduction, where I highlighted the broader factors underlying disablism in Bulgaria. In this sense, disability studies are very much like feminist and queer studies, conceived as:

> theoretical efforts to identify certain wrongful harms or injustices, locate and explain their sources in institutions and social relations, and propose directions for institutionally oriented action to change them. This latter set of tasks requires the theorist to have an account not only of individual experience, subjectivity, and identity, but also of social structures. (Young, 2005: 19-20)

My second methodological consideration has to do with my theoretical points of departure. I relied on two major concepts – the notion of 'disablism' borrowed from disability studies and the notion of the 'lived body' borrowed from phenomenology. While the former was explicitly used throughout the analysis, the latter was mostly implied in the ongoing refusal to take the negativity of impairment for granted. I see this refusal as crucial for challenging disablism. The notion of 'lived body' is useful for disability studies because it provides for such a refusal while retaining an embodied understanding of human being. It cannot be denied that physicality *delimits* human capacities (cf. Shakespeare and Watson, 2001), but neither can it be denied that these limits appear *as limits* and *matter* only within what phenomenologists call 'clearing' or 'world' – a 'context within which relations of objects and activities are organized and make sense' (Wrathal, 2006: 38). From this perspective, any 'excess' with respect to meaning is itself constituted within the meaning-giving context: 'Sense itself opens the difference to what is not sense, without transforming it into another piece of sense' (Steinmann, 2011: 48, cited in Polt, 2011: 49). Even if impairment is conceived in terms of such 'excess', it still cannot be reduced to a 'limit without possibility' (Titchkosky, 2005: 657). On the most general level, what exceeds meaning has the unique power to feed back and *refresh* it: 'Encounters with excess can develop into crisis points, historical events in which meaning is refreshed or transformed; such events open new realms of meaning that, in turn, make it possible for us to encounter excess afresh.' (Polt, 2011: 28) More specifically, bodily differences – including those identified as 'impairments' – bear the potential to refashion not only our customary identities and practices, but also the worlds we inhabit. In a disablist culture there is a pressing need to

realise this potential through strategies for recognition and affirmation. An important first step is breaking the silence surrounding the conjunction of disability and sexuality.

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