

Between a Shrinking and a Shifting Space: The Symbolic Inclusion of the Disability Movement in Policy-Making in Romania

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Abstract. *In this paper, we explore how political opportunity structures for the inclusion of the disability movement in Romania are shaped from the perspective of self-advocacy and service provider NGOs active in the field of disability. Building on in-depth semi-structured interviews with nine representatives of self-advocacy and service provider organizations, we explore how they understood the processes by which they participated in policy formulation processes. Our results show that both service provider and self-advocacy organizations feel that their inclusion in the policy-making process is mostly symbolic and tokenistic, but that this can and did change in the last years. However, despite a general concern for a shrinking space for civil society organizations influence on policy-making in Central and East European countries, disability organizations in Romania describe the political opportunity landscape as a fluctuating one, rather than one that is evolving in one direction. Moreover, whereas service provider organizations seem to perceive higher levels of inclusion on the national level, whereas self-advocacy NGOs seem to perceive themselves as being better included and more influential on local levels. This also reflects the presence of bottom-up federative efforts of service provider organizations as opposed to the lack of successful bottom-up federative efforts in the field of disability based self-advocacy organizations. Finally, our paper problematizes inclusion in policy-making as an unequivocally positive process, showing how disability organizations sometimes choose not to participate in order not to legitimize problematic decisions through their symbolic presence in the negotiation process.*

Keywords : disability movement, self-advocacy, political participation, inclusion, advocacy

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Introduction

Who has the opportunity to contribute to policy formulation in the disability field in Romania in the present context ? In this paper, we seek to answer this question by analyzing the contexts in which self-advocacy and service provider organizations in the disability field try to influence policy-making. Our analysis is based on a set of semi-structured interviews with eight representatives from NGOs active in policy advocacy in the disability field as service-provider and self-advocacy organizations and one public authority representative.

This question is particularly relevant in the present context because of a series of aspects. First of all, the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006 ; hereafter CRPD), the leading framing document for disability policy formulation worldwide clearly attributes through Article 29 (paragraph b) on participation in political and public life that the participation of persons with disabilities in public affairs on an equal basis with other through NGOs, as well as specifically through organizations of persons with disabilities. The CRPD, in Article 33(3) of the CRPD also provides legal basis and obligation to State Parties to involve disabled people, through their representative organizations, in the monitoring and implementation of the Convention (United Nations, 2006). Romania has ratified the CRPD through the law no. 221/11.11.2010 thus partaking in the responsibility of implementing the convention. This equal political participation is crucial and has epistemological and organizational implications. However, as our research has shown it has remained mostly declarative.

The CRPD is based on the social model of disability was introduced into social inquiries through a term first coined by Mike Oliver (1983, Oliver et al., 2012) by building on the activist work of the Union of the Physically Impaired against Segregation (UPIAS) work in the UK in the 1970s. The work itself (Oliver et al., 2012) was from its first edition aimed at shaping the professional pathways and awareness of social workers in a respectful and equal relationship with service users with disabilities. In a nutshell, the social model (Barnes, 2019) refers to seeing disability as the relationship between impairment and barriers present in the society (see preamble to the CRPD, UN 2006). The CRPD has formalized the introduction of the social model of disability into international and national legislation. At the same time and in close connection to this process, recently the disability movement internationally has come to be dominated by a new “human rights model” of disability (Degener, 2016). This has led to concerns especially when formally recognized rights and their achievement take full precedence over the evolving nature of disability as a concept (Berghs et al., 2019). However, local and national disability movement do not always follow the same human rights agenda as international organizations, and their advocacy strategies may also differ from international disability organizations. (see e.g. Meyers, 2014).

The political context of this inquiry is also relevant, since recently Central and Eastern European countries have been referred to as ‘backsliding democracies’ (Cianetti et al., 2020 ; Labanino, Dobbins, 2023), in which the space for civil society’s organizations influence on policies is either closing (Carothers, Brechenmacher, 2014) or “shrinking” (Muiznieks, 2017). Yet, as Roggebrand and Krizsan (2021) convincingly show this closure of advocacy space for civil society is often a selective one, affecting liberal-democratic oriented organizations more than other civil society organizations. Where than do self-advocacy organizations of persons with disabilities in Romania stand in relation to this selective closure? And where is service provider NGOs positioned?

Romania cannot easily be conceptualized as a typical case study for democratic backsliding. Generally, articles discussing democratic backsliding in Romania have done so in relation

to the aftermath of the EU accession pointing to the “success” of EU actors in countering backsliding in Romania (Sedelmeier, 2014 ; Sitter, Bakke, 2019). Although this process of top-down countering of democratic backsliding may not always be convincing, it is still worth asking whether democratic backsliding is operating in similar way in Romania as in other Central and Eastern-European countries (most notably, Hungary and Poland).

Specific to the disability policy field, the postsocialist context of neoliberalization also created a specific way in which disability and persons with disability were understood and represented: as both outside of the productivist imaginary of socio-economic relations promoted by state socialism and as stigmatized welfare assistance recipients in the context of the postsocialist neoliberalization of disability policies (Mladenov, 2018, 68f).

Beyond, the political context shaping the opportunity structures for influencing policies it is also important to keep in mind the internal hierarchies present in the movement of persons with disabilities in relation to social, economic, cultural and even impairment (Meyers et al., 2023) – thus far from being a homogenous movement, the movement of persons with disabilities is in itself highly unequally and uneven.

Moreover, previous research (McColl, Boyce, 2003) has shown that disability organizations have been known to diverge also in terms of their practical dimensions. These differences can range from organizations that build their membership of people who identify as having disabilities or using services to service providers, and in terms of using volunteer work as opposed to employing human resources. Finally, organizations can also see their goal as mainly advocacy or mainly service oriented – there is evidence that many disability organizations in Central and Eastern Europe also pursue service provision along their advocacy work, and this influences their engagement with governments (Holland, 2008). Thus, internal divisions and organizational strategies have implications for how the space of advocacy can and is being used by organizations. For example, as our study will show, service provider organizations are more likely to employ human resources and thus have other opportunities to organize politically as well, creating a difference in whose voice can be heard.

As Mike Oliver (1999) has pointed out, the very existence of support professions, such as social work, may depend on their willingness and capacity to work with persons with disabilities to develop new modalities of professional practice. These new modalities of professional practice should be in line with the social model of disability. Otherwise, it is possible that their services will appear redundant or inefficient. Since we cannot suppose that one voice, be it that of professional social workers or disabled self-advocates, can equal the other, we want to interrogate how the hierarchies of voices in the field of disability appears in relation to both the external and internal dynamics of self-advocacy and service provider organizations. This point is particularly relevant to understanding the field of disability today and is one of the questions our paper seeks to contribute to.

Methodology

The research this paper is based on was part of a postdoctoral research project led by Gabor Petri and based at the Democracy Institute at Central European University. The project was aimed at studying disability movements in Central and Eastern Europe’s backsliding democracies through the lens of participation in policy-making.

In our team, Gabriela Tănăsan and Leyla Safta-Zecheria conducted the research in Romania and Gabor Petri coordinated the research project, providing the research design and giving feedback on the development of the interview guide and the data interpretation. The Romanian duo united their positions and relevant experiences : experience in self-advocacy and experience

of disability, as well as research experience. In this regard, the study was an inclusive research project (see Walmsley et al., 2018 ; Bigby et al., 2014 ; Nind, 2017) in which researchers with and without disabilities worked together through all relevant phases from research design to reporting. Thus, our questions and interpretations are built on a dialogue that incorporates different positions.

We interviewed nine people in eight separate interviews all of which took place online over Zoom and were recorded and transcribed to enable analysis. Two interviewees chose to participate in the interview together, a disabled self-advocate and a support person that was also involved in disability advocacy and also answered our questions. Interviews lasted between 60 and 140 minutes. The interviews took place between October-December 2022 and were conducted online via videoconferencing software. The study was approved by the Ethical Research Committee of the Central European University in July 2022.

In this study, we use an inclusive approach to explore the Romanian disability movement. In our understanding, the disability movement is composed of disabled people's organizations (DPOs or OPDs in English), but also of other entities like parents' organizations, service providers with an advocacy profile, human rights NGOs, civic or other local citizen organizations, non-formal activist groups and even individual activists that all pursue advocacy to advance disability rights and influence policies. While acknowledging the major differences between organizations in terms of who they represent, who controls them or what founding values drive their work for (see also Shakespeare, 1993 ; and the CRPD Committee's General Comment No. 7), since our study is interested in how policy-making can be influenced by the disability movement, we included a broad variety of organizations in our sampling for interviews. Our interview partners represented disability organizations actively advocating for policies, including those led by self-advocacy activists with disabilities, service provider organizations and service provider federations, as well as one public authority representative active in a region without strong advocacy activities. All the organizations that we interviewed were NGOs active either locally, regionally, nationally and internationally, but neither of them was part of the official consultation bodies connected to the government (Romanian National Disability Council). We contacted this organization as well but have not managed to obtain an interview. This can pose significant limitations on the reach of our conclusions, as this national body represents persons with disabilities in the national-level policy-making process.

Most organizations that were represented in our study, both of service providers and of self-advocacy, were established in the period from the early to mid 2010s (2011-2017). Only one organization, a mental health related service provider organization was established in the early 1990s. All of the representatives that granted us interviews had been with the organization since its founding and were now in their mid-thirties to early fifties. Only the three representatives of organizations of people with disabilities interviewed identified as having disabilities. Three of our interview partners were male, the other six were female. The county level head of social services for a county that also granted us an interview is a woman and has been in the field for more than 20 years, 11 of which in the field of disability. Our interview partners came from different geographic areas in Romania and were active in both rural areas, county capitals and the national capital.

The service provider organizations had the following objectives : providing mental health care, community services and empowering users through training them in advocacy ; service provision to facilitate labor market inclusion for risk groups, as well as advocacy for disability rights and for the rights of other disadvantaged groups. The representatives of the social service federation focused on improving the quality of social services and public policy advocacy for service provider organizations that are members of the federation ; assessing social service needs and mapping them in different regions in the country.

Self-advocacy NGOs considered to have the following objectives : giving voice to members who are self-advocating people with disabilities, as well as changing the perspective on disability through awareness raising, accessibility and deinstitutionalization ; promotion of rights of people with disabilities on a local level ; social inclusion, education and environment, as well as accessibility and right to access services. Most self-advocacy NGOs have activities at the local levels, in partnership with the mayor's office or through campaigning on a local level.

We also interviewed one representative of a public authority that was in charge of supervising and managing for social services on a county level, in a county with very little NGO presence. This helped us get a different regional perspective on the absence of advocacy structures and potential explanations thereof. The public authorities' goals were deinstitutionalization and respect for human rights of people with disabilities.

To understand the position of organizations in policy-making, in the interview we used three different scales of political participation. The interviewees were shown each scale then they were asked to position their organization on the scale and explain why they chose the specific position and how this position had evolved in time. In this paper, we only report about results of one of the three scales. In case of participants with visual disabilities or who did not have access to a large screen during the interview, the items on the scale were read out loud. After each scale of participation was introduced, the interview continued as a in-depth semi-structured interview based on an interview guide. The structure of the guide loosely follows the content of the scale in order to explore the same topics in-depth.

The interviews were auto-transcribed with the MS Word transcribe function and then edited. After a primary analysis of the data and discussion of this analysis in Romanian, a final report in English was drawn up and discussed with the project lead. It was then reworked into the final version of the interpretation. The results of this process were then presented to representatives of the disability movement organization, as well as members of the academic community in Timișoara in March 2023.

In this paper we will discuss the data collected in relation to political opportunities to participate in the policy-making process. The political opportunities scale refers to opportunities civil society organizations get to participate in public policy-making. The scale (adapted from Zentai et al., 2020, Roggeband, Krizsán, 2021) vaguely relates to Arnstein's ladder of citizen's participation (1969), but it is more specific to civil society involvement. Arnstein's ladder of citizen's participation (1969) was aimed at distinguishing between authentic and influential forms of involving citizens in policy-making known as citizens' power (where involvement translates into concrete policy results), tokenistic forms of participation (such as informing citizens or consulting them without having to implement the results of the consultation process), as well as non-participation (such as therapy or manipulation). In our case, the scale is structured similarly – its' degrees range from non-participation to co-governance or partnership between civil society organizations and public authorities.

This scale explores the ways in which disability advocacy organizations perceive their inclusion in or exclusion from involvement in policy-making processes, including disability advisory bodies, consultative bodies and other national consultation mechanisms. However, our exploration was not limited to the national level ; we explicitly encourage interview partners to differentiate their answers in relation to local, regional, national and international levels and to explain which level they consider to be most relevant. In this regard, other experiences were also explored through this scale, for example how disability advocacy organizations influence local policies (city council) or EU-program implementation (Structural Funds planning and monitoring, etc.) or other national laws and policies.

Political participation scale

4. Partnership/ co-governance (participation in agenda setting or in monitoring and implementation of policies, stable working relations between authorities & civil society, shared responsibilities).
3. Consultation/ deliberation (DPOs provide knowledge expertise, structured dialogue exists with tangible influence).
2. Tokenistic inclusion (inclusion in meetings or consultative bodies, information sharing but no impact on agenda or outcomes).
1. Information sharing (DPOs get information but have no influence on them).
0. No consultation (exclusion from platforms, services).

Source : The scale is based on the Participation Scale developed by Roggeband and Krizsán (2021, 26), but was adapted by the third author for the purpose of this study

Findings

National level participation in the policy process

All interview partners considered that the opportunity structures they were faced fluctuated in time, positioning them in different places on the scale. Nevertheless, some observed positive evolutions in time, whereas others saw negative trends, and others felt trends were volatile, with ups and downs :

At a national level, I would say we are between 2 and 3. Speaking of symbolic inclusion, yes, we are part of different commissions, sometimes we invite ourselves [to relevant discussions], we make phone calls and put pressure to have NGOs included in debates. From one legislature to the next things change and sometimes we even tend towards 4. The informal part works very, very much since in the Senate or the Chamber of Deputies has had people who come from civil society among its members and they were a lot more open to taking us into account. (mental health service provider NGO representative)

A similar, relatively positive picture of the national level opportunity for participating in policy formulations was painted by a representative of a self-advocacy NGO for persons with disabilities. This is however counterbalanced by the lack of actual implementation measures carried out :

We have participated both face-to-face and online in creating the national strategy for persons with disabilities and they were very interested in our opinions. We collaborate with authorities, we are quite active. We are at 4 [partnership/ co-governance]. Because strategies remain only as paperwork, we do not feel that something is actually happening. (representative of a self-advocacy NGO of persons with disabilities)

Other disabled self-advocate and local activists also engaged in national policy advocacy on issues that were directly relevant to their personal situations and that had legal implications :

At a national level, I sent my amendments about professional personal assistants to several members of parliament. The intervention is in the context of my need of a personal assistant – I am in a specific condition as an adult that cannot care for himself, I live with my professional personal assistant that is partially paid by the state, and the rest of the fee is covered by me, from my own salary. I have sent an official address from my organization to a member of parliament who is close to disability related commissions and have received constant feedback. I was told that the team working on this topic will take my arguments into consideration and that these arguments are valid. (disabled self-advocate part of a local civic group)

While the engagement in policy-making on a national level of organizations of self-representatives is real, there are serious limitations in regards to implementing the policy documents developed :

We [our organization of disabled self-advocates] continue to be invited to events. Deinstitutionalization will be piloted in five Romanian institutions. We will participate in training as trainers. Things are moving. We are not co-governing, but if we take into account that through another NGO [name removed to secure anonymity] we are involved in monitoring residential institutions, we have written reports and met with rapporteurs from the United Nations. Our members are involved as experts through experience in the creation of strategies, but strategies remain at the level of paperwork and this is how we do not solve a great deal. Practice is killing us. (support worker, non-disabled representative of a self-advocacy NGO)

For service providers, the national level advocacy seems to be channeled through service provider federations, of which there are two active that co-operate and cater to different regions. We interviewed two representatives, from the larger more present federation and they placed the organization differently on the scale – at 2 and at 4, pointing to different interpretations of how much the involvement in advocacy practices and dialogues actually has a tangible impact :

An accepted, rather forced partnership [between the federation and public authorities] [...] we don't make the agenda, but we follow a public agenda which we consider we need to influence. [...] In a society in which consulting with NGOs and their participation are not part of the etiquette in relationships between NGOs, public authorities and decision-makers, a series of different situations arise. We are in the spaces between 4-2, and everything depends on political opportunity. During the regime of the Social Democratic Party, participation was mere formal, later there was a greater opening, this is now gone again. (representative of a service provider federation)

I would place things at level 2, because one can say that in most cases the doors are closed. The door seems to be open to everyone. The procedure, however, is still very bureaucratic. [...] Of course there is a box that they need to tick. When people participate in these consultative bodies, and even when there are relevant feedback, opinions and information exchange, they do not come to find themselves in the decisions taken afterwards. I think the level of consultation is weak, determined on the one hand by the attitude of the authorities and on the other hand, especially in the field of disability, by the weak training that people have to participate in such meeting. There is a very rudimentary understanding of the process of policymaking. There are not enough competences in the representative organizations,

generally speaking. Of course, there are exceptions, strong organizations but generally the overall picture of organizations is that they are dominated by partisan interests. I couldn't say that in Romania we have a movement of people with disabilities, it has not grown together in all these years and this is visible in such types of participation. I think this symbolic inclusion has two main culprits, the national authority for people with disabilities on the one side, because they did not encourage this and did not educate the movement of people with disabilities to participate truly and efficiently in consultation processes. On the other hand, organizations of people with disabilities because they do not have the resources, they do not necessarily want to grow organizationally and to train their people. This all together leads to level 2. In disability, I have not remarked any evolution, it was the same 10-15 years ago. (representative of a service provider federation, different representative from the one quoted above, but within the same organization)

Service provider organizations do not always see that their main task to engage in advocacy directly :

For us it was quite difficult to engage in this double role, as an organization that provides services and makes policy proposals. We do this to a limited extent and it is more in terms of a consultant that acts through experts. When I say our experts, I mean both our beneficiaries [mental health service users] and our specialists. We give you [the government and public authorities] this information, this is the reality we are facing, use this to make public policy. We have offered diverse entities [local and national public authorities] information, but the political instability has also affected [the field of] mental health. (representative of mental health service provider organization)

Moreover, recent attempts (2019) to form a national coalition of organizations of persons with disabilities by one of our interview partners did not result in a concrete organization. These points to the fact that self-advocacy organizations outside of the public official consultation mechanisms act locally and on their own in national advocacy processes.

The fact that political participation opportunities for organizations range between 2 and 4 seems to be shared by county level regional authorities too, as our interview partner explained :

I think that at a national level, there is not yet a structured dialogue, but they have an impact. I am thinking of the new legislation in the project with the World Bank [the development of the national inclusion strategy]. I think they [organizations of persons with disabilities and service providers] started at 2 and are now at 4. (representative of a county-level public authority tasked with social service provision)

The fluctuations in opportunity structures seem to also be explained by proximity to elections, as well as the ability of federations and organizations to gain the support of certain politicians and parties :

There has been an increase in terms of public consultation from political decision-makers and authorities in general as a result of the efforts we have made : our insistence on going public when decisions were made without consultation determined some politicians to be more receptive, their reactions differ according to their competences and the moment at which we approach them, the closer we are to the moment of elections, the greater their availability for consultation processes. The reverse is also true [the farther the elections, the smaller the interest in consultation processes]. Everything is seen in relation to the politician's interest and not in relationship to a correct functioning of society in which the citizen is important. USR (Uniunea Salvați România), [a relatively new political party] brought a new

type of politician, that has studied abroad, with a different understanding of citizens and more willing to engage in dialogue with civil society. The desire to work together with civil society has changed but the reverse also happened: the more vocal and open some were, the more the others closed their doors. (representative of service provider federation)

Another important point is that structured dialogue is not always unproblematic as a process, since it legitimizes interventions with which representatives are not at all in accord through their participation:

There is no dialogue with the Council for Monitoring the Implementation of the UNCRPD, although we have tried to have a consequential dialogue with those who are leading it. After supporting a professional and apolitical candidate to the presidency of this Council. The immense incompetence of people there bothers you and you realize that your presence only legitimizes a step in their trajectory in which they discuss it with you. The dialogue is broken. Theoretically, we have built the agenda [through contributing to the creation of the council], but practically we do not have structured dialogue. (representative of service provider federation)

Local and regional level engagement

All of the self-advocacy organizations that we interviewed were active on a local level, two out of three were primarily active on the local level. Policy advocacy actions on a local level mainly centered on accessibility and were not always successful, sometimes requiring the creation of specific contexts to make the access process work.

We are somewhere between 1 and 2. It depends on the situation. There is a certain influence of our association, but in big aspects, there isn't any. [...] we started from 0 and we are on a rising trend, but currently we are not even being consulted on accessibility issues. Only certain organizations are called for consultations, even when projects are proposed that would affect the disability area. There is also a communication problem. The law on disability includes the obligation of local public authorities to include in reception committees for works carried out with public money, a representative of an organization that fights for the rights of persons with disabilities. They have avoided to include such a representative, and I had to re-initiate the correspondence with the urbanism and construction discipline bureau. The people there are not aware of the importance of respecting legal provisions and they are also not aware that we offer expertise on accessibility free of charge. (disabled self-advocate)

Another disabled self-advocate interview partner mentioned that he was part of a civic group that includes different organizations that have as a common goal the improvement of the quality of life through promoting sustainability on a local level. In this capacity, the civic group and the mayor's office concluded a partnership on accessibility:

Only as a group could we find openness from the mayor's office, he [the mayor] supports us as a coherent group. Being carried up the stairs [to meetings] should not be humiliating for us, it should be humiliating for them. We are happy about the openness and we want to continue in this direction. We have visibility and voice, our messages are taken up by the press. Our goal: making the streets and in institutions in the city [name removed to ensure anonymity] accessible. (disabled self-advocate)

Local authorities also perceive that on the local level the policy participation of NGOs is limited by a lack of strategy building on the side of public authorities :

On a local level, we do not have many NGOs in the county, I think the participation is somewhere between 0-1. We do not have a strategy to go up to 1 [on the scale]. The intention is there through a partnership with NGOs. It depends on who is leading the County Council [county level governance body], on the political conjuncture. At a certain point in time, there was even a campaign against NGOs : “why are ‘they’ coming at us ?” (representative of a county-level public authority tasked with social service provision)

Yet, there are also more optimistic success stories from local level advocacy groups, especially when they have been around for longer periods of time :

At a local level, things are looking better [than the national one]. We have a pro-active mayor, but actually we have also worked for a long time with local authorities in awareness raising and accessibility, but we still have problems with accessibility in public transportation, especially for wheelchair users and blind people. (support worker, non-disabled representative of a self-advocacy NGO)

Service provider NGOs that provide services in different localities throughout the country situate themselves differently within each locality :

On a local level, in one county [name removed to preserve anonymity] we are at 4. In almost 30 years, we have relationships in all social assistance authorities, and when it comes to developing social policies or diverse partnerships, we are invited. [...] In another county, we are at level 2. We are recognized, but the recognition is symbolic. We meet, we say hello, we sometimes invite each other in commissions and committees, but beyond this, it doesn't translate into making concrete steps to improve the lives of our beneficiaries [service users]. In yet another county, we are between 3 and 4. It is a status that we gained with much labor and many actions that led our activity to be recognized. It had not always been this way – we started at 0 around 12 years ago and we have made it step by step to 4. In another county, we have been there since the mid-nineties, and we have great informal relationships with the management of all [public] institutions. But when it comes to concrete support related to our actions, in the last five years we have seen no concrete results. In that county, we started off at 0-1, we grew to 4 and then at present we are somewhere between 1 and 2. (mental health service provider NGO representative)

Another variation in the ways in which service provider NGOs feel included in the opportunities for local policy-making is related to the structure of county level commissions and how the field of disability relates to the commission structures :

We are part of the Commission on Social Inclusion, [...] they need us, we are invited for consultations, our contribution is recognized, but they do not incorporate anything into the agenda that participating organizations have proposed, so that would be exactly level 2 as it has been described. The Commission on Human Trafficking [...] is the only one where we tend towards a level 3, because there our suggestions and the measures we propose are taken into account. We are part of a total of six consultative structures. The commission that deals with disability is the Commission on Social Inclusion where we deal with the topic of accessibility, education of children and adults with disabilities, access to education and to a small extent employment services. We are invited to this commission once a year. Generally, we are not taken into account. (representative of service provider NGO)

Discussion

We learned that most organizations feel that they are only symbolically included in the process of policy formulation through consultation processes. They saw themselves as being included only in a tokenistic, symbolic way in policy formulation processes. Service provider NGOs felt better represented on the national level and sometimes would see their inclusion in the political opportunity structures as going beyond tokenistic inclusion – but would consider those moments to bring them closer to partnership and to sharing co-governance structures with national authorities. At the other end, self-advocacy NGOs and disabled self-advocates working as part of civic NGOs saw themselves as having less political opportunities. Only one NGO mentioned enjoying co-governance and partnership on the national level, but they also explained that the major challenge is that although policy formulation may include their perspectives, the impact remains invisible as long as the implementation of policy decisions is neglected and excludes their participation.

These developments can be explained through the structure of political opportunities that is very different for organizations of people with disabilities that are either part of the national consultation structures (Council of Persons with Disabilities) or conduct advocacy on the local, national and European levels from a local base that is mostly outside the capital city of Bucharest. A recent bottom-up attempt (2019) to build a national coalition of organizations of people with disabilities did not yield concrete results, thus the self-advocacy landscape remains largely made up of individual organizations acting on their own and the national council that appears inaccessible to these organizations.

Another important finding of our study is that inclusion in political opportunity structures is not always seen as an unproblematically positive development, due to two reasons. First of all, the fact that policy formulation processes involve consultation with service providers and organizations of people with disabilities does not guarantee the impact of the positions stated and included in policy formulations. This is due to the lack of implementation of such policies and the lack of possibilities for participation of advocacy organizations in the implementation processes. Secondly, sometimes inclusion into consultative processes does not translate into influence on policy formulation. Thus, participation legitimates processes that organizations disagree with from a value perspective. This is important since in such situations, organizations often choose to strategically withdraw from participatory structures.

Conclusions

Service provider NGOs, especially those that are united in a federation of service providers, perceive themselves as having the relatively better position for influencing national policies, whereas self-advocacy NGOs seem to be limited to influencing local policies, mostly with a focus on accessibility issues. However, irrespective of their position, both service providers and disabled self-advocates are frustrated with the fact that their inclusion in policy-making is usually merely symbolic or tokenistic and is carried out in order to comply with the formal need for a consultation with stakeholders.

Our analysis also brings into view two aspects that have been less discussed in the literature on disability advocacy: one of them is that involvement in policy formulation is not perceived as a direct route to producing change. The lack of implementation of policies, however well and inclusively formulated, makes it difficult to see the impact of participating in policy

advocacy for both self-advocates and service providers. This opens up the question of other forms of symbolic inclusion – such as symbolically granting rights which, in the absence of a litigation culture, will remain declarative even when they are officially part of national disability policies.

The second point is that participation in consultations is not always seen as desirable by disability advocates as it may legitimize policy outcomes advocates themselves have little influence about. This strategic abstention, the refusal to participate in consultative bodies can be read as a form of influencing policy outcomes.

Conclusively, the political opportunities for the disability movement in Romania is not necessarily shrinking or not only shrinking. Rather, the changes in political opportunity structures can best be described as a shifting space that fluctuates mainly around symbolic or tokenistic inclusion, with moments when more inclusion becomes possible and moments when exclusion is the norm. Moreover, inclusion is not always viewed as desirable by advocates. However, the space can also be described as a highly uneven and unequal one, in which organizations of persons with disabilities with strong local ties are pushed down and sometimes choose to withdraw to the margins of the national policy landscape, while making clear impact on policy-making on the local level.

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