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Political Representation and the Human Rights Model of Disability: A Bulgarian Case

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RESEARCH

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ABSTRACT

Bulgaria ratified the UNCRPD in 2012 but what can be observed locally is a chronic failure to embrace and implement its fundamental principles. This article explores the current state and the future of the human rights model of disability in Bulgaria. It focuses on a fundamental pillar of the human rights model, namely the participation of disabled people in all decision making that affects them. We expose how the local definition of political "representation" diverges from what the human rights model envisages, and we argue that the organisations that are expected to "represent" disabled people remain stuck into needs-based attitudes and models. This makes them agents not of change but of further affirmation and cementing of practices and solutions that turn disabled people into "objects" of care, lock them into paternalist forms of dependency, and strongly depoliticise disability issues in the country.

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INTRODUCTION

This article explores the current state and the future of the human rights model of disability in Bulgaria. It focuses on a fundamental pillar of the human rights model that is enshrined in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Degener 2017), namely the participation of disabled people in all decision making that affects them (we adopt identity-first language, unless our sources use person-first language). We demonstrate that in Bulgaria, the mechanisms that are officially presented as complying with this obligation diverge from the meaning and the intentions of the CRPD, which continuously undermines its implementation and the future of the human rights model locally.

In Bulgaria, the participation of disabled people in decision making is officially claimed to be guaranteed through the involvement of the so-called 'nationally representative organisations' (NROs) of and for disabled people in consultative and monitoring procedures. The 'representativeness' of NROs, however, stems from a paternalist model grounded in a needs-based paradigm that is in tension with the rights-based one (Oliver 1996: Ch. 5). However, this tension is masked by a linguistic coincidence – the CRPD speaks about 'representative organisations', which invites the assumption that the local 'national representativeness' has the same or at least similar meaning. Such an assumption covers up the deeply problematic substitution present in the official documents reporting on the progress in the implementation of the CRPD. Consequently, the disenfranchisement, the absence of co-production of disability policies, and the lack of independent monitoring by disabled people cannot even be registered. For an outside observer, it appears that the state is complying with the general obligation stipulated in Article 4(3) and is moving, albeit slowly, along the trajectory outlined by the CRPD, having the political will to enforce it.

The nature of this substitution and its effects have not been discussed in the documents and reports that describe the progress of the Bulgarian state in the implementation of the CRPD. Moreover, it is not commented upon in the shadow reports provided by the Bulgarian non-governmental organisations (NGOs), neither in other reports on the rights of disabled people in Bulgaria, with the notable exception of analyses produced by the Centre for Independent Living – Sofia (e.g. Mladenov 2007; Panayotova & Todorov 2007). At the same time, the implications are far-reaching, as this substitution enables NROs to monopolise key positions in advisory and monitoring bodies, and to receive and demand support and respect from the state, referring precisely to its obligations under the CRPD.

On the following pages, we expose the actual state of participation in disability policy making in Bulgaria. We also discuss how the local definition of political 'representation' diverges from what the human rights model envisages. Additionally, we argue that the organisations that are expected to 'represent' disabled people remain stuck into needs-based attitudes and models. This makes them agents not of change but of further affirmation and cementing of practices and solutions that turn disabled people into 'objects' of care, lock them into paternalist forms of dependency, and strongly depoliticise disability issues in the country.

We draw on data collected in the framework of a participatory research project that focused on the role of disabled people's organisations (DPOs) in decision-making in Central and Eastern Europe (CEE) in the context of accelerating illiberalism in the region (Graff & Korolczuk 2021). In the first section, we outline the key role of the principle of political representation in the human rights model and the meaning of the concept of 'representative organisations' of disabled people, as envisioned by the CRPD. In the second section, we describe the data and the methods we use. The third section introduces the local state of the disability sphere, emphasising its harmful legacies and the steps already made towards implementing the CRPD. The fourth section presents the results of the research. We pay specific attention to the image of the NROs as defenders of social rights in the context of the growing illiberalism in Bulgaria. In the conclusion, we summarise the factors that prevent the human rights model from being harnessed by disabled Bulgarians so that it becomes an instrument affirming their position as rights-holders. We finish by emphasising the importance of revising the criteria of 'national representativeness' as a precondition for realising the human rights model of disability in Bulgaria.

1. PARTICIPATION AS A PILLAR OF THE HUMAN RIGHTS MODEL OF DISABILITY

It is widely accepted that the CRPD embodies a shift towards a new disability rights paradigm (Harpur 2012) or a human rights model of disability (Degener 2017; UN CRPD 2018a). This model operationalises the 'profound message in the Convention' that persons with disabilities are not 'objects' to be managed or cared for, but human 'subjects' enjoying human rights on an equal basis with others' (Quinn 2009: 216). It endorses the social model's fundamental tenets but builds on them in important aspects that are more sensitive to social justice, human diversity, identity issues, and to the need to stress positive rights and impairment prevention policies (Degener 2017). These features are encompassed in the novel notion of inclusive equality through its four dimensions: fair redistribution, recognition, participation, and accommodation (UN CRPD 2018a; Degener & de Castro 2022). All of them are crucial when devising domestic models of implementation of CRPD, but in our focus here is the participation of disabled people in all matters that affect them, that is participation 'as a principle, an obligation and a procedural attribute of substantial rights' (Lorion 2019: 247).

Accordingly, the obligations of the states under the CRPD are conceived as countermeasures that should subvert the traditional model in which third parties – professionals, relatives, policy makers – speak and decide on behalf of disabled people. Thus, the CRPD 'recognizes participation as both a general obligation and a cross-cutting issue' (UN CRPD 2018b: §3) and obligates state parties to 'closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations' (Article 4(3) of the CRPD), and involve them in the monitoring process (Article 33(3) of the CRPD). The CRPD Committee additionally stresses the importance of participation and representation in its Guidelines on the Participation of Disabled Persons' Organizations (DPOs) and Civil Society Organizations in the Work of the Committee (2014) and in its General Comments, particularly in General Comment No. 7 (UN CRPD 2018b). In the latter, a definition of 'representative organisation' is provided, together with important comments on what distinguishes these organisations from entities that are run on behalf of disabled people.

The Committee on the Rights of Persons with Disabilities (2018b: §11) states that representative organisations 'can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves'. These organisations are firmly distinguished from 'third-party representatives, such as organisations 'for' persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities'. This distinction is crucial, since the advocacy that 'speaks on behalf of', no matter how benevolent it may be or seem to be, has been at the roots of the oppression that disabled people have traditionally experienced. It becomes even more dangerous and harder to challenge when those who 'speak on behalf of' appear supportive (Russo 2023; Dimitrova 2023). Notably, certain groups of disabled people, such as people with an intellectual disability and autistic people are still represented in the disability movement dominantly by others such as parents or professionals (Petri et al. 2017).

According to the Committee on the Rights of Persons with Disabilities (2018b: §11), the (genuinely) representative organisations have three main features:

> (a) They are established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities...; (b) They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves; (c) They are not affiliated, in the majority of cases, to any political party and are independent from public authorities...

Additionally, and ensuing from the need to keep service providing organisations at bay, paragraph 61(b) recommends that the states prioritise allocating 'resources to organizations of persons with disabilities that focus primarily on advocacy for disability rights', while paragraph 44 stipulates that states should not require that an organisation of persons with disabilities is registered as a prerequisite for taking part in broad consultation processes (UN CRPD 2018b: §44 & §61).

Obviously, creating the mechanisms that enable these 'majestic generalities' of the CRPD (Quinn 2009: 217) to trickle down to the actual policy making and monitoring processes is a key

challenge, which is also underlined by the Committee (2018b: §8). This could be clearly seen in all Committee's Concluding Observations and Recommendations in relation to the country reports that are available thus far (Pyaneandee 2019: 24). The continuing non-participation or the lack of effective procedures for guaranteeing meaningful involvement of disabled people ensue from different constellations of legacies, legislative barriers, and forms of support (or the lack thereof). However, there is a lack of up-to-date research on the state of participation in the countries that have ratified the CRPD, including a dearth of studies scrutinising the working of political representation on the ground and who is actually sitting at the table where decision-making takes place. And yet, having in mind the recent political trends towards 'shrinking' the space for rights activism and civil society (Carothers & Brechenmacher 2014; Krizsán & Roggeband 2018), we can assume that the participation of DPOs is already negatively affected and that this process will continue.

A 2014 analysis of the European Union Agency for Fundamental Rights (FRA 2014) on whether DPOs are involved in the development of laws and policies that affect disabled people in the European Union (EU) countries shows the sheer diversity existing in this regard. The way Bulgaria is presented in this analysis reveals not only that the gap between the principles and their implementation can be huge, but also that there could be a mismatch (especially for those unfamiliar with the local context) between the *appearance* of the existing mechanisms for consultation and their *actuality* on the ground. The FRA's (2014) analysis stresses somewhat approvingly (and misleadingly) that although in Bulgaria 'consultation and involvement of DPOs in the development of laws and policies is not required by law', the country 'established mechanisms to ensure systematic consultation with DPOs', namely through 'consultative bodies of people with disabilities which include representatives from DPOs'.

To prevent such misconceptions, it is crucial to demonstrate the gap between the involvement that the state claims to facilitate and the actual state of participation of disabled people. We argue that the organisations officially identified as 'representative' in Bulgaria are government-operated nongovernmental organisations (Mamonova & Visser 2014: 501). In the following sections, we will support this claim with evidence, demonstrating how far the Bulgarian NROs are from the requirements of the CRPD and the definitions of the General Comment No. 7.

2. METHOD AND DATA

Our analysis is based on data collected through desk research and semi-structured interviews conducted in the framework of the project *Disabled People's Movements in Central and Eastern Europe*. The project was designed and led by the fourth author, funded by the Open Society University Network and the Central European University's Democracy Institute. It ran between July 2022 and January 2023 in four countries: Bulgaria, Hungary, Romania, and Serbia. In each country, the project was carried out by a tandem consisting of a disabled activist and a disability studies scholar.

The Bulgarian study draws on content analysis of textual sources including legal documents, local and international civil society reports, public reports of government bodies, public reports of NROs. The websites of some of these organisations were also used as a source of data. In addition, several of the organisations' online magazines were reviewed, including the periodicals *Zari* ('Dawns') of the Union of the Blind in Bulgaria, *Tishina* ('Silence') of the Union of the Deaf in Bulgaria, and *Kurazh* ('Courage') of the Union of Invalids in Bulgaria.

Further, eleven semi-structured interviews were conducted – five with representatives of NROs, two with representatives of NGOs led and controlled by disabled people, two with representatives of NGOs that are service providers engaged in volunteering and advocacy, and one interview with a social worker who is engaged in human rights advocacy and is a member of two advocacy organisations. The respondents were purposively selected according to the local study's purpose of comparing the experience of advocacy and participation of several types of organisations: NROs, NGOs led and controlled by disabled people, and NGOs that are service providers but are also engaged in volunteering and disability advocacy. The interviews were conducted in October and November 2022. Participation was voluntary. All participants received information about the study and had to give their informed consent before interviews. The anonymity of the respondents is ensured by using only the designations „NROs' and „non-

NROs' to reference participants' quotes. The study was approved by the Central European University's Ethical Research Committee in July 2022.

When recruiting respondents, we approached twelve out of the 21 Bulgarian NROs by email at the official addresses indicated on their websites.[1] We received a prompt and affirmative reply to our emails from four organisations, with which we subsequently conducted interviews. The other organisations did not commit to an interview. We could only speculate about the reasons – possibly outdated information on the websites (email addresses that are no longer used), lack of staff to check emails, or lack of interest in and/or motivation to assist with this type of research. Certainly, not covering all NROs is among the limitations of our study, together with the lack of a detailed review of their annual financial reports and of the meeting minutes of the National Council for Persons with Disabilities (introduced in the next section).

The non-NROs we approached responded readily, and some of them were even eager to provide additional information on the subject of the study. This indicates a pressing need to voice concerns about the state of the civil society sector in Bulgaria.

3. THE BULGARIAN CONTEXT

Disability politics in Bulgaria is deeply marked by the overlapping legacies of state socialism, the postsocialist transformations that moved disability policies in a neoliberal direction, and the continued weakness of disability activism, especially the self-advocacy initiatives of disabled people themselves (Mladenov 2018).

State socialist governance of disability can be broadly characterised as medicalised and productivist, generating strongly paternalist attitudes and policy solutions (Dimitrova 2019; Mladenov 2018; Phillips 2009; Dinu & Bengtsson 2023). The conceptualisation of disability in this period (that in Bulgaria lasted between 1944 and 1989) was based on the idea of inability to work and included various strategies for (re)insertion of disabled people into productive labour, including medical rehabilitation, sheltered employment, and redirection towards less demanding work. These methods for labour-market reintegration were specified by physicians after the so-called 'labour expert medical committees' had determined the degree of reduced working capacity and indicated what work the disabled person was fit for (Mladenov 2021). The strong paternalism and the central role of medical professionals characterising this system persisted after the collapse of the regime in 1989 and can be clearly seen in contemporary disability policies, where the medicalised assessment of disability is still in force.

These contemporary policies are unfolding in a context in which the market paradigm, including the imperatives of minimal state and personal responsibility and entrepreneurship, have been dominant for more than three decades now. This, on the one hand, reinforced some aspects of the inherited productivist values and affirmed a hierarchy in which disabled people who can be deemed 'productive' – the so-called 'able-disabled' (Titchkosky 2003) – are ranked higher than the 'welfare dependants'. On the other hand, neoliberal marketisation has enabled and legitimised initiatives to cut back the welfare state, resulting in a chronic lack of support for disabled people (Mladenov 2018) – inadequate 'invalid pensions'; underfunding of healthcare, social care, and community support; insufficient and inadequate assistive technologies; inaccessible environment; and lack of opportunities for education and integration in the non-segregated labour market. At the same time, the neoliberalisation of the social sphere and the lack of strict quality controls boosted the social services sector. Thus, social entrepreneurship assumed central place as approach to the integration of disabled people, although the drawbacks of applying market-based strategies to solve 'social problems' are well known (Chui et al. 2019; Maravelias 2020; Mauksch & Dey 2023).

1 We did not approach the following NROs: the National Association of Employers of People with Disabilities, the Bulgarian Diabetes Association, the Union of War Invalids and War Victims, the National Rehabilitation Centre for the Blind, the Bulgarian Association for Recreation, Integration and Sport, the National Alliance for Social Responsibility, the National Consumer Cooperative of the Blind in Bulgaria, the National Association of People with Acquired Disabilities, and the Bulgarian Association for Neuromuscular Diseases. The rationale for this exclusion was that these are organisations: (a) prioritise a specific type of activity different from advocacy, such as support in providing employment, organising sports initiatives, providing access to tourism; (b) whose activities target disabled people who are already represented by another major organisation; or (c) are focused on medical conditions, thus prioritising the provision of medical care for a specific condition (e.g. diabetes).

It was in this disability policy context that Bulgaria ratified the CRPD in the beginning of 2012. As steps towards its implementation, three laws were enacted – the Personal Assistance Act of 2018, the Social Services Act of 2019, and the Persons with Disabilities Act of 2018.[2] In addition, two institutional entities were established, allegedly to fulfil the obligations of the state under Articles 4(3) and 33(3) of the CRPD – the National Council for People with Disabilities, and the Monitoring Council. We will now briefly describe these two bodies because the toxicity of the local mechanisms of political representation of disabled people are palpable in their composition, functioning, and the relations between them.

The National Council for Persons with Disabilities (NCPD) at the Council of Ministers is the official decision-making partner of the state in defining and implementing policies on disability in general and on the CRPD in particular. It is an advisory body composed of government representatives nominated by the Council of Ministers, NROs, nationally representative organisations of employers, trade unions, and the National Association of Municipalities in the Republic of Bulgaria. The NCPD was formerly known as 'National Council for Integration of Persons with Disabilities' between 2004 and 2020, and as 'National Council on Rehabilitation and Social Integration' between 1996 and 2004, originally established by the Protection, Rehabilitation and Social Integration of the Invalids Act of 1995. Thus, this structure has existed for more than twenty years now, being created long before the ratification of the CRPD. It is worth noting that throughout its existence, both before and after the ratification, it has overwhelmingly included the same NROs as members, with the same persons representing the same organisations since 1996. After 2012, several new NROs were added but they had the same status of 'nationally representative' organisations, where 'representativeness' is defined in terms of territorial coverage and number of members (discussed below). In essence, the NCPD has inherited the paternalist and medicalised approach of its predecessors – an approach that has reproduced state socialist attitudes and policies towards disability (Mladenov 2009; 2018). Despite this, the simply renamed Council is formally presented as evidence that the obligations of the state under Article 4(3) of the CRPD are fulfilled.

The other institution created in 2019 to meet the requirements of the CRPD is the Monitoring Council, intended to promote, protect, and monitor the implementation of the Convention. It consists of nine members, four of which represent disabled people. Three of them are representatives of the NROs, only one is a representative of an independent, parent-led NGO, and among them only one is a disabled person – the chairperson of the NRO Union of the Blind in Bulgaria, Vassil Dolapchiev. Notably, the NROs included in the Monitoring Council are also members of the NCPD, including Dolapchiev himself. This means that the monitoring body – in its segment that represents disabled people – would be unable to provide 'independent monitoring'. In its founding protocol, all four representatives are officially presented as 'NGO representatives', which masks their status of government-operated nongovernmental organisations, as well as the fact that they are long-time insiders not only of the needs-based disability politics after 1989, but for some of them even before that. The first annual report of the Monitoring Council contains few activities but many photos from the meetings. In 2021 and 2022, the Council held three meetings annually, whereas the law requires them to convene 'at least once each three months' (Article 15(1) of the Persons with Disabilities Act), which amounts to at least four meetings annually.

The activities of the Monitoring Council are formulated in its programmes very loosely and generally. Good example are the most recent ones that are planned for 2023. Under the heading 'Protection of the rights of people with disabilities', we read that the Council envisages '[preparing] recommendations to the heads of the responsible authorities for the ratification of the Optional Protocol'. After that, the '[p]romotion and advancement of rights according to CRPD' is to be fulfilled through celebration of 3 December, the International Day of People with Disabilities, by organising discussions. The Council also envisages '[p]articipation in various working groups and forums' through activities as 'promotion of the Council and the CRPD through participation in working groups, forums, seminars, trainings, etc.' (Monitoring Council 2023: 1–2).

2 The latter is a revised version of the Integration of Persons with Disabilities Act of 2004 and some disabled activists define it as continuation of the old medicalised and paternalist disability paradigm (see Centre for Independent Living 2020).

The formal way in which this mechanism of political participation is organised in Bulgaria clearly shows the hollowness of the claims that the state fulfils its obligations under Articles 4(3) and 33(3) of the CRPD. In the next section, we will draw on the findings of the *Disabled People's Movements in Central and Eastern Europe* project to explore in more detail the characteristics of the NROs. This will enable us to highlight the futility of the expectation that these organisations would be willing and able to move the local disability politics in the direction of the human rights model.

4. FINDINGS

4.1. THE MECHANISM OF 'REPRESENTATION' IN BULGARIA

4.1.1. Legal criteria for representativeness and funding of NROs

Bulgarian disability policy, which traditionally has been strongly influenced by the NROs, has been criticised long before the ratification of the CRPD – most consistently by the Centre for Independent Living – Sofia (see, for example, Centre for Independent Living-Sofia & Trust for Civil Society in Central and Eastern Europe 2011; Mladenov 2007; Mladenov 2009). The requirements that must be fulfilled for an organisation to be recognised as 'nationally representative' are included in Chapter five of the current Persons with Disabilities Act (henceforth, 'the Act'). The latter has been in force since the beginning of 2019 and was officially pronounced by the state to be a decisive step towards aligning the local legislation with the CRPD. To be officially recognised as 'representative' according to Article 92 of the Act, organisations need:

> (1) to be registered under the Non-Profit Legal Entities Act as public benefit legal entities or under the Cooperatives Act to carry out activities in the field of social inclusion of persons with disabilities for at least 5 years prior to submitting the request for recognition of national representation; (2) have at least 5 years of proven experience in the field of social inclusion of persons with disabilities; (3) have members in at least 25 percent of the municipalities in the country.

These requirements make it impossible for many organisations of disabled people to attain the status of 'nationally representative' and, respectively, become members of the NCPD and get involved in official decision making. On the other hand, the legal criteria for representativeness enable passive and even 'fake' organisations to attain this status and policy access (Mladenov 2009). It is important to point out that the logic of 'representativeness' underpinning the provisions in the Act is not new and has nothing to do with any declared ambitions of the state to fulfil the requirements of the CRPD. This logic was the same in the preceding legislation, the Integration of Persons with Disabilities Act of 2004, as summarised by Mladenov:

> Being 'representative' means being able to speak and act on behalf of X number of people in Y number of places. The bigger the number of people and places, i.e. the bigger the values of X and Y, the more 'representative' the organisation is, and therefore the more legitimate (Mladenov 2007: 3).

This understanding of representativeness is very different from the one underpinning the definitions in General Comment No. 7 (UN CRPD 2018b), where formal registration is not even required as a condition for participation in decision making. Notably, there have been a number of calls to revisit this logic of political representation. For example, in 2007, the Centre for Independent Living – Sofia petitioned the Ombudsman; in 2015, the same organisation filed a lawsuit against the criteria for national representativeness; and in 2018, the national representativeness was attacked during nationwide protests of parents of disabled children who demanded for the local disability policy to be more closely aligned with the CRPD. However, in all such instances, the NROs immediately formed a stronghold to counteract the critique, mobilising their established ties with trade unions, leftist NGOs, and experts involved in the disability assessment expert medical commissions (for an example of weaving such a reactionary alliance during the 2018 protests, see Dimitrova 2020).

Naturally, the NROs do not want to lose their political standing, but also the material and economic advantages conferred by the status of 'national representativeness' – the state provides funding to these organisations in the form of annual subsidies, and some of the

European Union Operational Programs are exclusively available to them. Additionally, NROs can receive ad hoc funding from the Bulgarian Agency for People with Disabilities and can provide delegated social services. These organisations also collect membership fees and receive donations. All their expenses and activities are reported annually before the NCPD – the consultative body of which they are part. This type of deep entrenchment in the state structures is the reason why they cannot be properly called 'civil organisations' but are, as noted above, government-operated nongovernmental organisations – or clientelist entities, as the non-NROs in Bulgaria call them.

Last, but not least, the NROs largely reproduce the medical model of disability in their attitudes and practices, which has traditionally been the dominant policy approach adopted by the Bulgarian state since the state socialist period. This needs-based paternalistic framework, in which disabled people are objects of care, and which the CRPD rejects, is evident in these organisations' discourse, the content and logic of their online publications, and the vocabulary used in the meetings of the NCPD, as evidenced in the protocols from these meetings. The names of the NROs are also indicative – e.g. Union of the Invalids in Bulgaria (although in the English version they use 'disability'), National Federation of Employers of Invalids (at least until 2015), Union of the War Invalids. Notably, the word 'invalid' (In Bulgarian, *инвалид*) is as stigmatising in Bulgarian as it is in English.

4.1.2. What and for whom are the NROs?

Along the lines of the distinction between organisations 'for' and 'of' disabled people, the Bulgarian NROs have consistently displayed 'some or all of the characteristics attributed by British [social model] analysts and activists exclusively to 'organisations for' [disabled people]' (Mladenov 2009: 40). This continues to be the case, with the addition that now these organisations are able to co-opt the language of the CRPD in order to increase further their legitimacy and power. Their websites do not discuss this issue and the way they self-identify and position themselves does not refer to this distinction. This in itself, is indicative of the level of understanding of the CRPD, the will to implement it, and the possibility of adopting a human rights model in Bulgaria – the fundamental principles of involvement and self-determination, and the risks when third parties appropriate the voices of disabled people, are swept under the carpet.

What is the profile of the 21 NROs officially sanctioned to speak on behalf of disabled people in Bulgaria? What is evident from their websites and public positioning is that they include five parent-led organisations, five organisations chaired by a disabled person, and a number of organisations focused on (a) providing employment to disabled people (such as Cooperative Union 'National Union of Labour Productive Cooperatives'; National Association of Employers of People with Disabilities; and National Consumer Cooperative of the Blind in Bulgaria), and (b) providing social services (such as Bulgarian Association for Recreation, Integration and Sport; National Alliance for Social Responsibility; Bulgarian Association for Recreation and Tourism; Centre for Psychological Research; and National Association of People with Acquired Disabilities). Information about the composition of the governing bodies of the organisations is not included in the reports, minutes, and public presentations of the organisations. From the interview with a representative of one of the oldest and largest NROs with a disabled person as chairman, we learned that:

> now in management we have a total of four [non-disabled] women..., a [non-disabled] editor-in-chief, and me [the respondent is disabled]; two [disabled] people as technical support..., and three [disabled] janitors.

It should also be noted that some of these organisations are not even exclusively 'for' disabled people, but are open to members without disabilities, which means that they may attain the status of 'national representativeness' thanks to the participation of people without disabilities. The Centre for Psychological Research, for example, defines its membership in the broadest possible way, covering virtually all possible conditions, difficulties, even inequalities ('disadvantaged women'); the Diabetes Association is in practice a patient organisation. The NROs also implement activities that do not seem to include disabled persons – as an example, two of the three current projects of the National Association of People with Acquired Disabilities do not target disabled persons but 'youth' (in general).

Overall, the activities of the NROs are directed at servicing their members and include support in obtaining medical care; organising sporting events, trips, parties, and trainings; job placement; providing social assistance in cash or in kind – food, medicine, clothing, etc.; providing scholarships for students; retailing; renting out facilities; providing group recreation and rehabilitation opportunities; support in communicating with institutions, including residential care; providing home care. These are all services, which shows that NROs are functioning as service providers, for which they receive not only external funding but also additional public funds on top of their annual state subsidy. This is in tension with the recommendations that the states prioritise 'resources to organisations of persons with disabilities that focus primarily on advocacy for disability rights' and deprioritise 'organizations 'for' persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities, which, in practice, may result in a conflict of interests in which such organizations prioritize their purpose as private entities over the rights of persons with disabilities' (UN CRPD 2018b: §61(b) and §13).

To summarise, Bulgarian NROs hardly meet the definition of 'representative organisations' included in General Comment No. 7. Most of them are also not 'umbrella organisations' par excellence – most of the NROs are structured as single-entity or diagnosis-based organisations with regional branches. Those that could be defined as 'umbrella organisations' are one of the parent-led organisations (the Bulgarian Association for Persons with Intellectual Disabilities), the organisation of employers, and the organisations focused on social entrepreneurship. In this regard, the General Comment No. 7 recommends that 'there should be only one or two umbrella organizations at each level of decision-making' (CRPD 2018b: § 12(a)).

Moreover, the structure of NROs raises the question of whether they provide mechanisms for members' views and preferences to reach the leadership – in other words, whether and how representation within the organisations is ensured. As the Bulgarian Helsinki Committee points out, 'it is still unclear how nationally representative organisations select their members and representatives and how they provide them with information' (BHC 2017: 20). The focus on the number of members when receiving the status of 'national representativeness' – an organisation must have at least 1800 members and provide services to at least 4,500 individuals annually (Persons with Disabilities Act, Article 92(3); these numbers are reduced for organisations of deaf-blind people and little people) – is an obvious obstacle in this regard. And this is directly related to the continuous depoliticisation suffered by the local disability sphere (Mladenov 2018).

4.1.3. The NROs as defenders of social rights

A key principle of the human rights model is the indivisibility and interdependence of the civil and social rights. As Degener (2017: 45) states, the CRPD 'not only contains both sets of human rights, the text itself is evidence of the interdependence and interrelatedness of these rights'. But despite the adoption of the CRPD, in many European countries – and particularly in the postsocialist countries of CEE, mostly due to the entrenchment of state socialist legacies of medicalisation and paternalism – an alternative, needs-based model still dominates disability governance. The latter frames disability as a welfare issue, emphasising 'the most urgent needs so to say, the right to basic healthcare and education… a minimum standard of living, rights which all happen generally to be categorized as social rights' (Flóvenz 2017: 258).

The tension between rights and needs in disability governance has been closely examined in one of Michael Oliver's (1996: Ch. 5) seminal monographs, *Understanding Disability*. There, Oliver (1996: 75) points out that 'professionalised service provision within a needs-based system of welfare has added to existing forms of discrimination' instead of dismantling them. In this sense, the needs-based model has enhanced professional power and, accordingly, disempowered those subjected to professional interventions. We argue that Bulgarian NROs consistently reproduce the needs-based logic in their approach to disability, thus perpetuating the status quo of segregation, misrecognition, and disempowerment of disabled Bulgarians. This can be evidenced by the programmatic address of the long-standing leader of the Union of the Blind in Bulgaria, Vassil Dolapchiev, who has directed the organisation since 1998. On the occasion of the ratification of the CRPD, Dolapchiev wrote:

> The synchronization of Bulgarian legislation… with the requirements of the Convention will be a long process… the norms of the Convention have a very broad

> scope, allowing each country to find the best solutions depending on its national specificities… The current legislation of our country regulating the rights of persons with disabilities is highly compliant with the basic requirements of the Convention… It is clear to all of us that an active social sector policies can be made by countries with developed economies… We believe that until 2020 the main source of funding for the activities and services regulated by the Convention will be the European [Union Structural Funds] Operational Programmes. Our organisation has gained experience in developing and implementing projects to different donor sources (Dolapchiev 2012: n.p.)

In this statement, Dolapchiev clearly sought to neutralise the imperative for policy change inherent in the rights-based approach of the CRPD. First, he discounted the urgency of the reform, suggesting that it will be 'a long process'. Then, he defended the status quo by mobilising a relativist argument – 'national specificities' call for re-interpretations of the CRPD's provisions (arguably to serve NROs' interests). The status quo has also been bolstered by (misleadingly) referring to the Bulgarian legislation at the time as compliant with the CRPD. Finally, Dolapchiev absolved the state of its responsibility to implement the changes by seeking support for the reform from EU and donor funding – sources that, since the end of the 2000s, have tended to crowd out rights-based advocacy activities, promoting instead the needs-based, service-oriented interventions favoured by the NROs.

Let us consider another example of neutralising the rights-based model. In the magazine of the Union of Invalids *Courage*, in the issue announcing the ratification of the CRPD, the cover headline reads 'Project Implementation – European Pathway to Social Progress' (Stoyanova 2012). The article beneath promotes a market-based strategy in the form of social entrepreneurship, absolving the state of its responsibility for implementing the reform required by the CRPD in a way that echoes Dolapchiev's (2012) piece. The text also advocates for sheltered employment, emphasising the need to maintain the status quo of segregated services inherited from state socialist disability policy:

> Because of the world crisis, people are talking now of a 'social economy' that can compensate for the limited capacity of the state to deal with the growing problems of the vulnerable social groups and revive in a successful way the destroyed by the competition cooperatives of the disabled, which solved the problem to some extent in the not too distant past. (Stoyanova 2012: 5)

At the same time, the focus on welfare allows the NROs to present themselves as promoters of the rights of disabled people, stripping the concept of its civil aspects. But what they foreground as a struggle for rights is in fact a struggle for meagre benefits, which locks disabled people within a paternalist and segregating welfare system and cuts them off from other social systems (justice, education, employment, leisure) since 'it is much easier to fall back on social programmes that perpetuate helplessness than it is to consciously craft social systems that liberate individuals' (Quinn 2019: 224). Clear evidence for this is the Annual Report of the Governing Board of the Union of the Blind for 2021, where in the section 'Human Rights Advocacy' we read the following: 'We demanded an increase in the income from pensions and various social payments of the social group we represent.' (Union of the Blind 2021: 2)

Of note is also that the NROs opposed the new Personal Assistance Act, insisting that personal assistance should be regulated by the Social Services Act on a par with all other services. Their arguments remained firmly grounded in the needs-based logic, as suggested by this opinion piece published in *Tishina*, the newsletter of the Union of the Deaf in Bulgaria:

> the personal assistance in question is only one aspect of the support that should be provided to people with disabilities and there is no point in developing it in a separate law. Furthermore, it was decided that such a law would provide care disproportionately to a small minority of those in need (those with over 90% disability, around 80 thousand people), pitting them against others with other needs – potentially 10 times as many people (Gancheva 2019: 2).

The idea of the partnership of DPOs with the state, enshrined in CRPD, is in Bulgaria conveniently converted into cooperating with the state to maintain the status quo of socially created

disablement (and keep subsidies flowing). This type of cooperation requires – as we will see in the discussion of the interviews in the next section – always 'reaching a consensus', 'finding a balance', or 'being diplomatic' because 'there is not enough money for everyone'. And for the sake of this, the Union of Invalids (Kotsev 2011: 15) warns: 'Individual needs do not always coincide with the public interest, and our goal should be to align them without favouring group interests.' In practice, the adherence to the needs-based model naturally entails adherence only to a consensus approach rather than to conflict-oriented activist strategies (Holland 2008). Again, the vocabulary of the CRPD is perfectly co-opted, and the meanings of its provisions are reinterpreted to serve vested interests.

4.2. SELF-PRESENTATION OF THE ORGANISATIONS IN THE INTERVIEWS

Our interviews revealed a persistent pattern – informants from both the NROs and non-NROs highlighted 'national representativeness' as a key feature of Bulgarian disability policy. However, non-NROs were radically critical of this feature and identified it as a key reason for local disability policy going awry. In contrast, NROs unequivocally applauded 'national representativeness' as a successful mechanism that just needs more time to bring visible results. Thus, the distinction between 'representative' and 'non-representative' organisations emerged as a major dividing line, more important than the division along the line of the social versus the medical model, or whether an organisation is also a provider of social services or engages exclusively in advocacy, or whether it is a parent-led organisation, or an organisation led and controlled by disabled people.

That said, ideological distinctions were also highlighted. Informants from non-NROs emphasised that 'a substantial level of philosophical division is present – the basic question what disability is and how we should treat it' (respondent 2, non-NRO). They discussed the fundamental tensions between the respective disability models: 'Conflicts within disability community [are due to the fact that] for a long time they wanted to 'take care of us', but now we're talking about empowerment. These differences in disability philosophy are actually the reason why we are still stuck' (respondent 1, non-NRO). What the informants from the NROs described as 'quiet activism' (discussed below), the organisations on the other side of the divide denoted as 'conformism' and 'inability to exert significant pressure, because they are already so deeply entrenched within state politics that they rather protect the status quo' (respondent 3, non-NRO).

The informants from the NROs chose to speak exclusively for their own organisations when commenting on the question about the involvement of DPOs in policy making. They hardly commented on the work and initiatives of other organisations, unless specifically asked. An exception was the already mentioned protest of mothers of disabled children that resulted in the adoption of the Personal Assistance Act in 2019 – all our information from NROs criticised the intentions of the mothers and the Act itself as harmful, unnecessary and 'consuming a lot of money' (respondent 1, NRO).

Participants from NROs framed the role of their organisations in a similar way, highlighting three main features – the importance and success of the NROs, their 'quiet activism', and their 'real work', referring to the practical and material support which they provide to their members. The latter is a clear manifestation of the needs-based model that these organisations embrace and affirm.

All representatives of NROs stressed in the very beginning of the interviews that they are the civic entities that have the 'real influence', 'know best', and are 'the experts on disability issues'. One of them added that 'exactly in these organisations the real support is to be found because when you are among your own kind (in Bulgarian, *сред себеподобни*), you feel freer, safer' (respondent 2, NRO). The same segregated attitude was expressed by another interviewee more directly: 'In the past, there were, let›s call them, segregated schools – to me, though, that was more reasonable' (respondent 3, NRO).

After emphasising the importance and success of their own work, our informants from NROs tended to proceed to explaining the grim situation of disabled people and disability policies in Bulgaria, even without a prompt. The recurrent way of approaching this question was by emphasising that improvements in disability policies exist and are real, but are not 'visible from

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outside' and, moreover, happen very slowly – 'but in the West it has taken about a century' (respondent 1, NRO), and 'if it is fast, it will not be real' (respondent 3, NRO).

The specific way in which NRO informants referred to their involvement and participation in decision and policy making was as 'quiet activism' and 'positive pressure'. This 'pressure' was depicted in the following way (note how the organisation's members are treated as a passive and undifferentiated mass that can be controlled by the organisation rather than being able to control it):

> They [the state] know we›re a big force, we have close to two hundred thousand members, real membership, so we can get them out [in Bulgarian, можем да ги изкараме], and they know we can get them out... and [the protest in] 2018 was a demonstration of this, we brought (in Bulgarian, доведохме) only 7,000 people... we can do something more serious but we prefer to talk, to be understood. (respondent 1, NRO)

The emphasis on consensus mentioned in the previous section was very strong in our interviews with NRO representatives, emerging as a key aspect of their identity and self-presentation as 'social partners' of the state. The same respondent continued: 'They [NROs] don›t shout, they rarely go out to protest... if they go, they speak positively, they want things to happen and the institutions to notice that these people need support... And this is the quieter way to work' (respondent 1, NRO). Another informant stressed that he does not support the 'aggressive way of acquiring or conquering... if you want to obtain something, you have – more or less – to comply... With a negative attitude, you will get nowhere... the union is what makes us strong' (respondent 3, NRO). And a third one stated that NROs are 'very active, but... have some dependence on state structures, because they are constantly checking them and they [the NROs] have to be diplomatic' (respondent 4, NRO).

The third important theme in the interviews with NRO participants was the stated devotion to NROs' members, with an overwhelming focus on providing direct support to the members, as opposed to trying to bring Bulgarian disability policy and legislation closer to the human rights model. An obvious motivation underpinning this needs-based focus of the NROs is to maintain and increase the number of their members in order not to lose the status of 'nationally representative organisations' (and the attendant subsidies). This means that 'national representativeness' binds the organisations to this type and level of support and makes them reluctant to advocate for policies perceived as 'abstract':

> If you make one wrong step and allow yourself something abstract, then the people will not forgive you and will punish you [implying that the members will cancel their membership]... If you tell Granny Pena [a common and archaic Bulgarian name used by the respondent as a collective designation of poor old disabled women] that she has rights, nothing will happen, but if you bring her a new wheelchair, she will be happy. (respondent 3, NRO)

NROs justify this approach with the argument that the harsh conditions in which most disabled people in Bulgaria live call for direct support. These conditions include poverty, lack of access to education, lack of medical care, and inaccessible environment – issues that are particularly prominent in small towns and rural areas. NROs even insist that they are responsible for the very survival of disabled people: 'we are sometimes fighting for human lives' (respondent 3, NRO). Thus, events organised by the NROs such as celebrations, in-kind provisioning of food and medicines, small financial help, even bringing out people who, due to the inaccessible environment and lack of personal assistance have been confined to their homes for years, are experienced by the members as something exceptional, for which they owe gratitude and loyalty to the NROs.

The approach that focuses on satisfaction of immediate needs through and provision of direct support and services is traditional for the NROs, but it has recently been reinforced due to the cost of living crisis, the deepening social abandonment in Bulgaria, and the illiberal sentiments that are growing stronger in the country and the CEE region as a whole (Dobbins & Labanino 2023; Cianetti et al. 2019). These developments have created a context of deepening poverty and growing disaffection with 'foreign ideas', in which the human rights agenda has been

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increasingly dismissed as irrelevant, elitist, externally imposed, and out of touch with local realities. Such a dismissal has been strong among our NRO respondents:

> What is violated? Tell me what? No one prevents them [disabled people] from doing whatever they want. There are possibilities created, there is integrated education, democracy, everyone can do whatever one wants. There are programmes, most schools are accessible… No one is disenfranchised, everyone can … eat, work, study, what is violated then? (respondent 3, NRO)

The same respondent distinguished between two types of rights – 'authentic' ones, which are inherent and have always been respected in Bulgaria (implying that there is no need to invoke them), and 'fake' ones, imported from the West, where rights appeared in attempts to oppose locally specific oppressions that have not obtained in the East (or at least in Bulgaria):

> Rights are an American topic, imported; the concept appeared there because they had slavery, that's how they built America, France, England, Spain, Brussels, the Netherlands… They went and looted. We, here, have always respected human rights… This is why we wonder what 'advocacy' means… These modern words – advocacy, lobbying, etc., which Brussels wants so much to impose… What is 'empowerment'? What are these slogans, even the communists weren't so fake… These are pompous words, let people use them, I use them too, but the main thing is the real work to be done. (respondent 3, NRO)

This disparaging of rights as empty phrases, propaganda, something that does not work in practice, something 'not applicable to Bulgaria', was shared by most of the interviewees from NROs. Such attitudes indicate the permeation of illiberal sentiments in the Bulgarian disability policy arena. This, in turn, has led to alliances between NROs and other entities such as some leftist NGOs, some public figures (journalists, bloggers), and one of the two main trade unions in Bulgaria, 'Podkrepa' (or at least several prominent figures in it). Notably, these allies have openly endorsed illiberal positions (see, for example, Podkrepa 2018). The result is a growing affirmation of paternalist forms of support, coupled with a dismissal of the human rights model of disability as 'Western propaganda'. That is why it was hardly surprising that when asked what the landmark events in the local history of disability activism and disability policy were, no person among our NRO respondents pointed to the ratification of the CRPD.

In comparison, the general attitude towards the CRPD of the non-NROs is of one of deep disappointment that, in practice, the 'fundamental policies that are very important to achieve inclusion – accessible environment, opportunities for employment, and independent living – were not embraced' (respondent 2, non-NRO). This respondent, who is a social worker and activist in two NGOs, categorically stated that the 'CRPD changed nothing… For my colleagues it is an exotic word and nothing else.' That said, one of our non-NRO respondents regarded the CRPD as a crucial factor for the activist success and an important basis for the changes that were achieved, as exemplified by the adoption of the Bulgarian Sign Language Act in 2021.

Non-NRO respondents generally commented with great alarm that opportunities for promoting the human rights agenda and 'pure' advocacy have almost vanished. Respondent 2 even directly identified the effects of the illiberal turn:

> The topic of rights has been losing its power recently… it has lost its influence due to the recent campaigns that have taken place [referring to the attack against the 'Istanbul Convention' and the National Strategy of the Child]… If the CRPD were to be ratified now [after losing the battle for the 'Istanbul Convention'], it may not have happened. (respondent 2, non-NRO)

The division along the lines of national representativeness gives rise to several fundamental contradictions, both in the understanding of disability itself and in the key policies that should be implemented. Respondents from the non-NROs framed this as 'paternalist care versus empowerment' that holds back the whole sphere and defined the role of the NROs as amounting to a 'piecemeal' approach, which is doomed to failure in the long run but is convenient for the state. The responses of our NRO participants effectively affirmed this assessment of their approach, but presented it positively, suggesting that it is better to focus

on the people themselves and their needs here and now: 'let's not talk about abstractions… to save even five people – this is what's important' (respondent 3, NRO).

CONCLUSION

Our analysis showed how the human rights model enshrined in the CRPD and conceived by Lawson and Beckett (2021: 18) as an 'oppositional device' has either been co-opted to serve the traditional needs-based disability approach, or outrightly rejected as 'Western propaganda' by the organisations representing disabled people in the official disability policy making in Bulgaria. Crucial in this process is the way in which the principle of participation of disabled people in decision making, implementation, and monitoring of policies that affect them is operationalised. The potential implications of this situation on EU policies such as the planning, implementation and monitoring of EU Structural Funds is considerable because much of the existing policy influence of the disability movement in Bulgaria is exercised by NROs with their needs-based approach, locking out initiatives that fight for a CRPD-based scrutiny of public policies.

The Bulgarian case provides an example for what Quinn (2009: 22) identifies as a 'powerful blocking force' that is even worse than exercising a veto over change or slowing down the process of transformation. As such a 'blocking force', we have identified the co-opting or negation of the rights-based model to rationalise and legitimise the needs-based status quo of marginalisation, impoverishment, and disempowerment of disabled people. In Bulgaria, this co-option is enabled by the officially sanctioned and legislated criteria for 'national representativeness'. Consequently, the substantial revision of these criteria – along the lines suggested by the General Comment No. 7 (UN CRPD 2018b) – is a necessary (although not sufficient) condition for the transformation of disabled Bulgarians into "'subjects' enjoying human rights on an equal basis with others' (Quinn 2009: 216).

The sheer fakeness of the political representation of disabled people in Bulgaria, embodied in the NROs, is not new. However, since the ratification of the CRPD, this sham representation has become even more toxic. It has transformed the CRPD from an 'oppositional device' that helps dismantle disablement and enhance self-determination and inclusion into a 'blocking force' that preserves the needs-based status quo of reducing disabled people to objects of care. The efforts of small, advocacy-oriented, critical organisation such as the Centre for Independent Living – Sofia to revise 'national representatives' have proven path-defining but unsuccessful. Our article has followed these pioneering efforts in the hope to reenergise the struggle for revision of 'national representativeness' in Bulgarian disability politics.

The Bulgarian case reminds disability rights defenders around the world that anti-human-rights discourses, illiberalism, and the shrinking space for human rights advocacy (Butler 2017; Carothers 2016) strongly affect disability movements internationally, while being related to conditions rooted in the period before the CRPD. Members of disability movements, including organisations of disabled people, exist in historical-political contexts where the movements' internal divisions, dominant discourses, access to resources, and opportunities to influence policy-making usually mirror conditions in broader politics. What seems as the 'voice of the disabled people' may in fact be a force that blocks progress while simply co-opting the human rights language. It is therefore imperative to explore and contextualise issues *internal* to disability movements around the world to tackle current impasses of disability politics.

COMPETING INTERESTS

The authors have no competing interests to declare.

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