

Vjollca Krasniqi

**DISABILITY, POLITICS AND CULTURE IN KOSOVO**

*The article focuses on social policy, politics and cultural representations of disability in post-war and post-independence (2008) Kosovo. It recounts the living conditions of people with disabilities that continue to be harsh as they face multiple levels of exclusion and oppression, stigmatisation, and violence. Seeking to understand agency, the article analyses the relationship between the state and disability movement. It also explores the ways in which disability, as an embodied condition and a form of social identity, functions in the cultural imagination and systems of representation. Three specific points will be made. First, the article seeks to show that the legislative instruments concerning disability ensure de jure but not de facto equality. The existing legal model of disability has not eased the social divisions and inequalities in the broader social structure in Kosovo. Second, it explains how participation of the disability movement in the political processes in general, and social policy formation in particular, has challenged the hierarchical 'social geography' and opposed the ideologies of ableism. Third, disability as an embodied condition and a form of social identity in the cultural imagination is predominantly that of an abject body. The categories of the body dominant in discursive representations are those of physically disabled and war-induced disabilities, rendering other types of disabilities invisible. The article will show how the body politic as well as social, economic, and cultural discourses and formations in Kosovo are premised on a binary matrix of the abled and disabled body and identities.*

*Key words: body, identity, agency, representation, handicap.*

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**OVIRANOST, POLITIKA IN KULTURA NA KOSOVU**

*Članek se osredotoča na socialne ukrepe, politiko in kulturne reprezentacije oviranosti v povojnem in neodvisnem (2008) Kosovu. Poroča o žuljenjskih razmerah ljudi z ovirami, ki so še naprej izključeni na več ravneh, zatirani, stigmatizirani in izpostavljeni nasilju. Pri razumevanju zastopništva raziskuje odnos med državo in gibanjem oviranih. Raziskuje tudi, kako oviranost funkcionira v kulturnih predstavah in sistemih reprezentacij. Predstavi tri okoliščine. Prvič, poskuša pokazati, da pravni instrumenti na področju oviranosti zagotavljajo de jure, ne pa tudi de facto enakopravnost. Obstoječi zakonski model oviranosti ni odpravil družbenih delitev in neenakopravnosti v širši družbeni strukturi Kosova. Drugič, pojasni, kako je participacija gibanja oviranih v političnih procesih na sploh in še zlasti v oblikovanju socialne politike načela hierarhije »družbene geografije« in kako nasprotuje ideologijam »neprizadetega telesa« (abelism). Tretjič, oviranost – kot utelešeno stanje in oblika družbene identitete v kulturni imaginaciji – se predusem nanaša na zavrženo telo. Kategorije, ki prevladujejo v diskurzivnih reprezentacijah, se nanašajo na fizično oviranost in tiste hendikepe, ki jih je povzročila vojna – druge oblike oviranosti pa so nevidne. Članek pokaže, kako telesne tehnike kot tudi socialni, ekonomski in kulturni diskurzi in formacije na Kosovu temeljijo na binarni matriki oviranega in neoviranega telesa in identitet.*

*Ključne besede: telo, identiteta, zastopništvo, reprezentacija, hendikep.*

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**Introduction**

In Kosovo disability has been recast as a human rights issue and also made part of social policy. Yet disability policy and practice in Kosovo has predominantly been premised on physical and mental impairments through a medical approach to rehabilitation, paying little attention to other types of impairments (Turmusani 2002: 1). Scholarship on disability in Kosovo is yet to emerge. Whilst the body of scholarly work has dealt with Kosovo's history, war experience, post-war reconstruction, as well as nation- and state-building, disability has gained little attention. Hence the lived experience: social, economic, political and cultural, of the people with disabilities<sup>1</sup> in Kosovo remain unaccounted for in academic scholarship. This text seeks to fill this gap.

<sup>1</sup> In this text the term 'people with disabilities' is used to underline the definition made by the people with disabilities themselves. This is to acknowledge their agency and striving for a dignified representation (see [www.disabilityisnatural.com](http://www.disabilityisnatural.com)).

However, some action research has focused on disability in Kosovo (Turmusani 2002, Mental Disability Rights International 2002, KOAPS 2006, Coalition 'Equal Opportunity' 2007, Broad Survey of Persons with Disabilities in Kosovo 2011), and on others disability was situated in the analysis of the social policy or within the framework on children's rights (UNICEF 2009, UNDP 2010, Friedrich Ebert Stiftung and Center for Human Rights 2010). The relevance of this study lies in its engagement with a set of concepts on disability, disability policy and its effects on the lives of the people with disabilities; agency; and last, but not least, contextual materiality of the body and culture in Kosovo.

This article analyses the evolving pattern of the social policy on disability. It looks at the institutional: state and civil society responses on disability, on one hand, and the enmeshment of corporeality in the symbolic systems on the other. It provides an overview of the legal articulations on disability in Kosovo as it has developed over the last fourteen years, as well as the social services available to people with disabilities. The analysis provided here takes into consideration the legacy that the socialist state left behind as well as the 1998–1999 Kosovo war and venues that such legacies have opened up for social policy and disability in post-war reconstruction. The article recounts the living conditions of people with disabilities, which continue to be harsh as they face multiple levels of exclusion and oppression, stigmatisation, and violence. Seeking to understand agency, the article analyses the relationship between the state and the disability movement. Last but not least, it explores the ways in which disability, as an embodied condition and a form of social identity, functions in the cultural imagination and systems of representation.

As a matter of method, this inquiry into disability is grounded in the materialist theory studying disability as a socio-political and cultural construction. In this process attention is paid to social conditions that have mediated responses to disability involving unequal relations of power and the effects on people's lives: economic, social, and psychological (Wendell 1996: 23, Garland-Thomson 2001: 5, Russell 2011). The analysis provided here draws on readings of different texts: laws and regulations on disability, social statistics and representations of disability, as well as interviews with the disability activists in Kosovo.

The article makes three specific points. Firstly, the legal model of disability is embedded in the principle of universalism and uniform redistribution – the flat amount of €60 per month disability pension is a case in point. It has not eased the existing social divisions and inequalities in the broader social structure in Kosovo. The legislative instruments concerning disability ensure *de jure* but not *de facto equality*. As a consequence people with disabilities lack integration in Kosovan society. Secondly, I contend that participation of the disability movement in the political processes in general and social policy formation in particular, has challenged the hierarchical 'social geography' and opposed the ideologies of ableism. *Thirdly*, in the cultural imagination, disability as an embodied condition and a form of social identity is predominantly that of an abject body. This signification is reinstated in the symbolic ordering through a range of emotions encompassing bewilderment, fear, guilt – maintaining unequal power relations grounded in the body. Yet the categories of the body dominant in discursive representations are those of physically disabled and war induced disabilities, rendering other types of disabilities invisible.

### **Situating disability: who is disabled in Kosovo?**

Following Susan Wendell's (1996) approach, I resume the inquiry into disability by posing the question: who are the disabled in Kosovo? According to the official statistics there are 93,288 persons with disabilities in Kosovo. Physical disability ranges from the most severe, followed by disabilities due to a long-term illness, to other types of disability present among the Kosovo population such as hearing disability, blindness or impaired sight, mental and learning or intellectual disability (see Table 1). The state is the key actor in regulating social, economic and political life. It is the chief promoter of the 'accepted political reality', setting the institutional and ideological parameters, and regulates law-making (Moore 1988). Hence

Table 1: Demographic data on persons with disabilities in Kosovo, by age, type of disability and gender.

Age	Deaf or hard of hearing	Blindness or low vision	Physical disability	Learning/intellectual disability	Mental disability	Other disabilities and long term illness
0–14	355	431	1,050	684	616	865
15–19	123	155	513	348	351	418
20–24	200	127	562	315	385	398
25–29	191	135	608	318	456	522
30–34	212	146	926	334	536	708
35–39	245	220	1,312	366	738	1,178
40–44	321	299	1,644	351	780	1,497
45–49	401	488	2,181	294	725	2,068
50–54	564	732	2,587	312	693	2,915
55–59	687	946	3,211	284	667	3,430
60–64	928	1,073	3,515	340	595	3,817
65–69	1,197	1,170	3,745	368	464	3,764
70–74	1,434	1,189	3,757	451	456	3,172
75–79	1,365	1,091	3,054	403	313	2,177
80+	1,712	1,233	2,902	439	358	1,682
<b>Total</b>	<b>9,935</b>	<b>9,435</b>	<b>31,567</b>	<b>5,607</b>	<b>8,133</b>	<b>28,611</b>
Female	4,683	4,788	16,990	2,966	3,916	16,567
Male	5,252	4,647	14,577	2,641	4,217	12,044

Source: Kosovo Agency of Statistics (2013: 109).

I look at how the state defines disability. Let me begin with a presentation on the definitions of disability in the legislation concerning the rights of persons with disabilities in Kosovo.

The sources of policy on disability in Kosovo are to be seen in the light of Kosovo's international state-building and interventions of the different international organisations<sup>2</sup> engaged in the Kosovo protectorate. The state-building project is premised in civic terms and hence on citizenship rights. Thus, as part of the internationally led state-building agenda, the Kosovo state has endorsed all internationally recognised documents on human rights and fundamental freedoms.<sup>3</sup> Grounded in the international human rights standards, the Constitution of the Republic of Kosovo has paid attention to persons with disabilities as one of the social groups whose rights it guarantees. It states that

<sup>2</sup> After the 1998–1999 Kosovo war, the number of international non-governmental organisations engaged in post-war reconstruction was hovering around 300. Disability issues have received particular attention from international organisations. Around 30 international organisations worked with people with disabilities. However, the international responses to civil society development have been criticised for their inability to create an empowering platform and for having enforced dependency on international help instead (Turmusani 2002, KIPRED 2005, Fagan 2006, 2010, Krasniqi 2010).

<sup>3</sup> The following international agreements and instruments are directly applicable in the Constitution of Kosovo (2008: Art. 22): the Universal Declaration of Human Rights; the European Convention for the Protection of Human Rights and Fundamental Freedoms and its Protocols; the International Covenant on Civil and Political Rights and its Protocols; the Council of Europe Framework Convention for the Protection of National Minorities; the Convention for the Elimination of All Forms of Racial Discrimination; the Convention for the Elimination of All Forms of Discrimination against Women; the Convention on the Rights of the Child; the European Charter for Regional or Minority Languages, and the Convention against Torture and Other Cruel, Inhumane or Degrading Treatment or Punishment.

No one shall be discriminated against on grounds of race, color, gender, language, religion, political or other opinion, national or social origin, relation to any community, property, economic and social condition, sexual orientation, birth, disability or other personal states. (Constitution of the Republic of Kosovo 2008, Art. 24.)

Moreover, several legal provisions: laws and regulations, address specifically the rights of people with disabilities.<sup>4</sup> In addition, there is a national council and a national strategy on disability was put in place in 2009, as part of the state's response on disability.

As a category within the legal framework in Kosovo, disability encompasses persons with physical, sensory or mental impairments that limit full participation of persons with disabilities in everyday life. There are several definitions of disability at work, albeit relating to different social groups. They pertain to education, social welfare (including pensions), labour rights, and health. In the pre-university education system the term 'children with special needs' is used, referring to children 'whose progress in school is impeded for various reasons' and need additional support in studying (UNICEF 2009: 7). In addition, another definition is that of children with disabilities known as 'permanently disabled children of physical, mental and sensory forms', encompassing children up to 18 years old needing other people's help to carry out daily activities (Law On Material Support for Families of Children with Permanent Disability 2008, Art. 2).

The second set of definitions of disability relates to pensions as a part of the welfare system in Kosovo. In this instance disability is defined in connection with the capability to work. An individual with disability is defined as 'a person totally and permanently disabled and incapable of any form of occupational activity' (Law on Disability Pensions 2003, Section 1, 1.3). Disability defined in health terms encompasses the nexus 'persons with mental disability' and 'physical or mental disabilities'. Moreover, a specific definition of disability relates to the 1998–1999 Kosovo war including two categories: (1) 'the civil invalid of war' and (2) 'invalid of war'. While the former category encompasses disability as a consequence of impairment caused during the 1998–1999 Kosovo war and after the war from the explosive devices left behind when the war ended, the latter includes the ex-combatants of the Kosovo Liberation Army (see Law on the Status and the Rights of the Martyrs, Invalids, Veterans, Members of Kosovo Liberation Army, Civilian Victims of War and their Families 2011, Art. 3, 1.7 and 1.8).

The legislation on disability might be grounded in the international standards on human rights, yet disability as a category in social policy and law-making in Kosovo is defined in a deterministic way. Moreover, the use of the term 'invalid' as a principle of categorisation in social policy is problematic. As Darja Zaviršek has argued, in the post socialist countries of Eastern Europe, and this applies also to Kosovo, people with disabilities are labeled as '*invalid*' – a term signifying inactivity, powerlessness and lack of agency (Zaviršek 2006:2). In Kosovo, the terms *work invalid* and *war invalid* – in the Albanian language *invalid i punës* and *invalid i luftës* – signify dependency, inability to live independently, and posits persons with disabilities as passive recipients of social services and needing care.

Disability is neither a homogeneous notion nor a homogeneous social group. People with disabilities are a diverse group living different forms of embodiment and coping strategies. The fact that disability is experienced differently across class, gender, age and locality, goes unnoticed in the legal model of disability in Kosovo. Moreover, embedded in the principle of universalism, this legal model entails a 'paradox of redistribution' (Korpi, Palme 1998) characterised by the

<sup>4</sup> Legislation on disability in Kosovo includes the following laws and regulations: (1) on disability pensions; (2) families of children with disabilities, and (3) vocational ability and employment of (4) social assistance and (5) benefits for war invalids and next of kin of those who died in war. Disability has been made an integral part also in the Anti-Discrimination Law (2004); the Labour Law (2010), and the Law on Construction (2004), and in two administrative instructions related to construction and work: (1) Construction Buildings Technical Terms of Accessibility for People with Disabilities (2007); and (2) Administrative instruction for Procedures of Application for Rights in Recognition of Skills, Rehabilitation, and Employment of People with Disabilities (2010). In addition, a three year action plan on disability has been devised under the auspices of the Kosovo Government.

uniform system of redistribution, assumed to be a salient approach to reduce social divisions. Indeed, ‘discussions of universalism within a service as desirable in itself and because it advances equality in society’ (Hill 2006: 192) remain open in the scholarship, but with reverberations at the practical level. The disability policy in Kosovo is an exemplar of this uniform approach to entitlements for the disability groups. Regardless of the type of disability, they are entitled to a flat amount of €60 per month disability pension. And the families of a child with a disability – around 2000 children with disabilities are recipients of this scheme – are entitled to €100 per month. In both instances the differing needs of people with disabilities, as well as different experiences of disability based on gender, age, and class, is given no weight. It can be argued that such a legal model of disability is flattening out the differences among people with disabilities, rendering invisible their differential social positioning, and ignoring their varying needs, as articulated by the persons with disabilities themselves. Such a response is failing to dismantle the structural inequalities which people with disabilities in Kosovo are facing. This is in no way a pursuit of an ‘individualistic logic’ akin to liberal individualism, but a contestation of the hierarchical organisation of the social space (Russell 2011: 200).

Disability definitions in Kosovo are largely centered on medical notions. Moreover, disability is assumed as a fixed category and a static condition. The fact that globally the number of people with disabilities is growing is not reflected in this context. For example, the higher risk of disability due to ageing and also of chronic health conditions associated with disability, such as diabetes, cardiovascular diseases and mental illness, or disability influenced by trends in health conditions and those related to environment and other factors – such as road traffic crashes, natural disasters, conflict and substance abuse (WHO and WB 2012: 8), as well as difficult access to health services, are given little consideration in the law-making on disability in Kosovo.

### Disability: from legislation to practice

In Kosovo, while there is a legal system to address the rights of people with disabilities, overall awareness among the Kosovo population of its existence is rather low. As shown in Table 2 below, the prevailing public opinion regarding the existing legislation on disability in Kosovo is that while the legislation ensures *de jure* legal protection, it lacks implementation; it is not *de facto* (see Table 2).

Taking a closer look at the data in Table 2, it is noticeable that older people, women and members of the Roma communities are far less aware of the existence of the laws and rights of people with disabilities. For certain, the pessimistic outlook in the broader public opinion in Kosovo is a reflection of the overall low level of trust in the state institutions (see UNDP 2013), and dissatisfaction with economic conditions and quality of life, which the state has failed to address. Kosovo ranks as the poorest country in Europe. One out of every two Kosovars is without a job. Half of the population lives in poverty, on less than €1.40 a day (Kosovo Agency of Statistics 2013).

The aim here has been to explain the gaps and slippages from policy to everyday practice and their limitations, to account for the effects it has in the lives of people with disabilities. The gap between the legal language and practice is evident in countless instances. For example, people with disabilities cannot physically access the health and education facilities they desperately need. They grapple to cover costly medicines, unable to resource appropriate treatment to improve their life opportunities; are largely shut out of the labour market, and thus without any social alliance to improve their wellbeing (UNDP 2010: 13). Today 18,427 people with disabilities, who live on the disability pension (Kosovo Agency of Statistics 2013) of €60 per month, cannot meet the most basic needs: nutrition and medicines. They live below the poverty line of €1.4 a day. Indeed, depending on type of disability, children with special needs attend special schools, they also attend regular schools where they are either clustered in separate classrooms – an attached class, or are included in regular classrooms. In Kosovo there are seven special schools

Table 2: Information on laws on the rights of persons with disability in Kosovo by age, gender, ethnicity and type of settlement (in %).

		Awareness of laws on the rights of persons with disabilities	Lack of knowledge of laws on the rights of persons with disabilities	Don't know/ No answer
Total	All respondents	42	32	26
	19-30 years old	44	36	20
	31-45 years old	46	29	25
	46-64 years old	39	30	31
	65 and over	24	40	36
Gender	Men	48	31	21
	Women	34	34	32
Ethnicity	Albanian	42	32	26
	Serb	43	37	20
	Roma, Ashkali and Egyptian	18	45	37
	Other ethnicities	48	22	30
Type of settlement	Urban	41	32	27
	Rural	43	33	24

Source: Broad Survey of Persons with Disability in Kosovo (2011: 15).

for children with special needs in education and two classrooms are part of the regular school in each municipality<sup>5</sup> (MEST 2013: 33). Yet children with disabilities have a high percentage of exclusion from education. Barriers faced by children with disabilities are poverty, lack of resources and aid, lack of transportation to and from educational facilities, stigma, inattentive teachers, and the absence of appropriate infrastructure (UNDP 2010: 60).

The quotes below are just a glimpse of the sentiments that people with disabilities in Kosovo live with. The feelings of exclusion, discrimination, and cultural devaluation, permeate the narrators' text as they reflect on their lived experiences.

Yes, in a way we feel culturally excluded. The only activities that are organised for people with disabilities in Kosovo are those that are planned by the non-governmental organisations that we are part of. Also, we would love to have a TV programme once every two weeks dedicated to people with disabilities in Kosovo. (Male person with disability quoted in *ibid.*: 80.)

As a female with disabilities you are doubly discriminated against, especially when considering rural/urban biases. For example, in villages, women with disabilities are totally excluded from society. (Female person with disability quoted in *ibid.*: 83.)

Indeed, women with disabilities, especially those living in the rural areas, experience higher levels of exclusion. This stems from both structural and cultural factors. Indeed, in rural areas the infrastructure is not barrier free for people with disabilities, nor is it in the cities/towns. In both locations traditional cultural norms about gender roles are prevailing. But the social pressure to conform to traditional gender roles and sexuality is less tight in the urban settings. The social pressure for conformity is looser in urban areas. This is due to the dispersal of

<sup>5</sup> Special schools for children with disabilities are located in Mitrovica, Priština, Peć, and Prizren. In total there are 453 children in the special schools in Kosovo. Out of which 234 are children with intellectual impairments, 61 with hearing impairments, 39 with sight impairment, 8 with physical disability, and 111 with multiple impairments (MEST 2013: 35). In the attached classes in schools there are 533 children, out of which 319 are children with intellectual impairments, 37 with impaired hearing, and 8 with sight impairment; 25 with physical disability, and 144 with multiple impairments (UNICEF 2009: 37). Yet 80 per cent of children with disabilities are not included in the education system (see Ministry of education, science and technology 2013).

kinship in the urban localities, contrary to proximity and concentrated dwellings based on kinship in rural areas, thus enabling ‘policing’ of gender and sexuality.

The government itself, despite being the main actor for guaranteeing the rights of people with disabilities, does not do so. The government buildings offer no access for persons with disabilities. Moreover, they do not comply with the law provisions which oblige all organisations to employ one person with disability per every 50 employees (Law on Vocational Ability, Rehabilitation and Employment of People with Disabilities 2008). Yet one positive example is the Disability Mentoring Day campaign that is based on the international practice. It did succeed in employing a number of people with disability for a short period of time (ranging from a few days to a couple of weeks) in participating companies and government offices. Alas, the campaign has had no long-term effect, as none or very few people have obtained a permanent job following their short-term and probation ‘employment’ during the campaign (NESst 2011: 14). However, such campaigns raise awareness on disability rights.

Another segment that points to the limitations of the disability policy in Kosovo relates to the politics of care. It is evident that the overall system of social care in Kosovo is weak, including the care for persons with disabilities. In fact, Kosovo’s care system is highly dependent on informal care. The empirical data indicate that the majority of care providers for people with disability in Kosovo are women (59 per cent), in fact, mothers (Broad Survey of Persons with Disability in Kosovo 2011: 39). Care is embedded in social values, expectations and institutions. No doubt, parenting and care giving to persons with disabilities, as the data indicate, is gendered. It rests on traditional gender roles reenacting the gendered division of the public and private spheres (Tronto 1992: 183). Moreover, this constitutes a form of ‘*compulsory altruism*’ (Hill 2006: 222) because women are assigned the roles of care for children, the elderly, and persons with disabilities. As the broad survey on disability has indicated in Kosovo, it is the mothers (31 per cent) more than fathers (20 per cent) that are the care providers for persons with disabilities, followed by siblings (11 per cent), and a grandparent (3 per cent). Nurses comprise only one per

Table 3: Assistance provided to persons with disabilities, by gender and ethnicity (in %).

	Total	Gender		Ethnicity			
	All	Men	Women	Albanian	Serb	Roma, Ashkali, Egyptian	Other
Family members/relatives	73	70	76	73	75	83	66
People from neighbourhood	1	1	1	1	2	3	3
Municipality	3	3	2	3	2	0	7
State	0	0	0	0	1	0	0
Public institutions	0	0	0	0	3	0	0
NGO/Women’s NGOs	3	3	3	3	5	1	4
Religious organisations	0	0	0	0	2	0	2
Private sector organisations	0	0	0	0	0	0	0
International organisations	1	1	1	1	1	1	0
Other	0	1	0	0	0	0	0
Nobody	17	19	15	18	3	10	14
Don’t know/ Don’t want to answer	2	2	1	1	6	2	4

Source: Broad Survey of Persons with Disability in Kosovo (2011: 37).

cent of the care providers to people with disabilities in Kosovo (Broad Survey of Persons with Disability in Kosovo 2011: 39). As the data reveal, a considerable number of people with disabilities live without any assistance from relatives, the state or other social institutions (see Table 3). Nonetheless, the role of relatives in providing care to persons with disabilities is paramount. Yet this is also an indicator of the state's gendered performance shifting social responsibility to the families, more precisely women, to provide care for people with disabilities.

However, I am mindful not to romanticise the private/familial care based system as a site of equal power relations, freed from coercive power. I have domestic violence in general in mind, and violence against persons with disabilities, in particular. The prevalence of domestic violence against people with disabilities in Kosovo is yet to be documented. However, the disability organisations providing support to persons with disabilities have noted that people with disability are subjected to violence at home, especially women with disability. Forms of violence which persons with disabilities have endured include

being criticized by other family members, called names, sworn at, isolated, made to feel guilty all the time, have decisions made for them without their consent, their pension appropriated by other family members, or threatened with removal from home (KWN 2008: 46).

Physical violence is especially present against persons with mental disabilities. Most of the persons with disabilities are confined to the private domain and live in isolation – which constitutes a form of violence (*ibid.*: 45), and with no place to turn to for help. It is true that the stigma associated with disability in Kosovo is strong, and that persons with disability, especially children, are hidden from the public eye. But the disability organisations have made the point that

it is rather the lack of social services as well as lack of support to families of people with disability that confines them to isolation. It is not the families to be blamed but the state, which does not provide opportunities for integration for people with disabilities. (Disability activist, interviewed by the author, July 2013.)

### Disability as political arena

To show how disability as a discourse has been constructed and also shaped social formations in Kosovo it is necessary to take into account activism and practices of the disability movement. The aim here is also to understand the ways in which the disability groups are carving space for themselves in civil society and politics in Kosovo.<sup>6</sup> The state and civil society do meet and they can be understood relationally. The emergence of the civil society in Kosovo during the 1990s – a decade that was termed as ‘the civil resistance in Kosovo’ (see Clark 2000) – was a response and a form of collective organising to counter the exclusionary and brutal regime of the Serbian leader Slobodan Milošević that deprived Kosovo Albanians of political autonomy, the right to education, health, social provisions, and subjected them to imprisonment, forced migration, and war.

Having had to respond to such political and economic cleavages in the 1990s, the civil society organizations were the substitute for the lack of social services, a role which they continued to play in the post-war period. For instance in 1999–2000, 76 per cent of the non-governmental organisations were recorded as service providers (KIPRED 2005: 15). To be sure, I resist framing the civil society development in general and the disability movement in particular, in post-war Kosovo through dichotomous and oppositional categories, such as service providers

<sup>6</sup> I deploy the term of ‘civil society’ similarly to Susan Gal and Gail Kligman, meaning ‘not primarily as a set of determinate institutions and organisations, which it also is, but as an ideological formation that produces the quite real social effect of newly perceptible boundaries between the state organisations or what can now, as a result of such boundaries, be called voluntary, independent, or “non-governmental» organisations’ (Gal, Kligman 2000: 94).



or advocacy groups. I find this misleading because such ‘metrics’ fail to take into account the historical trajectory of the collapse of the socialist state, war, and post-war protectorate and international state-building processes through which the civil society emerged, was shaped, and has entered the politics and culture in Kosovo. Instead, I pay attention to practices of the disability organisations and responses by the state.

The disability movement in Kosovo includes different non-governmental organisations.<sup>7</sup> However, they are not yet joined in a network; most of them being supported financially by international organisations. Indeed, it is the Association of Paraplegic Children HANDIKOS – a Kosovo based NGO – that has been at the forefront of disability activism in Kosovo. It has also been the main carrier of the community based rehabilitation platform for people with disability.<sup>8</sup> The relationship between the state and the disability movement in Kosovo is complex. I would like to draw attention to two examples to illustrate this relationship and also to show how disability is reconstructed as an arena of political action. The first example is the following:

In August 2010, the Association of Paraplegic Children HANDIKOS donated wheelchairs to the University Clinical Centre of Kosovo – an action that was proudly announced on the webpage of the Ministry of Health (HANDIKOS 2010). Such a practice recurred also in June 2013, when HANDIKOS donated five wheelchairs for another public institution: the Institute of Mental Health (HANDIKOS 2013). True, the disability organisations have been supported by international organisations, bringing important resources as well as ideas and practices on disability issues. But, as a disability activist, has remarked

It is a paradox, a non-governmental organisation to donate wheelchairs to the public hospital and hence to take on the role of the state. (Disability activist, interviewed by the author, July 2013.)

Moreover, the example given here as a part of a ‘political economy of gift exchange’ should be read in relation to state-building agenda and the accommodation of the social issues in the state politics. This surely attests to the marginalisation of social issues by the Kosovo state, including disability. Looking at the state budget, one can notice that only 8.8 percent of the Kosovo budget is dedicated to the Ministry of Health and 18.4 per cent to the Ministry of Labour and Social Welfare (see KWN 2013). This mirrors the neo-liberal economic policies and institutional restructuring, to use the concept coined by David Harvey of ‘accumulation by dispossession’, (Harvey 2003: 137–183) as a strategy of the state handing over responsibilities, through privatization—including social services—to the market and non-state actors. A shortage of budget allocation to social issues is a staple of neo-liberal policies pursued by the Kosovo state.

Indeed, the interaction of the disability movement and the state has not always translated into cooperation, especially not in the processes of policy formation. It has required intense pressure by the disability organisations to be taken into account as actors in the policy formulation on disability. According to the disability rights activist

Disability organisations were sidelined in the process of the development of the national strategy on disability. We did exert pressure for our inclusion by lobbying the key decision-makers. It required much pressure for our request to be taken into account. (Disability activist, interviewed by the author, July 2013.)

Indeed, these two examples show that the disability movement in Kosovo has made visible the state’s evasive tactics from social responsibility: neglect of real social issues, unequal redistribution,

<sup>7</sup> Disability organisations in Kosovo include the following: The Association of Blind Persons and Persons with Visual Impairment of Kosovo; the Parents Organisation of Children with Disabilities of Kosovo ‘OPFAKKOS’, the Association of Deaf People of Kosovo, the Federation of Sports of People with Disability of Kosovo; the Association of People with Muscular Dystrophy of Kosovo; Club ‘Dëshira’ [Desire]; the Association ‘HANDICAP Kosovo’, and the Association of Paraplegic Children of Kosovo HANDIKOS.

<sup>8</sup> The Association of Paraplegic Children of Kosovo HANDIKOS has 14 community rehabilitation centres and 12 community groups throughout Kosovo. The community groups collect data, identify, and map persons with disabilities as well as provide information on disability issues.

and political marginalization of the agencies representing people with disabilities. This process, however, is hierarchical. War related categories defined ‘war veterans’, ‘the civil invalids of war’ and ‘war invalids’ and their next of kin have been a key feature in the nation-building narratives. They have been symbolically validated in relation to the idea of the ‘sublime sacrifice’, and on such grounds incorporated in social policy and welfare protection, albeit enabling redefinition of citizenship and welfare rights, and enjoying greater privileges in employment; health services both in Kosovo and abroad; priority to housing; release from property taxes; exemption from tuition fees and priority in admission to education, among others (see the Law on the Status and the Rights of the Martyrs, Invalids, Veterans and Members of the Kosova Liberation Army, Civilian Victims of War and their Families 2011, Art. 8).

### Culture and representation

As feminist scholars have long argued, disability is a cultural rather than individual or medical issue, and they have insisted on examining power relations (Garland-Thomson 2001, Wendell 1989: 1996) and the effects of power on the body, politics and culture. Disability is a discursive representation and an expression of the relationship between the body and language. As Stuart Hall has pointed out

Sounds, words, notes, gestures, expressions, clothes – are part of our natural and material world; but their importance for language is not what they *are* but what they *do*, their function. They construct meaning and transmit it. They signify. (Hall 1997: 5.)

Hence, to read how disability is framed in language and maintained in the symbolic systems, it is important to explore the language and stereotypes – as they are an expression of unequal power relations, influence the disability discourse and practice. Stereotypes are derivative of the culturally accepted norms and values about the body. Foremost, stereotypes relate to ableism as a form of social prejudice and discrimination. The stereotypical views posit people with disability as unfit for independent living, but they are also perceived as mentally ill, sick, and asexual. Stereotypes that affect and cause discrimination, oppression and violence against people with disabilities are those that position them as physically and intellectually less able, emotionally fragile and untrustworthy, with mental health problems.

Attempts to reconstruct the categorisation of people with disabilities as an abject body and subordinated are reflected in the everyday language. Negative and derogatory language is deployed to refer to persons with disabilities. Handicapped person, invalid, deaf, and mute are some of the most common expressions. The term widely accepted by people with disability and disability organizations as best representing their voices is the term ‘person with disability’ (Coalition ‘Equal Opportunity’ 2007: 7).

To be sure, the cultural imagining of the body as well as its social meaning is not fixed. The circulation of representations of the body, however, is not monolith, neither in genre nor scenario. In Kosovo, in the flow of imagery depicting the body, it is the sexualised female body that has been made central. Everyday Kosovars are served with various advertisements featuring a sexualised female body in the public sphere. It is not only private capital which is a vector within this system of representation, but also the media, as well as political propaganda. Such representations are not isolated images, rather they form a cultural phenomenon deployed selectively to maximise economic profit and justify international interventions, branding the Kosovar nation, and fashioning a Western/European way of life in Kosovo (Krasniqi 2007).

However, in this proliferation of body imagery in the public space in Kosovo, disability has assumed a role, too. Representations of disability have largely been deployed in connection with awareness raising campaigns on human rights, disability issues, or on specific international human rights days, by different actors: the disability movement, international organisations, as well as the state. Yet as such, these representations have been

constant visible reminders to the abled-bodied that the society they live in is shot through with inequity and suffering, that they live in a counterfeit paradise, and that they too are vulnerable (Murphy 1987: 55–56).

In Kosovo, in the dominant visual coding, a particular type of disability has been given prominence – the physically disabled body. A case in point is Image 1, representing disability by the organisation of the Association of Paraplegic Children HANDIKOS which, as mentioned earlier, has been the main actor on disability rights in Kosovo. Image 2 is a representation of disability in the Kosovo media. More precisely, Image 2 appeared in the electronic media in Kosovo on 3 December 2013, to mark the International Day of persons with disabilities. Such images were deployed largely by the print media, not only on this day, but whenever discussing the issue of disability.

Several elements should be highlighted in these two images. Foregrounding the male body confined to the wheelchair, these representations show how gender and culture relate to identity, corporality and subjectivity. It reifies the subjectivities of people with disabilities by flattening identities of people with disabilities, reducing it to that of the male body physically disabled. These images maintain a symbolic landscape of the body mediated by an ‘affective economy’ – to borrow the term from Sara Ahmed (Ahmed 2004: 8), to instill bewilderment, fear, guilt, and pity. Yet this ‘flow of emotions’ running through these representations naturalises the broader social/political/economic/cultural discourses and formations premised on a binary matrix of the able and disabled body and identities.

## Conclusions

Disability is contingent on the social and cultural context that effect practices of people with disability (Linton 1998: 527). How disability is understood not only has an enormous impact on the ways people with disabilities make sense of themselves and their lives but also on how institutions shape and perpetuate their practices. By focusing on Kosovo, I have argued here that the disability policy signifies a heightened sensitivity of the state toward the needs of people with disabilities. The legal model of disability as well as social practices at large have regarded persons with disabilities as unable to work, unfit for society, sick, and incapable of independent living. Yet it is war related disability that has assumed a greater symbolic importance in the nation-building ideologies, but also helped reconfigure citizenship and welfare rights.

The disability model gives primacy to medical approaches at the expense of social and cultural constructions that view disability as a product of an adverse environment that discriminates against people with disabilities and assigns them an inferior status in society. Moreover, as has been shown here, people with disability enjoy poor social protection and services as the state’s neo-liberal agenda has maintained social issues on the margins. To be sure, effects of the neo-liberal ideology and economic policies in the Kosovo state-building politics, on the lives of people with disability in Kosovo, have yet to be documented and theorised. Disability has

Image 1: Representing disability.



Source: HANDIKOS (2013).

Image 2: Representation of disability in the media.



Source: Telegrafi (2013).

emerged as a new social identity and it has been accommodated as a category in social policy and welfare provisions. A critical analysis of the limits and the potential of the disability policy and institutional practices should involve radical politics that question and rework the binary reconstruction of identities, politics, language and culture.

In the cultural imagination disability is perceived as an abject body and sustained through stereotypes against people with disabilities. It is a fact that stereotypes underpin the public imagination and interact in such a way as to establish hierarchical restructuring of fixed identities around able-bodiedness, gender, disability, and class. Indeed, this is by no means uncontested. The disability movement, apart from having introduced disability as a political arena, has also been an important source of support and care for people with disabilities in Kosovo as the state has failed to provide quality social services for the people with disabilities.

In the proliferation of body imagery in the public space in Kosovo disability has also assumed a role. Yet in the symbolic landscape the image of the male body with physical disabilities has maintained a central position naturalising the broader social/political/economic/cultural discourses and formations on the gender and body binaries and hierarchies.

This study of disability in Kosovo has proved the usefulness of the materialist theory to challenge norms and practices based on power relations and for transformative politics by intervening in the process of policy making. This involves resisting practices which operate through top down approaches and limiting agency.

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