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‘WHO HAS BEEN DENIED EQUALITY AND WHY?’ – DISABILITY MOVEMENTS IN CHANGING AND ERODING DEMOCRACIES OF CENTRAL AND EASTERN EUROPE

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CEU CENTRAL EUROPEAN UNIVERSITY

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ABOUT THE AUTHORS

Gabor Petri is a post-doctoral researcher at the CEU Democracy Institute. He received his PhD at the University of Kent, Tizard Centre in 2019, where his research explored the position of self-advocates in the learning disability and autism advocacy movement. He has worked in the disability field since 1999. He has held various positions at disability rights organizations in Hungary and the EU and worked at public administration bodies as well. He was a member of the Board of Directors of the European Disability Forum from 2013 to 2022, representing Mental Health Europe. In 2022, he was an OSUN fellow: his research explored the position of the disabled people's movement in public policy-making. He is Senior Policy Adviser at Mental Health Europe and Honorary Lecturer at the University of Kent, Tizard Centre.

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ABSTRACT

Disability is rarely studied in the context of democracy even though disabled people represent 16% of the population and the disabled people's movement has been influencing laws and policies in all modern democracies. This study explored how disability movements work in changing and eroding democracies in Central and Eastern Europe (CEE). Data was collected in Bulgaria, Hungary, Romania and Serbia.

The study confirms that democratization and de-democratization influence disability movements and their position. Although the inclusion of disability movements in policy-making has been established through formal consultative and monitoring platforms, disability movements' participation in policy-making remains mostly tokenistic in CEE. Democratic backsliding affects movements' coalition-building capacities, and mobilization becomes harder. Where democratic erosion is stronger, movement organizations exercise self-censorship and avoid open criticism of government politics. The study argues that reactions to democratic erosion are influenced by movement organizations' resources, their embeddedness in state structures, and other factors. The paper offers a typology of disability movement organizations in CEE and points at potential risks for re-democratization efforts.

KEYWORDS

Democracy, disability, democratic erosion, social movement, human rights

INTRODUCTION

The relationship between disability and democracy is largely unexplored, even though disabled people represent a significant proportion of electorates. Disabled people are 16% of the world population (WHO, 2023) so a large part of our societies – including family members approx. 35-40% – experiences political, social, economic, and human rights issues related to disability. The work of the disabled people’s movement (DPM) bears relevance to how democracies function. Where democracies enter periods of erosion, DPMs will inevitably experience shifts in political opportunities and the question is how they react to changes in democratic systems. This study will demonstrate that disability politics matter in democracies even when disabled people are hindered from joining or doing politics.[1]

Political science offers theories of disability (Kimberlin, 2009; Simplican, 2015), but disability politics is invisible in the study of democracy. Why? Some factors are evident: the historical exclusion of disabled people from elites and political parties; dominant narratives framing disability as individual tragedy; the marginalisation of disabled activists in social movements; weak representation of disabled people in academia; research priorities ignoring disability in political science and social movement research. This article is an attempt to partly fill this gap by exploring the relationship between disability and democracy through the work of Central and Eastern European (CEE) DPMs. Civil society organisations (and DPMs) play a crucial role in promoting democratic values, stimulating political participation, and articulating and channelling special interests onto the political agenda (Diamond, 1994). Like other movements, the DPM has evolved on several levels: local activists challenge local authorities; national DPMs engage with governments; and the international DPM lobby international organisations. I will focus on the national level. Just like democracy that exists mostly on the country level, the national level has been seminal for DPMs, because that is where authorities have the most leverage to introduce changes. I will explore the situation in Bulgaria, Hungary, Romania, and Serbia where periods or protracted trends of de-democratisation are identified (Greskovits, 2015; Rupnik, 2021).

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[1] Disabled people are under-represented in politics: 15% of EU citizens live with a disability, but even in developed democracies only 1% of politicians identify as disabled (Waltz & Schippers, 2021).

NOTE ON TERMINOLOGY

National policies use different disability assessments and classifications, leading to erratic datasets in cross-national studies (Tøssebro & Hvinden, 2017). When I use the term 'disabled people', it covers a broad social category of those diagnosed, labelled or self-identified as disabled people, including people with mobility limitations; people with visual impairment; members of the deaf community; people with intellectual disabilities; autistic and other neurodivergent people; people with psychosocial disabilities; people with multiple or chronic conditions etc. Disability is an ever-evolving concept, so the above labels seem arbitrary or incomplete in different jurisprudences.

There is no consensus on terminology. In English, some use 'person first' terms, while others prefer identity-first language. I will employ the latter ('disabled people'), following traditions of the social model of disability (Oliver, 2009) and leading organisations of the Independent Living Movement (ILM)[2].

Of categorisations of DPM entities (Waldschmidt et al., 2015; CRPD, 2018), the distinction between organisations *of* (led by disabled people) and organisations *for* disabled people (led by non-disabled people) is central. Another typology – the three waves of the DPM (Wehmeyer et al., 2000) – is also revealing: (a) organisations led by non-disabled experts; (b) entities led by family members of disabled people; and (c) organisations controlled by disabled people ('disabled people's organisations' or DPOs). DPOs are the most recent wave – they embody the self-determination of disabled people.

DISABILITY AND DEMOCRACY

Disability is political. This is the idea the DPM was founded upon, and leading theorists – including Marxist (Oliver, 1990; Finkelstein, 2001), bioethicist (Shakespeare et al., 1996), feminist (Garland-Thomson, 2005), and critical disability studies scholars (Goodley, 2014) – have repeatedly put forward theories to assert this. However dominant cultural narratives frame disability differently: as individual tragedy related to impairments or as a diversion from normative notions of bodily or cognitive functioning. To understand how the 'disability problem' relates to democracy, we must briefly discuss theoretical models that shape disability politics. Although models of disability co-exist (Goodley, 2012), unpicking the two most dominant models helps develop analytical tools for this study.

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[2] The ILM's principles include self-determination; equal opportunities; social inclusion; human rights; democracy. See the European Network on Independent Living (ENIL): https://enil.eu/about-enil/#whatAreThePrinciples.

First, the 'medical' or 'individual tragedy' model frames disability as a primarily biological issue, where physical, sensory or cognitive impairments result in degrees of loss in 'normal' functioning. The explanatory power of this model is known to everyone: one becomes disabled by not being able to move or see or hear or think or behave like others. Consequently, disability 'needs' medical interventions, some social welfare responses and positivist epistemologies that come with these: one's condition is described by 'experts', doctors, and others who use medicalised language to prescribe treatment. Policies under these epistemologies focus on the individual body: rehabilitation, therapy, and social benefits are based on 'degrees' of impairment.

In contrast, stands the 'social model of disability' (Barnes, 2012). In its popularised version, this model sets a dichotomy between 'impairment' and 'disability'. *Impairment* is the bodily, sensory or cognitive condition located in someone's body or mind – and *disability* is present on the social level where people with bodily, sensory or cognitive/behavioural differences are disabled by a host of barriers, including oppressive political, economic, cultural and social processes, institutions, and practices. This 'politics of disablement' (Oliver, 1990) includes regimes that restrict disabled people's legal capacity rendering them to 'legal death' (Dhanda, 2006); denying their right to vote or to stand for election; confining them to closed institutions, often for a lifetime; segregate them from early childhood in 'special' schools with poor outcomes; lock them out of public spaces; exclude them from politics. The list could go on. The social model has a descriptive power to identify social barriers that lead to disablement. The model has been used by DPMs as an 'oppositional device' (Beckett & Campbell, 2015).[3]

In the relationship between democracy and disability, the social model is a key concept, because political representation in disability is largely missing through traditional institutions like parliaments (where disability representation is minimal, see Waltz & Schippers, 2021) or political parties (that lock disabled people out from politics and venues where politics happen). The social model emphasises equal citizenship, empowerment, and self-representation, and puts the DPM and its mission to tackle structures of disablement in the centre of disability politics. Studying DPMs is not only useful, but I would argue, a necessary task when we enquire about the state of democracy and its impact on disabled citizens' lives.

The legal relevance of the social model is also evident. The social model was incorporated into influential laws like the Americans with Disabilities Act (1990), and the UN CRPD (2007)[4]. The social model enables DPMs to define diagnostic frames (Benford & Snow, 2000) appropriate to their political environment and constituencies' needs[5]. The social

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[3] Debates around the social model have been vivid for decades (Barnes, 2012, Oliver, 2013, Owens, 2015).

[4] About the relationship between the social and a 'human rights model' of disability, see Lawson & Beckett, 2021.

[5] Different diagnostic frames will be employed by deaf communities focusing on language equality or non-discrimination, and by intellectual disability movements lobbying against outdated legal capacity laws.

model informs research on democracy: let me point at issues relevant to the study of democracy and (de)democratisation.

First, the social model has enabled DPMs to address disabling barriers outside rehabilitation and care. Today's disability politics go well beyond discussing social care[6] so DPMs work on a plethora of policies. Social movement analysis must recognise this and avoid a care-focussed approach.

Second, the social model has informed human rights laws. Today, a 'human rights model' (Degener, 2016) is a master frame (Benford & Snow, 2000) of the international DPM[7]. The CRPD has brought about a tide of national and EU policy changes (Garcia-Iriarte et al., 2016; Arsenjeva, 2023). Under the *global* CRPD framework, states face human rights framings of a broad spectrum of *national* policies (Table 1.).

UN CRPD		Policy implications on national levels
Article 9	Accessibility	Laws regulating buildings, public services, public transport. Standardisation. Public websites and mobile apps.
Article 11	Humanitarian emergencies	Disability-inclusive humanitarian response and preparedness
Article 12	Equal recognition before the law	Legal capacity, guardianship regimes. Supported decision-making. Civil codes. Judicial processes.
Article 13	Access to justice	Right to legal aid and representation. Judiciary.
Article 14	Liberty and security	Deprivation of liberty based on actual or perceived impairment (social, medical care, forensic facilities)
Article 15	Freedom from torture and inhumane treatment	Freedom from involuntary medical treatments and coercion
Article 16	Freedom from exploitation, violence and abuse	Protection from sexual or other exploitation and violence and abuse. Gender-based violence.
Article 19	Living independently and living in the community	Deinstitutionalisation, long-term care, community-based services. Housing.
Article 20	Personal mobility	Access to transportation, special aids and assistive devices
Article 21	Freedom of expression and access to information	Accessible public information incl. in media, recognition of sign language, Braille or other alternative communication
Article 22	Respect to privacy	Information protection
Article 23	Respect for home and family	Access to sexual & reproductive health-care services, right to live in a family
Article 24	Education	Equal access to education, right to education
Article 25	Health	Equal access to healthcare, screening and preventive services, accessible consent forms
Article 26	Habilitation and rehabilitation	Access to habilitation & rehabilitation services. Special aids systems.
Article 27	Work and employment	Accessible workplaces, inclusive employment strategies, right to reasonable adjustments
Article 28	Adequate standards of living	Social security and poverty reduction. Housing, water, sanitation, accessibility of dwellings.

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[6] For a good summary about the social model and care politics in CEE, see Mladenov, 2021.

[7] Human rights are used unevenly across the DPMs. Local or grassroots groups may employ framings different from those set by international or national DPMs (Meyers, 2014; Grischow, 2014; Petri et al., 2017).

Article 29	Participation in political life	Right to vote, be elected, hold office or perform all public functions. Accessibility in election procedures and secret vote.
Article 30	Participation in cultural life, leisure and sport	Sport, museums, cultural facilities, parks etc. Tourism.

Table 1. Examples of policy areas of concern for DPMs (adapted from Bickenbach 2010; OHCHR 2020)

Third, since the 1990s, disability has become a 'protected' group under anti-discrimination laws in many countries (Waddington & Lawson, 2010). The CRPD also mandates states to create monitoring and implementation mechanisms (Stein & Lord, 2010). Thus, today's DPMs use established human rights institutions and mechanisms to put pressure on governments. Populist governments' attacks on international human rights and NGOs (Carothers, 2016) will impact disability rights. The analysis must explore how populist campaigns against human rights affect DPMs.

Fourth, the breadth of policies under the CRPD means that DPMs must be expansive in their technical expertise. Non-discrimination, civil law, education, social care, universal design (architects and engineers), electoral law, employment, and assistive technology expertise may be required to engage with state or market actors[8]. This assumes professionalized forms of advocacy and resources that may not be available evenly within the DPM. The analysis must go beyond identifying movement resources for campaigns and must seek information about resources for sustained policy expertise.

HISTORICAL CONTEXT IN CEE

DPMs are socially, politically, and historically embedded and we can only understand what they do today if we understand where they come from. Where they existed, disability organisations were kept under strong control in Soviet-influenced Europe before 1989. Some organisations, like charities for blind people, existed preceding the Second World War. Small forms of activism were present from the 1950s in the GDR (Schmüser, 2021), and even in the Soviet Union (Phillips, 2009; Fröhlich, 2012) but more organised DPM actions started only in the 1970s, on both sides of the Iron Curtain (Baar, 2015; Baar 2022). When the UN Year of Disabled People in 1981 defined disability as a human rights issue, an opportunity for new framing opened, in contrast with state-socialist notions of disability as a medical-productivist problem (Mladenov, 2017).

Some DPM organisations worked internationally already before the fall of the Iron Curtain: Hungarian groups were in contact with Austrian, French and West-German DPOs (Baar, 2015). From 1982, annual events were organised by disabled activists at Lake Balaton (Hungary), attended by up to 300 DPM disability advocates from Austria,

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[8] Medicine, assistive and IT devices are produced by private companies which supply these to clients and to states that subsidize and regulate products under public insurance schemes.

Switzerland, Italy, West-Germany, Finland and from socialist countries like Czechoslovakia, Poland, Albania, Yugoslavia, and the Soviet Union (Hegedűs et al., 2009).[9]

In the 1990s, as a reaction to devastating social crises, rising inequality and demand for social assistance (Heyns, 2005), many organisations in CEE started service provision for their members and other disabled people. Home assistance, transport, daily support, education, rehabilitation, and group homes were increasingly founded and run by DPOs and NGOs. In autism and intellectual disabilities, parents started organising and focused both on services and advocacy (Šiška, 2006; Balázs & Petri, 2010). Committing to service provision affected movement organisations' readiness to engage in confrontative action (Mladenov, 2017; Holland, 2008; Fröhlich, 2012).

From the late-1990s, legal progress started when a wave of disability-specific human rights legislation (Vanhala, 2015) was enacted (e.g. UK, 1995; Hungary, 1998; Sweden, 1999; Germany, 2002; Bulgaria and Spain, 2003; Austria, Romania and Serbia, 2006 etc.). Thus, political opportunities opened: these new laws enabled DPMs to start using a rights-based framing of their demands.

In the 2000s, policies were shaped increasingly by the EU accession (Phillips 2012). This presented DPMs with opportunities and challenges: EU funding became available for long-awaited social reform but DPMs also had to learn highly technical EU policies to provide expertise and monitor how governments spend EU funds. This pressed many organisations toward professionalisation (Maloney et al., 2018). Europeanisation and policy transfer were highly legalistic: with driving frameworks on the global/European, and strong constraints on the national level (Priestley, 2007). DPMs in CEE have also 'Europeanised': Brussels-based DPM umbrellas recruited members from CEE that joined them eagerly to learn, access funding and use EU-level advocacy opportunities (Thiel & Ucarer, 2014).

In CEE, disability politics bear post-socialist characteristics and are also shaped by neoliberalisation. Pre-1990 state-socialist politics segregated disabled people; used productivist disability assessment; oppressed DPMs; and, in a political-economic system of full employment, rendered disabled people inferior who are a 'loss of labour'. Post-1990 systems inherited this heavy heritage, and parallel to democratisation added new injustices to the existing ones: welfare cuts; workfare; stigmatisation of social assistance; and depoliticization, captured by Mladenov's '*post-socialist disability matrix*' (2016; Table 3.), inspired by Nancy Fraser's dimensions of justice (Fraser, 2005).

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[9] This early-stage knowledge transfer and learning about 'Western' notions of civil rights, movement strategies, and independent living philosophy helped CEE movements improve their activist repertoires, adopt new framing strategies and build alliances that contributed to DPM resources.

	State socialist legacy	Post-socialist neoliberalisation
Economic redistribution	Segregated service provision: Sheltered workshops; Residential institutions	Restructuring and reducing social support: Decentralisation Benefit cuts Workfare
Cultural recognition	Medical-productivist understanding of disability (codified in disability assessment systems) Denial of disability (on the everyday level)	Stigmatisation of social assistance and 'dependency', accompanied by promotion of self-sufficiency Responsibilization
Political representation	Weak civil society: suppression of counter-publics and counter-discourses	Depoliticization through: Restriction of civil society to service provision Token (quasi-corporatist) participation

Table 2. Post-socialist disability matrix (Mladenov, 2016)

Mladenov’s model was developed before more recent trends became apparent, like the (re)centralisation of power by some governments (Sitter et al., 2016) or populist policy-making (Bartha et al., 2020). The model points to mechanisms of continued disablement during post-socialist neoliberalisation, but it does not feature intense democratic erosion in the region. Deliberative democracy indices (Chart 1.) have been dropping or fluctuating in the four countries covered in this study, with Romania experiencing volatile changes, and Bulgaria showing some improvement only recently. Today, social movements experience reducing political and advocacy opportunities in the region (of the robust literature see Labanino & Dobbins, 2023a; Krizsán & Roggeband, 2018; FRA, 2023).

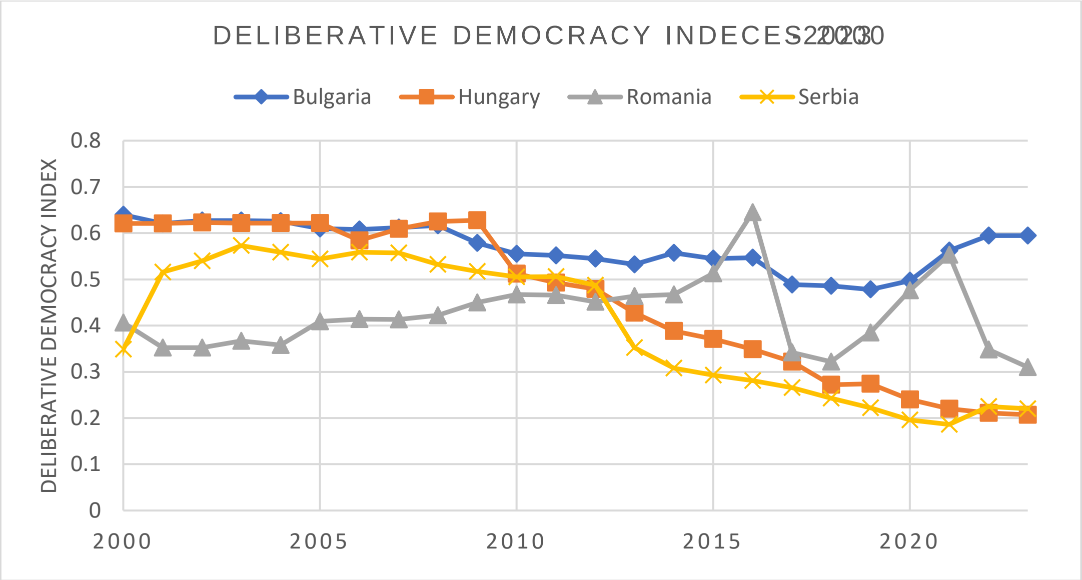

Chart 1. Scores of V-Dem’s deliberative democracy index, 2-2023 (Source: V-dem)

Although a range of factors shape DPM positions in CEE, I will focus on issues that data allows us to consider. The analysis will focus on two core factors: (a) mobilisation capacity and (b) position in policy-making. Mobilisation capacity is linked to coalition-building (Petrova & Tarrow, 2007), so I will pay close attention to divisions that hinder and factors that enable DPM organisations to find allies. I will explore DPM positions in policy-making across the four countries to find common characteristics.

CONTRIBUTIONS

This paper will contribute to literature by adding data about a social group previously overlooked in the study of democracy. Studying DPMs under fluctuating or downright eroding democratic systems helps better understand how governments deal with the welfare and human rights demands of a grossly marginalised and depoliticised group.

It remains a question how CEE pro-democratisation movements include DPMs and disability-related issues in their agendas. By discussing how alliances are formed between DPMs and other movements I will contribute to the understanding of coalition-building for re-democratisation.

This paper will contribute to the growing body of disability movement studies by proposing a new typology of DPM organisations in CEE. The typology will help us identify factors that make organisations vulnerable to democratic erosion.

Whereas LGBT+ rights, environmental, feminist, or migrants’ rights movements are campaigned against by right-wing populists (Ayoub & Stoeckl, 2024; Krizsán & Roggeband, 2021; Della Porta & Steinhilper, 2023), similarly open attacks against DPMs are yet to be identified. This study will contribute to a more nuanced understanding of how de-democratisation operates within established frameworks of disability human rights.

RESEARCH APPROACH AND METHODS

This paper is informed by social movement studies and principles of disability studies. The study ran for 12 months in 2022-2023 and explored how DPMs perceive the ‘shrinking space’ for civil society concept (Carothers, 2016), and DPMs’ inclusion in policy-making. I will identify the characteristics of four national DPMs, and where data allows, I will appraise similarities and differences. The question for this analysis is: ‘*How do DPMs navigate changing and eroding democratic systems?*’

To answer this question, I will appraise movement resources. Mobilisation capacities influence how movements can *react* to changing political environment, or how they can *initiate* actions progressively pushing for transformative politics in shifting policy or institutional landscapes. Movement resources are also pivotal, because governments often restrict access to funding to oppress critical movement organisations (Carothers, 2016). Since DPMs may need work in sustained and resource-demanding forms of organisational set-ups, the question of movement resources is central to exploring why and how DPM positions change.

I will use an inclusive approach: DPOs, parent-led, service provider and human rights NGOs will all be part of this study. I will acknowledge the key role of DPOs because the DPM has grown out of disabled people's struggle against misrepresentation by 'others' such as 'experts' or parents, and disabled people must be included in policies '*through their representative organisations'* that '*can only be those that are led, directed and governed by persons with disabilities'* (CRPD 2018, Art. 11.).

This study was inspired by participatory research traditions (Wickenden & Franco, 2021). Participatory approaches acknowledge and build on disabled people's experiential knowledge and include them in research teams. Participatory studies have the potential to avoid epistemic injustice that can exclude, silence, misinterpret or alter knowledge collected from oppressed groups, often resulting in unrecognised bias in academic works (Scully, 2020). Researchers in this study worked together on country-levels[10], in tandems of one researcher with experience in disability-related research, and one disabled co-researcher with experience in the DPM.

Data was collected through semi-structured interviews (Table 3.). We used purposive sampling and recruited senior advocates with robust experience in the DPM. For recruitment, we relied on activist networks and organisational websites. The sample was not fully balanced: in Romania, we were unable to interview members of the main consultative body of the government and had to rely on other organisations in local, regional or national levels. In Bulgaria and Hungary, some participants had also worked for public bodies. Several participants worked at more than one organisation (e.g. eight Serbian participants shared their experiences about eleven DPM organisations). Some participants worked for service-provider organisations that are part of the DPM.

Bulgaria	14 participants
Hungary	15 participants
Romania	9 participants
Serbia	8 participants
Total	46 participants

Table 3. Participants

Participation was voluntary and anonymous, protecting the identity of participants[11]. Interviews were conducted in the first language of participants, audio recorded, then transcribed into summaries with verbatim quotations. For the analysis of interviews, we used content analysis (Hsieh & Shannon, 2005). Policy documents were also analysed, including government documents, legal texts, DPM statements, human rights, and media reports. Documents were also acquired through freedom of information request.

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[10] The lead investigator was the author of this report. Country-level researchers were Gabriela Tanasan and Leyla Safta-Zecheria (Romania); Lazar Stefanovic and Rados Keravica (Serbia); Mitko Nikolov and Ina Dimitrova (Bulgaria); Erika Hrusko and Gabor Petri (Hungary). I am grateful for their committed work and support.

[11] The project was funded by the Open Society University Network.

Interviews and policy documents were analysed at the country level. The study received approval from the CEU's Ethical Research Committee in July 2022.

In the following sections, I will first briefly present country cases from Bulgaria, Hungary, Romania and Serbia, then, under 'Conclusions' I will identify common patterns in DPMs mobilisations and position in policy-making in the four countries. I will then introduce a typology of DPM organisations that can aid a better understanding of typical movement behaviour in the region. I will conclude this paper by outlining some implications for democracy and the study of democracy.

LIMITATIONS

The project ran as an individual post-doc fellowship for 12 months with strong time constraints – ethical review, recruitment and interviews had to be completed in three months. This resulted in uneven data quality. Thus, a more thorough comparative analysis cannot be made. The analysis will focus on issues where interview and policy data allow for comparisons to be made.

Researchers must be aware of DPM divisions and hierarchies (Meyers et al., 2023), the different demands, positions and identities within the DPM. Earlier research suggested that the DPM may not be a single movement but an alliance of movements with loosely fitting common aims and identities (Beckett, 2006). Under the social model, a common framing has been available for strands of the DPM, and human rights laws enabled the movement to work under a unified framework (Lawson & Beckett, 2021). Here, I will not appraise impairment group or otherwise specific[12] struggles within the DPM but will focus on factors that influence the position of the movement as a whole.

FINDINGS – COUNTRY CASES

BULGARIA[13]

Mobilization capacity

The Bulgarian DPM is dominated by impairment-specific organisations, like the Union of the Blind, the Association for Persons with Intellectual Disabilities, etc. Cross-disability entities are present: the National Council of People with Disabilities (NCDPB) is an

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[12] Organizations led by autistic people are forming separately from parent-led NGOs; (ex)-users and survivors of psychiatry and collectives of people with psychosocial disabilities are often evolving outside the DPM.

[13] See also Dimitrova et al., 2024.

umbrella composed of ten national-level organisations, including ones that represent employers and groups of professionals. The NCDPB started in 1992 when four DPOs signed an agreement demonstrating that cross-disability coordination was already a strategic aim during the democratic transition. The NCDPB ‘*represents 150.000 disabled people’* (source: disability.bg). Another cross-disability umbrella is the Union of Disabled People (disability-bg.org) that has local, regional branches and over 26,000 individual members.

The Bulgarian movement is strongly divided, a dominant takeaway from interviews. Two main camps were framed in interviews: ‘nationally representative organisations’ (NROs) on the one hand, and the rest of the DPM (non-NROs) on the other. The NRO category is defined by the 151/2019 decree of the council of ministers. There were 21 NROs in 2023. NROs are primary partners for the state. Their status is granted by the Council of Ministers; however, rules of recognition are criticised because not all legal criteria are duly checked by authorities – not all NROs may have a majority of or are controlled by disabled members, despite their name ‘representative’ (Dimitrova et al., 2024). NROs receive annual state funding under the Disability Act, giving them financial security. At the time of data collection, NROs received BGN 5,099,400 (EUR 2,600,000). NROs enjoy advantages in public procurement and can access EU funds easier than other DPM organisations. Most NROs focus on service provision.

Funding is more insecure for non-NROs that often do both service-provision and advocacy. Human rights organisations focus on advocacy, for example the Bulgarian Helsinki Committee played a role in the Stanev v. Bulgaria judgment in 2012 at the European Court of Human Rights (ECtHR) – the case advanced a human rights framing of disability in Bulgaria and is considered groundbreaking in the jurisprudence of the ECtHR. There are very few DPM organisations that have a clear advocacy profile and follow a clear human rights agenda (e.g. CIL - Centre for Independent Living; the Bulgarian Helsinki Committee). Despite funding problems, some non-NROs have been able to mobilize for policy change: for example, the issue of ‘personal assistance’ policy was first set on the agenda by CIL in 2009 (Nikolov, 2019). CIL and its late leader Kapka Panayotova have been prominent critiques of government policies.

International advocacy has played a key role in Bulgaria: English-language reports exposing dire conditions in residential institutions have helped keep disability rights on the government agenda since an infamous BBC report ‘*Mogilino – Bulgaria’s abandoned children’* in 2008. Many DPM organisations work in impairment-specific transnational organisations (e.g. the Federation of the Blind in Bulgaria is member of the European Blind Union). International allies have helped drafting critical reports and taking domestic issues to international bodies like the UN and the EU Commission (ENIL, 2019a; Validity, 2021; Validity, 2024) demonstrating the use of international advocacy when opportunities are limited domestically (Labanino & Dobbins, 2023b). Despite their mission to represent disabled people in human rights procedures, many NROs were absent from the CRPD-review of Bulgaria in 2018, while non-NROs (CIL, the parent-led Spina Bifida and Hydrocephalus BG, the Bulgarian Helsinki Committee, a children's rights NGO and an NGO against gender-based violence) reported to the CRPD.

The Bulgarian DPM has demonstrated their capacity to mobilize for confrontative action. NROs engaged in protest activities occasionally in the 1990s and 2008. In 2015, non-NROs started significant mobilisation. Parents of disabled people set up tents for seven months in front of the National Assembly to call for more support for families caring for disabled relatives. Demonstrations continued in 2016 and 2017, and a bigger campaign titled '*The system kills us*' (2018), raised the issue of care and low living standards (Lazarova, 2018). Actions in Sofia were supported by activists wearing t-shirts across Bulgaria. The campaign got good media coverage, and support from opposition parties, and led to the resignation of vice-president Valeri Simeonov who called protesters "*wailing women with allegedly sick children*" (ibid.). The campaign helped adopt a new Disability Act and the Personal Assistance Act, and parents received a new social benefit from 2019. Campaigners joined protests against prime minister Borisov in 2021. '*The system kills us*' led to tensions in the DPM: NROs used human rights language to critique protesters, while mothers employed neoliberal-conceived framing to articulate demands (Dimitrova, 2020).

Position in policy-making

Membership in consultative bodies determine organisations' position by giving them access to information and opportunities. In Bulgaria, the National Council for Persons with Disabilities (NCPD) is the core advisory body under the Council of Ministers. Its role is to develop and monitor disability policies. The NCPD is chaired by the deputy prime-minister and works with authorities set by the Persons with Disabilities Act (Posarac et al., 2022). Members of the NCPD are government officials, NROs, organisations of employees, employers' organisations, and the association of municipalities. A separate entity, the Monitoring Committee of the CRPD, formed in 2019, is an independent body that safeguards and monitors the implementation of the Convention.

Several activists voiced concerns about the above two consultative bodies, for example some of them thought the NCPD's work was formal, lacking influence and criticised its limited transparency. Critiques echoed concerns by Mladenov that the NCPD '*bears a significant risk of increasing state power at the expense of disempowering civil organisations*' (2009, p. 42), and depoliticize disabled people's grievances. Many participants thought state-funding kept DPM organisations, especially NROs back from due criticism of the government.

Participants were asked about their organisations' level of involvement in policy-making[14]. Responses showed a division between NROs and non-NROs. Most NROs told that they were in the highest level of partnership/co-governance, claiming full influence on policy-making. NRO-respondents also claimed that they operated in a free political environment, without restrictions to choose advocacy actions. One NRO participant, from a regional branch said they may restrict their opinion to avoid conflict with authorities: this indicates that NROs employ different strategies locally. In contrast, non-NRO organisations felt they were excluded, reaching only levels of tokenistic involvement or merely receiving information about policies, without opportunities to influence them. Non-NROs had diverse perceptions of their advocacy space: some restricted their opinions due to fear, others felt vilified by the government, but one organisation said they had full freedom to operate.

The DPM's repertoire is non-confrontative: transactional activism is dominant. Some called this 'silent activism', stating that much of what the DPM does is invisible to the public. According to an NRO leader:

'*...if you want to achieve something, you have – more or less – to comply... with a negative attitude, you will not get anywhere*'.

'*The system kills us*' campaign was an exception, with street protests, sit-ins, online mobilisation (social media and email campaign), work with opposition parties and symbolic actions (T-shirts). Perhaps partly due to its confrontative tactics, the campaign was criticised by NROs (Dimitrova, 2020).

Funding is very limited that hinders involvement in policy-making. According to a non-NRO respondent, disability activism is a '*luxury*', because most organisations lack money to pay experts for consultations or for legal action, or to fund mobilisation.

Human rights are disputed in the DPM. Despite the formal power of human rights laws and processes under the CRPD, many participants were sceptical. For example, some were critical with terms used in human rights, for example they found terms like 'empowerment' and 'advocacy' distant and traced these back to 'Brussels' or called them 'pompous words'. Some NRO representatives contextualised services-provision in contrast to systemic changes under human rights:

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[14] To determine position in policy-making, we modified a scale developed in an earlier study (Roggeband & Krizsán, 2021). We asked participants to use the scale to appraise their organization's level of involvement in policy-making. The scale had five grades: 0. No consultation (exclusion from platforms, services).; 1. Information sharing (DPOs receive information but have no influence on them); 2. Tokenistic inclusion (inclusion in meetings / consultative bodies; information sharing but no impact on agenda or outcomes). 3. Consultation/deliberation (DPOs provide expertise; structured dialogue exists with tangible influence). 4. Partnership/co-governance (participation in agenda setting; monitoring or implementation of policies; stable working relations between authorities & civil society; shared responsibilities). (Petri & Hruskó, 2024 p. 357-358)

'If you tell Granny Pena[15] that she has rights, nothing will happen, but if you bring her a new wheelchair, then she blossoms'.

The effectiveness of the CRPD was much debated. Some non-NROs claimed that the CRPD has made evident impact like the milestone Bulgarian Sign Language Act. However, others thought that disability rights was closely linked to the overall state of democracy and the Bulgarian illiberal turn is a threat toward the realisation of disability rights, in the words of an activist:

'The issue of rights has been losing its power recently (...) if the CRPD were to be ratified now [after losing the battle for the Istanbul Convention], it may not happen.'

NROs thought policy progress was slow but happening. Non-NROs were more pessimistic, with emblematic statements: *'the CRPD has changed nothing'*. Many activists from both camps said that policies are often not implemented or only exist on paper.

ROMANIA[16]

Mobilization capacity

The Romanian DPM is strongly siloed: composed of national, impairment-based entities, like the National Association for Children and Adults with Autism, the Romanian Muscular Dystrophy Association, etc. Most national organisations have local member organisations: e.g. the Romanian National Association of the Deaf has 37 local branches that engage and give services locally.

One central umbrella, the National Disability Council of Romania (CNDR) brings together eight national organisations and 17 observer members. The umbrella was founded in 2004 in response to EU-accession process, with support from transnational organisations like the EDF. The CNDR helps coordinate cross-disability advocacy. They collaborate with other social movements: for example, in 2021, with local development, social service, cultural and student organisations, they sent proposals for the Romanian Recovery and Resilience Plan. Cross-disability collectives also exist locally or regionally: for example, in Timisoara the *'Something to Say'* (cevadespus.ro) targets local communities with awareness-raising activities about disability rights.

Funding is available unevenly. The National Authority for the Rights of Persons with Disabilities, Children and Adoptions (NARPDCA) is a central public administration body under the Ministry of Labor and Social Protection that supports financially a handful of

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[15] "A common, archaic Bulgarian name used here to represent a poor, old, and in this case disabled woman, living in the countryside.

[16] See also Safta-Zecheria et al., 2024.

DPM organisations including the CNDR. It is unclear how the organisations were selected and how they are monitored (Grigoraș et al., 2021).

The Romanian DPM often works in local, regional and national alliances between traditional DPM organisations on the one hand, and service providers, civic initiatives, local councils, academic and other institutions on the other. This is probably related to the decentralisation of public policies and authorities in Romania.

Ever since global media reports about ‘Romanian orphanages’[17] emerged in the 1990s, scandals in the care sector have driven waves of movement actions (Safta-Zecheria, 2023). The human rights NGO Centre for Legal Resources (CLR) revealed horrific abuse (people in cages, beaten, tied to beds, force-fed) in residential institutions repeatedly (e.g. in 2004, 2013, and 2019). These reports helped bring human rights of residents of institutions to agenda of the government and EU bodies.

Of the four countries in this study, the Romanian DPM seems the readiest to organise for confrontative actions. National DPM campaigns are often joined by local organisations or allies outside the DPM. For example, in 2019 the federation of social services (FONSS), with the CNDR and children’s rights NGOs, organised a demonstration in Bucharest opposing the Law on State budget that would have transferred funds for social services to the local level (Ionescu, 2019), and similar demonstrations were held by national and local organisations in 23 counties across Romania (AGERPRES, 2019). In May 2023, the CNDR launched an open letter to the government co-signed by 150 NGOs and DPOs, criticising plans affecting children with special education needs. In September 2024, the CNDP in coalition with organisations like Coalition of Organisations of Patients with Chronic Diseases and National Alliance for Rare Diseases organised demonstrations in Bucharest to oppose pensions cuts for disabled people.

The Romanian DPM works internationally, under impairment-specific EU umbrellas, and CNDR works closely with the EDF that has given leverage to open letters (2020: COVID-related concerns in a psychiatric care home; 2023: demanding accessible and safer public transport). The Ukrainian war brought about international support that was used by the DPM to voice concerns not only about disabled refugees’ needs but also about the overall situation of disabled people in Romania.

Position in policy-making

Most DPM representatives said that they were on a tokenistic level of participation in policy-making. (In the lack of participants from the CNDR, we cannot determine the position of members of that body.) There was a recurring theme in interviews that

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[17] These ‘orphanages’ were care homes for disabled children, a fact that was omitted from most news features.

positions in policy-making can and do change, following fluctuating political opportunities, also reflected in V-DEM deliberative democracy index (see p. 12). Participants explained this with changes in the government – one activist observed:

'During the regime of the Social Democratic Party, participation was mere formality, later there was a greater opening, this is now gone again.'

Some movement organisations, especially smaller DPOs face financial barriers to participation in policy-making and monitoring: travelling to Bucharest to meetings and providing expertise in consultation processes is challenging due to limited resources:

There is also a financial barrier, for example, the National Authority for the Protection of People with Disabilities launched their strategy, and they invited us to Bucharest three days before the event. They did not cover airplane tickets, accommodation, and other things, so, of course we did not go because we do not have a budget for this.

Participants criticized the DPM's limited capacity to deploy expertise necessary for advising the government on complex policies. Some participants said that capacity-building of DPOs and NGOs should be better supported by authorities that do not have an interest in creating a unified and resourceful disability movement.

Dialogue with authorities, even when meaningful, is not seen as a clear mark of success – even if DPM proposals are formally accepted, policies may not lead to positive outcomes, because many policies are not implemented, and authorities may ignore or break agreements. One representative said:

'The immense incompetence of people there bothers you and you realize that your presence only legitimizes a step in their trajectory in which they consult with you.'

Locally, formal consultations and bilateral meetings with officials are the most used strategies. More confrontative actions like open letters and petitions are less preferred: some participants said that demonstrations in the local context are ineffective if they want to keep good relationship with authorities. Litigation was seen as desirable but financially unfeasible for most DPM organisations.

The Romanian DPM, compared to other countries in this study, features stronger service provider organisations. The representative service providers organisation, FONSS launched campaigns opposing government plans that would have impacted disabled people adversely (2017; 2019).

Interview data suggests that Romanian DPM actors are reasonably free to choose their strategies or to criticise the government. Self-censorship is present but not practised widely, and organisations sometimes employ creative strategies to support each other to mitigate risks of critical statements:

We (...) have never asked ourselves whether to formulate a viewpoint or not or whether we are afraid to do it [...]. Maybe if one [member] organisation is dependent on funding or on the *relationship with [public] authorities and cannot afford to voice a viewpoint, then the federation takes public ownership of that viewpoint.*

HUNGARY

Mobilization capacity

The Hungarian DPM features central, impairment-specific organisations with large membership: for example, the National Federation of Organisations of People with Physical Disabilities has over 100.000 members in over 150 member organisations; the Hungarian Association for Persons with Intellectual Disability has 50 member associations, 25 local branches and 22.000 individual members etc. Most (but not all) of these organisations give services directly or through local chapters, including social services and legal aid to disabled people.

There is a cross-disability umbrella the National Council of Associations of Persons with Disabilities (NCAPD), composed of impairment-specific organisations. The need for better cross-disability coordination was already recognised in the 1990s, and the NCAPD was established in 2004 after long negotiations. Due to disputes, not all national-level impairment-specific organisations are members of NCAPD. Cross-disability coordination is weak (Keszi et al., 2014).

Access to resources is uneven in the DPM: a core group of national-level organisations have enjoyed government funding through the annual law on the state budget. Their funding even improved slightly in the last decade (Petri & Hruskó, 2024). New organisations were added to the list of state-funded organisations, demonstrating some impairment groups’ (i.e. psychosocial disabilities) successful lobby.

For the rest of the DPM, secure funding is unavailable. For example, newer organisations (including ILOs[18]) are run on a voluntary basis, with ad hoc funding. A dominant view among actors was that state funding limits national DPM organisations’ autonomy.

Confrontative actions used to be a preferred strategy in Hungary but over time – with the erosion of democracy in the 2010s – this has changed. From 1990 to the late 2000s, national-level, state funded organisations organised street actions regularly to put pressure on the government, but in the 2010s demonstrations became less frequent. The largest DPO, representing people with physical disabilities organised a protest in Budapest in 2012 opposing neoliberal retrenchment of disability pensions, but rallies after this were initiated mostly by individuals or grassroots groups. Public marches were organised (2014; 2015) celebrating disability identity, raising awareness and challenging

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[18] See footnote 3.

stigma. In 2018, parents of disabled people mobilised for street protests, action in Parliament and online petition to demand better financial remuneration for informal carers of disabled family members (Sebály, 2020). Pro-accessibility demonstrations were held the same year by disabled grassroots activists in Metro 3 in Budapest. National DPM organisations prefer consensus-seeking mobilisation: the parent-controlled Hungarian Autistic Society and its members across Hungary organise local events and solidarity marches annually on Autism Awareness Day. These seldom relate to policy demands.

Although DPM organisations occasionally work with other movements like children's rights NGOs, alliance-building outside the disability sector is weak. The cross-disability umbrella NCAPD has set to work with women's rights groups, but this has not gone beyond occasional participation at events. Many DPM organisations work with EU-level DPOs.

Human rights organisations have been vocal since the 1990s: the US-founded De Jure Foundation organised large cross-disability events under a human rights framing in the 1990s and 2000s and used strategic litigation to tackle discrimination. Since the late-2000s, the Hungarian Civil Liberties Union and Validity Foundation have launched legal action, for example about human rights violations in the '*Topház'* residential institution in Göd (MDAC, 2017). Validity's work led to a UN Inquiry and report that condemned Hungary (Allen, 2020).

The Hungarian DPM has become fractured (Petri & Hruskó, 2024). A coalition of DPM entities mobilized under the CRPD in 2011, and a comprehensive, cross-disability shadow report was published in cooperation between national DPOs (SINOSZ-MDAC-FESZT, 2010). However, at the next CRPD-review (2021), only few organisations submitted reports, and coordination was missing. Today, the work of NCAPD is limited the minimum. Contrary to studies that suggest 'SMOization' amid closing opportunity structures (Gerő et al., 2023), the Hungarian DPM is inert and reluctant to mobilise since 2018.

Position in policy-making

The Hungarian DPM has experienced a strong decline in their position in policy-in the last decade (Petri & Hruskó, 2024) – from a '*consultation / deliberation'* level[19] in the late-2000s, their position dropped to 'being informed' and token participation by 2022 (ibid.). The National Disability Council (NDC), the statutory consultative platform with the government, has lost its weight (ibid.). Public information about NDC proceedings is restricted.

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[19] See footnote 14.

Public consultations lack opportunities for meaningful involvement. DPM representatives had a dominant view that consultations on EU funded programmes were only formal and almost pointless[20]. One participant with experience from authorities recalled:

When, on behalf of the ministry, we responded to online inputs (by the DPM), so we basically replied that we (the government) agreed with them even if this was not the case. (…) Essentially, we had communication panels so that we wrote the same thing back to everyone.

The erosion of Hungarian democracy has made a severe impact on the DPM's relationship with democratic institutions. The Ombudsperson and the Constitutional Court have lost their significance for the movement by 2022. The Ombudsperson was thought to be partial, avoiding conflict with the government, whose reports are weightless. A post-2010 law stopped civil society from seeking legal remedy at the Constitutional Court (Chronowski, 2014). Governing parties' two-third majority in the Parliament, and 'governing by decree' (Mészáros, 2024) rendered parliamentary lobby pointless for the DPM. In the words of a veteran activist:

(…) any draft legislation is supposed to be put on the (government) website for us to comment, but… I don't know, at 11:00 PM they publish the proposal on the Parliament website, to be voted on by the Parliament the following day, so technically you could have your say, yes, but it's not a real thing. (…) you cannot submit proposals and write things up in an hour, when in the next hour or day the vote on it will have taken place already.

The DPM's access to media has been diminishing. State-funded media channels may refuse to report about service shortages (Petri & Hruskó, 2024). DPM actors avoid publishing statements in media that is independent from government because it is perceived with hostility by officials. One veteran activist said: '*The Hungarian disability movement has lost its media access*'. There is sporadic success though, for example street protests by parents of disabled people (Sebály, 2020) and campaigners for accessibility in 2018 were featured in both government and opposition press, illustrating that confrontative actions amid opening political opportunities can improve media coverage.

The movement's repertoire has changed in response to smear campaigns against civil society. Although DPM organisations were not targeted, attacks on environmental and human rights organisations since the 2010s (Gerő et al., 2023) have sent a message: open criticism may be retaliated. Although DPM organisations may still publish critical statements (ENIL, 2019b), but most of them are consensus-seekers. Interviewees said that the space to freely choose strategies shrank in the last decade. Even human rights NGOs not funded by the government said that they sometimes abstain from critical statements, for example when they think that their co-signing an open letter would 'just make it worse' for the rest of the DPM. Self-censorship is systemic:

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[20] Anecdotal data suggests improvements may have happened between 2022 and 2024.

We do not tell fully our opinion. Yes, we know that we should not say this or that about a given issue, because it will blow the Minister’s fuse and then we will be deprived of our funding. And I think this is a fear of voicing criticism (of the government).

Government attacks against human rights NGOs throughout the 2010s have changed the discursive position of human rights. References to disability rights are being replaced by top-down charity-type ‘care policy’ narratives in government communications. Many DPM leaders feel apathetic about human rights laws. One participant said that human rights ‘*are a pain in the government’s back*’. Another participant demonstrated the anti-human rights trend by actual examples in their work in intra-ministerial teams under consecutive governments:

Before 2010, what I saw in the ministry’s attitude (…) was that international law is to be respected, period. At the beginning (of the 2010s), there were only subtle relativisations of international norms. (…) Then there came a completely open, sometimes very strong criticism (of international human rights). (…). When we had a lengthy debate about whether people with moderate intellectual disabilities should be allowed to vote, I said, assuming that this would be a powerful argument: okay, but we had made an international legal commitment to dismantle the substitute decision-making system… Then, and this was a senior politician’s statement, although not public, he said quite openly that ‘yes, we know that this is written in the UN Convention, but it's bullshit and Hungary will most certainly not implement it’.

SERBIA

Mobilization capacity

Several leading DPM organisations in Serbia were founded under state-socialism or during the 1990s. Most of them are impairment-specific, like the Association of Cerebral Palsy, the Multiple Sclerosis Association, etc. These organisations are commonly referred to as ‘traditional’ DPOs that run services and leisure and sports events for their members. There are few cross-disability DPOs, for example ILOs and smaller NGOs. Like other countries, Serbia features a cross-disability umbrella the National Organisation of Persons with Disabilities (NOOIS) founded in 2007, with 26 member organisations – in 2024 the NOOIS represented ‘*more than 800.000 persons with disabilities and their legal representatives*’ (noois.rs). Only those can join the NOOIS that fulfil eligibility criteria: members must have min. 500 individual and five local organisational members – this requirement locks out most new and smaller DPM organisations that cannot achieve a sizeable membership, often due to limited resources. NOOIS does not require its members to be disabled-controlled (Waldschmidt et al., 2015). NOOIS is relatively resourceful compared to similar cross-disability umbrellas in the region, and runs activities including capacity-building for members, leadership academy for young disabled activists. NOOIS has managed the '*Serbia without barriers'* campaign since 2020 (srbijabezbarijera.rs), with the support of the Ministry of Labour and Social Affairs. The campaign addresses accessibility, inclusion in education, trains activists, and relies strongly on local initiatives.

Funding is accessed unevenly across the Serbian DPM. While 'traditional' organisations enjoy secure, although modest funding from the government, limited resources hinder the creation of new organisations. New organisations can only be funded through specific funding schemes after five years. To access funding, membership numbers that are basis for some operational grants may be inflated by some organisations. Most organisations, including ILOs have regular funding problems that limit their readiness to engage in contentious action. Interviewees reported a 'brain-drain' because experts and young leaders leave the DPM due to job insecurity. Decreasing funding from the state or from foreign donors was seen as restricting the Serbian DPMs capacities:

Overall, the NGO scene in Serbia is jeopardized because the presence of international donors has decreased compared to a period of democratic changes after 2000. The NGO sector is collapsing because those people who were prominent leaders and initiators of social change have moved to work for the institutions (…) many prominent leaders, not only disability leaders but others like women's rights leaders have moved to work in the (state or EU) institutions and that has weakened the NGO sector.

Foreign support has boosted DPM activities in Serbia: The Open Society Foundations funded disability rights projects from the 1990s (Stubbs, 2013), and later the Balkan Community Initiatives Fund (from 2013: Trag Foundation) sponsored capacity-building and advocacy actions by DPM organisations. Handicap International was instrumental in developing capacities of the Serbian DPM in the 1990s and early-2000s. The Mental Disability Rights Initiative – Serbia (MDRI-S, founded in 2008 by a U.S.-based NGO) has been a prominent human rights organisation that has criticised the government repeatedly about the lack of community-based services for disabled people, failed deinstitutionalisation and outdated legal capacity laws. MDRI-S works actively to publish critical information (Lazarevic et al., 2022). They have mobilized broad coalitions, for example in 2021, with 17 human rights, feminist, and children's rights organisations, they called on the government to broaden consultations on deinstitutionalisation. Legalistic approaches are limited and strategic litigation in Serbia is seen too costly.

The political environment in Serbia has an erratic approach toward street demonstrations: anti-government protests have faced fierce police response, and some human rights-framed protests were banned altogether (European Commission, 2022), but governments may condone protests without punitive measures. In this environment, street protests are rarely used by the DPM. In 2011 disabled activists, mostly wheelchair-users, blocked highways and roads twice in Belgrade and once in Novi Sad and demanded that social benefits for disabled people are brought to the level of the national minimum income (Mikuš, 2018) – initiators were activists under ‘traditional’ DPOs, including the Vojvodina Union of Paraplegics and Quadriplegics. In 2022, another DPO, the Fenix Association of Disabled People organised a rally at the Ministry of Labour in Belgrade and called for changes in personal assistance policy and improved accessibility of public transport (N1 Belgrade, 2022).

Coordinated mobilisation is hindered by a lack of trust in the Serbian DPM, a recurring theme in interviews. Several organisations keep distance from ‘traditional’ organisations, pointing at their close ties with the government as a sign of co-optation.

Position in policy-making

Public bodies are legally obliged (Art. 34 of Law on the Planning System) to hold consultations, and, in response to EU requirements, the Serbian government also developed policy ‘roadmaps’ in 2014 and 2020, to improve dialogue with civil society. There are various consultative bodies available for the DPM, both on the national and the local levels. Most important of these is the Council for Persons with Disabilities founded by the government (2021). The Council aims to ensure inter-sectoral coordination, the monitoring of the implementation of international and domestic law and policy, and the improvement of cooperation with civil society. The Council is composed of members representing DPOs (7), companies for rehabilitation and employment (3), representatives of ministries and state authorities (15) and one representative from academia. The webpage of the Council limits access to information about proceedings and decisions. Consultation has improved on the local level: the City of Belgrade created a *Council for the improvement of position of persons with disabilities* (2016), and similar councils were formed in Novi Sad, Kragujevac and Bor.

Although consultation platforms have been developed during Serbia’s ‘Europeanisation’, and EU funds have been available for DPM organisations to join monitoring and reporting (Wunsch, 2015), the assumed opening of opportunity structures have only had modest impact on practice. Many DPOs still lack expertise to access EU-funds, reinforcing their reliance on state funding. Existing platforms may also be ineffective: several DPM representatives said that they participate in formal avenues for policy-making (consultations, roundtables, hearings, government-led task groups), but these lack influence on policies. In the words of a representative:

When you send them a request or whatever else in written form, we’ve been writing to them regularly, open letters that we post on Facebook, their answers are not credible and always the same (…). The first page is always copy-paste (…), and on the second page, they claim that they are lacking authority or jurisdiction for a particular issue and they’re then sending you to other institutions that may help. (…) You can’t say they are not responsive, because they do respond.

Attacks on Serbian civil society are regular, and the freedom of media has shrunk (Vuković, 2021; European Commission, 2022), which affects how the DPM builds strategies. Most organisations follow consensus-seeking pathways and try to avoid open confrontation with the government. Several interviewees said that meeting one-on-one with officials and managing negotiations between DPM organisations directly with ministries were the most preferable strategy to achieve positive outcome – but these negotiations also mean that much of the Serbian movement’s work on policies is basically hidden from the broader DPM membership. One activist related this to expectations of their members:

I was against publishing online the letters we had sent to authorities, because parents (their members) would praise those letters, but then nothing happens, and the parents ask us “what happened”, “why do you lie to us?”.

Clientelism and corruption are present in DPM-state relations, for example one DPM participant recalled when a state official, in exchange for a grant, asked 20% of the awarded money. Physical barriers are persistent: many disabled activists cannot join consultations that may be held at inaccessible venues or at places where transport (accessible means such as taxi) is beyond what advocates can afford financially.

Several participants, especially from non-traditional organisations, held the view that the progressive phase of disability rights is over in Serbia. Policy progress has slowed or halted altogether, and some even saw regression – there were only some participants from ‘traditional’ DPOs that thought there is still linear progress in disability policies. Some thought that the progressive period of disability rights was between 2006 and 2012, around the ratification of the CRPD and that since 2012 the Serbian government has lost interest in furthering disability rights.

People with psychosocial disabilities or chronic illnesses and their organisations are excluded from state funding to the DPM, and they were not accepted as disabled in the national DPM umbrella. People with intellectual disabilities – without visible self-advocacy organisations – are only represented in the movement indirectly, by their parents.

CONCLUSIONS

POLICY INCLUSION

Data confirms that CEE DPMs have been formally included in policy-making platforms everywhere, based on legal grounds for public consultation. Laws establishing forms for consultation were lobbied for by DPMs – but their origin can be traced back to both Europeanisation and the pre-CRPD wave of disability rights (Vanhala, 2015) in the 1990s and early 2000s. Since the ratification of the CRPD, EU and UN requirements[21] have further strengthened formal consultation venues for DPMs in the four countries. Thus, data demonstrates that democratisation advances disability rights: when states incorporate international legal standards into domestic legislation, DPM positions can formally improve.

A common practice for ensuring policy inclusion of DPMs in the four countries is statutory advisory bodies in the form of 'national disability councils/committees' placed under social ministries. These have created platforms for dialogue between DPMs and governments. However, membership in these is restricted to a few national DPM entities almost everywhere, and transparency (proceedings, minutes etc.) is lacking. Mandates of these councils include consultation and monitoring (e.g. reporting cycles on national disability strategies, proposing or reviewing national policies, EU funds monitoring and sometimes CRPD monitoring roles). Separate monitoring bodies under the CRPD have also been established, creating parallel structures with disability councils (Bulgaria, Hungary). Other forms of consultations such as online and sometimes in-person EU and domestic consultations also exist, these offer opportunities to the rest of the DPM and the broader public to participate in policy-making.

However, despite multiple consultation platforms, a main finding is that DPMs lack meaningful influence on policies, both in domestic and in EU-related (e.g. EU Structural Funds) planning, implementation, and monitoring. Interviews show that involvement in consultation platforms is formal and tokenistic nearly everywhere. DPM organisations *without* membership in statutory platforms (national disability councils/committees) have limited access to information about policy cycles and lack influence on policy planning or monitoring carried out by these bodies.

Position in policy-making is related to how DPM organisations interact with governments and how they frame their messages to the public, especially where degrees of de-democratisation are observed (Serbia, Hungary). This study finds that DPMs in Bulgaria, Hungary and Serbia operate in a restricted political space and have limited freedom to choose their strategies. Many organisations employ levels of self-censorship, especially in Serbia and Hungary, where intimidation of civil society seems the strongest. Contrary to the claim of some respondents, self-censorship is not related only to state funding: it is also exercised by NGOs independent from state funding. Vilification and intimidation of DPM actors, although not widespread, exist in Bulgaria, Hungary and Serbia[22] where activists shared experiences about threats by state actors. Government attacks on civil society outside the DPM influence DPM leaders in planning their communications and movement strategies.

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[21] The two have been linked since the EU itself imposes some CRPD-standards to Member States to comply with its own obligations under the CRPD (Ferri & Subic, 2023)

[22] Note that we had limited data from national-level DPM organisations in Romania.

Several disability groups have a much lower position in policy-making than the rest of the DPM. People with psychosocial disabilities are not included everywhere in DPM umbrellas and state funding schemes – their campaigns hardly featured in interviews. People with intellectual disabilities – often at the bottom of a ‘*pecking order’* in the movement (Pelka, 2012, p. 322) are still infantilized systematically (Safta-Zecheria, 2018). Autistic people are practically invisible in each national-level DPM and are only represented by parent-led organisations or expert-led human rights NGOs. Limited financial resources hinder these groups’ ability to start organisations and represent themselves in DPMs (Petri et al., 2017).

Human rights NGOs working on disability rights have played a pivotal role everywhere, but their space is extremely limited where de-democratisation is stronger (Hungary, Serbia). Governments may try to intimidate disability human rights NGOs. This study found no evidence of open government attacks against the CRPD in the four countries, however, there have been discursive changes in how disability rights are framed: this was most accentuated in Hungary (Petri & Hruskó, 2024) and Bulgaria (Dimitrova et al., 2024).

Policy inclusion is wrecked if DPMs abstain from consultations. Abstention can be due to intimidation – a likely reason behind moderate DPM participation and coordination in the CRPD review of Hungary in 2022. However, policy inclusion also becomes limited if organisations are reluctant to join consultations in fear of legitimising tokenistic and ineffective ‘Potemkin committees’, like those in Bulgaria (Dimitrova & Mladenov, 2024). Some activists (Romania) openly said they stay away from consultations to prevent legitimising ‘fake’ processes, and many others in Hungary, Serbia and Bulgaria expressed that they knew the processes they joined were often tokenistic or meaningless.

MOVEMENT RESOURCES

This study finds that DPM access to resources is related to organisations’ position within structures of consultations and funding schemes offered by governments – the two appear to be tied to one another. DPM organisations deeply embedded in state structures are likely to receive secure state funding. In each country, these ‘fortunate ones’ are impairment-specific national umbrella organisations, often with a large membership, like hundreds or thousands of individuals and countrywide organisational membership. In some cases (Bulgaria), the basis of state funding for umbrellas is an assumed large membership, but evidence about actual membership can be limited, and membership size may be inflated to access funding elsewhere (Serbia). Most DPM organisations outside those enjoying state funding have limited access to resources, have small memberships or work without members. Thus, each national DPM is divided along two tiers: (a) those on the inner tier are included in state advisory bodies AND in state funding schemes (e.g. NROs in Bulgaria, ‘traditional’ organisations in Serbia, and NCD members in

Hungary), and (b) the rest of the movement, on the outer tier, with less funding. This division between the two tiers is probably less characteristic in Romania, where regional authorities and local/regional DPM organisations seem to be taking on more work, under local/regional consultation and funding opportunities. Further research should explore how positions/tiers influence the agenda of organisations, or which disability model (medical model v. social or human rights model) organisations practice more on the inner or outer tiers.

Human resources and expertise are unevenly distributed within DPMs. Again national, impairment-specific umbrellas rely on paid staff and paid experts, while other organisations usually work with volunteers and experts on temporary agreements. Providing policy expertise under national mechanisms can be challenging to most DPM organisations due to low resources, and only national, impairment-specific umbrellas, some human rights NGOs and service providers (in Romania and to an extent in Hungary) emerge as exceptions: they have the financial means to deploy policy expertise to influence EU-related programming or domestic legislation. Data cannot confirm whether DPM organisations can always deploy much-needed technical expertise to national authorities or EU-driven policy processes – but from a DPM perspective, it seems decisive that only a few organisations nationally can even consider giving such expertise, because the rest of the movement lacks resources.

Legal mobilisation is present in all DPMs. Many organisations provide legal aid to disabled people and support them to launch appeals, complaint, or other procedures, using both disability rights laws and broader human rights laws as a basis. However, strategic litigation for disability rights (Vanhala, 2010) requires specific legal expertise and our data shows that potential costs render litigation rare in the region. DPM actors can rarely afford to litigate. Again, only DPM organisations with secure (state) funding and some human rights NGOs funded by global donors can take on such cases.

DPMs do work in coalitions when they campaign for change, but coalition-building is more difficult where de-democratisation is more advanced (Hungary, Serbia). Fractures or open conflicts between DPM organisations were reported in Bulgaria and Hungary, and these relate both to embeddedness in state structures and to the framings organisations use.

International donors and transnational DPM organisations have contributed to national DPM resources, especially in Serbia, but to different degrees also in Romania, Bulgaria and Hungary.

DPM mobilisation strategies follow particular trends under different regimes: where political oppression is stronger (Serbia, Hungary), confrontative actions like protests are less frequent – when they happen, they are initiated not by DPM actors on the 'inner tier' but by smaller NGOs, grassroots groups or individuals whose campaigns often rely on volunteers and informal collectives. DPMs sometimes build alliances with others outside the DPM, including opposition parties (Bulgaria, Hungary, Romania), but these coalitions appear to be ad hoc and rather weak, with perhaps Romania emerging where such coalition-building is more used as a sustained strategy.

Affirmative, symbolic street actions are popular: DPMs launch solidarity marches and public awareness-raising events locally or regionally in Romania, Hungary, Bulgaria and Serbia. These share similar features: they are expressions of a shared identity between members of communities but usually lack a critical message and concrete policy demand. They put forward claims to be symbolically recognised but have little or nothing to say about redistribution. Many DPM organisations in Bulgaria, Romania, and Hungary use the EU-level for advocacy actions to varying degrees, confirming that 'multi-level venue shopping' (Labanino & Dobbins, 2023b) is an option when domestic structures close.

DISCUSSION – A TYPOLOGY OF DPM ORGANIZATIONS IN CEE

Findings show that DPMs have varied responses to fluctuating or eroding democratic structures. The common features across the four countries allow us to identify multiple factors that determine organisations' positions, their behaviour and their strategies. Previous accounts (Holland, 2008; Fröhlich, 2012; Mladenov, 2017) emphasised service provision as a core reason for DPM depoliticization and consensus-seeking with governments and studies also showed – echoing views of many respondents in this study – that state funding is a tool to co-opt and silence movements (Skokova et al., 2018; Roggeband & Krizsán, 2021; Gerő et al., 2023).

Explanations about DPM strategies amid de-democratisation needs to be broadened and pay closer attention to the varieties of DPM organisations presently working in CEE. Findings of this study suggest that funding and service provision are just two of many factors that influence DPM behaviour. I suggest that responses and vulnerability to changes in democracy will also depend on the *type of movement organization*. Here, I identify characteristics in addition to state funding and services, and map out the main types of DPM organisations in CEE (Table 4.). The below grouping is inspired by Fröhlich's earlier work in Russia (2012) and aims to inform future research about DPM reactions to changing democratic structures and democratic erosion in CEE or elsewhere.

The first and central type of DPM organisations I term '*first-generation*'. 'First-generation' organisations are usually the oldest and the most institutionalised in the movement and they are the core of the 'inner tier'. Many were established under state-socialism, but some started and entered the inner tier later. They are run on relatively secure state funding. Many of them seem to be textbook cases (Tarrow, 2022 p. 111) of large, professionalised entities that rely on a formally wide but often passive membership and sometimes distant leadership. They often have many local chapters that enjoy levels of independence from the central umbrella. 'First-generation' DPM organisations usually hold permanent seats in government consultation platforms. Early-established (i.e. in the 1990s) independent living organisations (ILOs) can belong to this category, like the Association for Independent Living in Hungary which works under a national ‘first generation’ DPO. Many first-generation organisations run social, transport or other services for members, including leisure and sports events. First-generation organisations sometimes follow human rights framings of their demands (many Hungarian and Romanian organisations do so), but some may employ a human rights language only in communications and rely on charity-like top-down approaches to their members (Bulgaria), closer to the medical model of disability. Far from being a homogenous group of loyal, GONGO-ized (FRA, 2023) entities or mere ‘charities’, first-generation organisations can and do support their members to mobilise locally. First-generation entities are primary actors in CRPD reviews. Many of them provide much-needed and sustained technical expertise for states, working on details of EU or domestic technicalities of policy-making. They also provide support to local community events, contributing to members’ well-being and tackling their isolation – in fact, they are often criticised for being more focused on local community events than on campaigns for human rights. First-generation DPM organisations are also critiqued for their embeddedness in state structures and their potential co-optation by governments. They are proud members of transnational advocacy networks (Keck & Sikkink, 1999) in the EU – they may also use EU-level advocacy to support domestic efforts. First-generation organisations can engage in confrontative action, but more typically rely on transactional activism (Petrova & Tarrow, 2007). They are permanent actors in DPMs in the four countries, often with the same leadership for many years or decades, and they never close due to funding problems.

	Origins	Typical forms	Funding	Policy-making	Typical strategies	Service provision
First-generation DPM organisations	Pre-1990, post-1990	Membership-based national DPOs & non-DPOs, parent-led NGOs (Local ILOs)	Annual state funding Access to EU funds	Membership in advisory & monitoring bodies Consultations	Transactional activism *Silent activism* Open letters EU & UN advocacy	Likely
Second-generation DPM organisations	Post-1990 or later	Grassroots DPOs, Activist networks, Parent-led NGOs ILOs	Ad hoc funding, foreign funding, no funding	Low access to advisory & monitoring bodies Consultations	Transactional activism Confrontative actions EU & UN advocacy	Likely
Human rights NGOs	Post-2000	Single issue non-DPOs General human rights NGOs	Foreign funding	Low access to advisory bodies Consultations	Legal action Confrontative actions EU & UN advocacy	No
Service providers	Post-1990	Service provider federation non-DPOs National service providers	State funding for services, service fees, EU funds	Membership in advisory & monitoring bodies Consultations	Transactional activism Confrontative actions EU advocacy	Yes

Table 4. Typology of disability movement organisations in CEE

'Second-generation' DPM organisations started later, and rely typically on ad hoc, occasional funding through state grants or other sponsorship. With their insecure funding, 'second-generation' organisations may close due to financial problems. Nearly all DPM organisations started after the 1990s belong to this type. Some second-generation organisations are grassroots groups registered as NGOs; some are activist networks without a legal entity; some are parent-led or other NGOs running services and advocating locally; many of them work only locally. Most ILOs (e.g. Centre for Independent Living in Bulgaria; the Centre Living Upright in Serbia; the 'Something to Say' group in Timisoara, Romania; and the 'Living Independently, Living in the Community' and Freekey in Budapest, Hungary) are second-generation organisations. In some cases, second-generation organisations join formal government consultation platforms, but most of them must rely on other strategies like bilateral bargaining with authorities (often locally where they work) or confrontative action to pursue policy change. Many second-generation organisations have a mixed advocacy and service-provider profile. These organisations can be members of international networks, but most of them lack resources and perhaps language skills to work internationally – they are usually more focused on tackling local problems and serving members' or clients' needs. Second-generation DPM organisations may join first-generation entities as members to improve their access to information.

The third group is '*human rights NGOs'* that do prominent work in each country, often featuring their best when they report about human rights abuse – for example, Validity in Hungary and Bulgaria; the Centre for Legal Resources in Romania; MDRI-Serbia; the Hungarian Civil Liberties Union – HCLU; and the Bulgarian Helsinki Committee etc. There are very few human rights NGOs working in DPMs, usually one to three per country. These NGOs can be single-issue organisations working only on disability rights (e.g. MDRI-Serbia and Validity), or they can be mainstream human rights NGOs with a disability rights portfolio (Bulgarian Helsinki Committee, HCLU). They are typically funded, sometimes generously, by global sponsors or UN bodies, and they may also run successful crowd-funding campaigns. They rarely hold permanent membership in government consultative platforms created for the DPM and where democratic erosion is stronger, their access to consultation and information may be further restricted by governments (Hungary). Human rights NGOs are not disabled-led but are controlled by legal experts. Although they typically have multi-language staff, they are not always well-embedded in the international DPM and if they run EU or UN campaigns, they do so in ad hoc coalitions with international NGOs / DPOs or on their own.

The last group is *'service providers'*, who work everywhere in CEE but perhaps are most visible on the national level in Romania, and to a smaller extent in Hungary. They are separate from first- or second-generation organisations because they focus on service provision and are rarely controlled by disabled people – service providers are often on the boundaries of the movement, led by professionals, and some of them (like FONSS in Romania) are not even disability-specific. Service providers may be seen as following different – financial or professional – interests than rights-based DPOs, parent-led NGOs and ILOs. They can hold membership in government consultative bodies and their size can make them more important partners for governments. Many service providers have highly qualified permanent staff and experts to delegate to government consultation. In some contexts (Romania, Hungary), echoing findings from Russia (Toepler & Fröhlich, 2020), service providers mobilize for disability rights.

The above four types are indicative to aid our understanding of *typical* forms of DPM entities. In practice, there can be organisations that may be placed under two categories at the same time. Organisations may also transfer or evolve from one type to another. This typology is relevant in CEE, but similar typologies may be developed and adapted to movement research in other regions.

Multiple divisions are observed within DPMs in the four countries and the typology above may help better understand how coalitions between organisations are formed. First, DPMs are divided along lines of embeddedness in state-structures. The 'inner tier' of DPMs (first-generation organisations, and sometimes service providers) have a troubled relationship with the 'outer tier' that is mostly composed of second-generation DPM organisations and human rights NGOs, away from state structures. Confrontative strategies like street actions are more likely to be initiated by organisations on the 'outer tier' because first-generation organisations may fear not only losing state funding but also breaking formal or informal government ties. Several respondents mentioned examples when critical human rights NGOs or second-generation DPOs became 'outcasts' or 'avoided' by DPM actors on the inner tier. Different positions in policy-making also create hierarchic relationships between inner and outer tiers: those second-generation and human rights organisations that have reduced opportunities to consult with states may miss out on information on government plans available to those in the inner circle – this affects their agenda-setting and ability to engage. This presents a paradox: those with more resources and more information are the most reluctant to engage in confrontative action or join broader coalitions with more critical DPOs or other partners critical toward governments. Sometimes tensions within the DPM become public: consider Bulgarian mothers' *'The System Kills Us'* campaign when organisations on the inner tier ('NROs') openly opposed second-generation campaigners' demands for higher social benefits.

Impairment-group separation is a primary dividing line between DPM organisations, a recurring characteristic of the DPM since its start (Beckett, 2006). The DPM, due to its impairment-focused organisational structure is more vulnerable to external pressure because of diverse group-based identities, demands and histories. Can impairment-based, siloed organisations build powerful coalitions to counter government oppression and democratic backsliding in CEE? This is an old challenge for disability movements (Pelka, 2012; Beckett, 2006). DPM entities created for cross-disability alliance (umbrellas composed almost exclusively of first-generation organisations) exist everywhere to tackle this: DPMs know that they need to coordinate between impairment-groups to counter powerful forces of disablement. But an overarching theme, emphasised in every country-level dataset in this study was the deep mistrust between organisations, making it harder to build alliances for sustained contentious politics or quick campaigns. Alliances are not entirely impossible but DPMs in CEE seem ever-more fractured. Data is limited so we can only make careful assumptions but where de-democratisation has made the most obvious impact on the DPM (Hungary), it is this coalition-building capacity that was impacted most visibly: impairment-specific first-generation organisations were able to form a broad 'disability caucus' in 2010 to publish shadow report under the CRPD but the same organisations worked separately in 2021, after a decade of de-democratisation.

Limited DPM resources hinder participation in policy processes in the four countries, despite decades of capacity-building efforts by international donors and transnational advocacy networks. Resources are present in the inner tier of the DPM, but those fringe groups, critical activist collectives and other DPOs and NGOs on the outer tier critically lack resources to launch campaigns or deploy experts to policy processes. Much-needed, sustained DPM expertise and technical knowledge in increasingly complex EU and UN policy environments should not be taken for granted in CEE.

The work of DPMs is intricately linked to democratic institutions and processes – and DPMs are impacted by changes in democratic structures. When states democratise and adopt international legal norms, DPMs have better opportunities for consultation and policy-making – however, formal platforms may still only offer a limited influence on policy-planning. When democratic backsliding happens, DPMs face intimidation, shrinking space for disability rights advocacy, and changing public discourses about human rights. The CEE serves as an example for both democratisation and de-democratisation: when Hungary, Romania, Bulgaria and Serbia made steps to adopt international human rights standards, DPM participation in policy-making improved. However, where democratic backsliding was most visible (Serbia and Hungary), DPM positions became largely weightless and hollowed-out. While keeping a formal hold in established consultation and advisory bodies, DPM repertoires narrowed, and actors started exercising self-censorship to avoid conflict with states. The fragmentation of DPMs is also accentuated amid de-democratisation. Notably, DPM organisations do not only survive democratic backsliding but can continue to work and even grow under regimes that use them to legitimize themselves (Toepler et al., 2020). The status of Hungarian and Serbian DPMs leads us to consider that the mere existence of human rights reviews and disability consultative bodies, and indeed DPMs may help legitimize hybrid regimes in CEE.

The question of how disability human rights laws are put into practice under changing and eroding democratic systems is central here. CRPD standards have been translated into national and local policies and practices in the last 15 years, a process lobbied for and mediated by DPMs. Across the four DPMs in this study, human rights were unequivocally acknowledged by DPM leaders and used to various degrees. The question, however, is how the translation from principles to practice happens and how this intersects with DPMs' aim to dismantle medical model-based disablement and develop social model-based progressive changes. The vernacularisation of human rights (Merry & Levitt, 2017; Ramberg, 2019) is practised across the whole DPM, including by big and resourceful first-generation DPM organisations when they work with their local chapters. The mediation between international, national, and local levels, based on DPM entities' resources, knowledge, epistemologies, support needs, and strategic interests influence what organisations do: how organisations support disabled people or how they campaign authorities for local policies and services. This study indicates that parallel disability models are practised across the movement: despite decade-long progress based on the social model and human rights, the medical and the social model are both still engrained in the DPMs' work, including in first-generation and second-generation organisations. These mixed-model approaches are usually present within the same organisation – for example, a first-generation national DPO or a second-generation, parent-led NGO running a group home or support service may maintain top-down, paternalistic service models while they support disabled people to launch legal complaints against discrimination. It is likely that only ILOs (where they survive financially) and human rights NGOs abstain from common practices that can be categorised under the medical model. More practice-focused research should confirm how these mixed models are employed by DPM organisations.

De-democratisation is a powerful factor that shapes this vernacularisation process. For example, governments in eroding democracies antagonise international human rights, campaign against 'liberal colonialism' and return to 'traditional values' that include segregation, medicalisation, and paternalism (Dimitrova & Mladenov, 2024). But neoliberal social abandonment, the continued lack of services and state support are equally strong factors (Parmenter, 2024), and neoliberalism did not start with the illiberal turn in CEE. In fact, the neoliberal consensus has never been questioned and challenged in the disability field in CEE (Mladenov, 2018) – most DPM organisations do not even use the word 'neoliberal' in their vocabulary.

Parent-led DPM mobilisations in Bulgaria and Hungary (and in Poland, see Pamula & Szarota, 2023) demonstrated their ability to create and use political opportunities and achieve better caregivers' benefits. However, this presents a dilemma regarding the progressive realisation of transformative CRPD politics because parents' preferences, aims and even their framings of demands may be markedly different from those of disabled people (Carey et al., 2019; Ne'eman, 2010; Waltz, 2013). So far, the outcomes of these parent-led campaigns bypassed the human rights and the self-determination of those disabled people who receive care in the family home. Data does not allow the appraisal of these campaigns, analysed elsewhere (Dimitrova, 2020; Sebály, 2020; Pamula & Szarota, 2023). What is significant is that these were not campaigns *by disabled people* receiving home care (or their peers in DPOs), fighting for the right to live, with appropriate support, in the community as the CRPD mandates in Article 19. Parent-led mobilisations did not use the social model or ILM framings (Dimitrova, 2020; Pamula & Szarota, 2023) in their campaigns. This shows that even successful campaigns must be understood and analysed with caution, because the DPM is a multi-layered, diverse movement where groups have hierarchical relationships, conflicting interests[23], epistemologies, and uneven resources.

This study also calls attention to a potential risk: the weakness of DPM coalition-building capacity, both internally and externally with other social movements, including pro-democratisation movements. True (re-)democratisation can only happen if movements that represent oppressed social groups can promote democratic values, stimulate political participation, and put demands onto the political agenda. Weak cooperation between DPMs and pro-democratic movements runs the risk of omitting the needs of millions of disabled people from the agenda for re-democratisation. This risk is very much present because the medical model still dominates the region's polity and '*paternalist care underpins the attitudes towards disability on the everyday level*' (Mladenov 2021 p. 21.). Pro-democratisation movements, themselves following outdated notions of disability as a medical or 'care problem', can make a tragic omission, unless they work closely with DPMs, including with the less visible and voiceless subgroups of DPMs. Without such cooperation, re-democratisation movements can misinterpret disability rights and will likely maintain old structures of 'illiberal disablement'.

Finally, I propose an addition to Mladenov's (2016) post-socialist disability matrix (Table 5.). A third, 'de-democratisation' column may be added to the original matrix.

	State socialist legacy	Post-socialist neoliberalisation	De-democratisation
Economic redistribution	Segregated service provision: Sheltered workshops; Residential institutions	Restructuring and reducing social support: Decentralisation Benefit cuts Workfare	
Cultural recognition	Medical-productivist understanding of disability (codified in disability assessment systems) Denial of disability (on the everyday level)	Stigmatisation of social assistance and 'dependency', accompanied by promotion of self-sufficiency Responsibilization	
Political representation	Weak civil society: suppression of counter-publics and counter-discourses	Depoliticization through: Restriction of civil society to service provision Token (quasi-corporatist) participation	*Shrinking space for disability movements* *Intimidation* *Self-censorship*

Table 5. Post-socialist disability matrix – amended with de-democratization

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[23] Anecdotal evidence from Hungary suggests that higher caregiver benefits, result of 2018 campaigns, withhold parents on low income from letting their disabled relatives move into supported living because they do not want to lose an important source of income (caregiver benefit) for the household.

Where democratic backsliding happens, political representation becomes restricted through intimidation and a shrinking advocacy space for DPM operations. Self-censorship is widely practised. Further research should appraise how the cultural recognition of disability and economic redistribution may change in de-democratising regimes in CEE and beyond.

Note: The quotation in the title of this paper belongs to Jason Stanley (Democracy Now: “Erasing History", Yale Prof. Jason Stanley on Why Fascists Attack Education & Critical Inquiry, 18 September 2024, available at https://www.youtube.com/watch?v=VDO-p1RFhG0)

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