EU Social Inclusion Policies in Post-Socialist Countries

Top-Down and Bottom-Up Perspectives on Implementation

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Chapter 2

Independent living in Central and Eastern Europe? The challenges of post-socialist deinstitutionalization

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Introduction

This chapter discusses efforts to realize the right of disabled people to independent living and community inclusion in the post-socialist Central and Eastern European (CEE) region. This right has been stipulated in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and its realization has been strongly associated with the discourses, agencies, and practices of deinstitutionalization (DI). Since its coming into force in 2008, the CRPD has been formally accepted through its ratification as *the* legal standard in disability policy-making by most countries around the world, including by the European Union (EU). The CRPD incorporates the social model of disability and the independent living philosophy in an ambitious attempt to legislate removal of disabling barriers, including institutional confinement. The latter is enshrined in Article 19 of the CRPD, titled 'Living independently and being included in the community', which recognizes 'the equal right of all persons with disabilities to live in the community, with choices equal to others'.

The reform of DI has been key for realizing the right codified in Article 19. Rooted in the disabled people's movement (Ratzka, 1996; Evans, 2002), the anti-psychiatry movement (Mansell *et al*., 2007: 1), the movement of mental health service users (Beresford, 2012), historical and social-scientific critiques of institutional life (Goffman, 1974; Foucault, 2006), and the approach of 'normalisation' (Duffy, 2010), DI has meant the closure of residential institutions for disabled people and their substitution with services in the community. However, in actual policies and practice, DI has often been reduced merely to the dismantling of large settings (EEG [European Expert Group], 2012: 27), a misappropriation of the term that has either disregarded the development of community alternatives or has construed DI as a process of replacing large institutions with small ones located in the community (Duffy, 2011). To avoid such misappropriations, recent analyses and policy guidelines have sought to replace the term 'DI' with more descriptive and process-oriented terms such as 'transition from institutional to community-based care' (EEG, 2012). In our present investigation, we retain the original term because of its brevity, familiarity, and critical energy – DI

implies discontinuous change through negation, whereas 'transition from institutional to community-based care' implies continuous change through modification.

The reform of DI is of paramount importance in post-socialist CEE states not least because most of the countries in the region have the highest numbers of disabled people living in residential institutions in Europe, while community-based services remain largely missing (Mansell *et al*., 2007; Turnpenny *et al*., 2018). The reasons for this are complex and historically conditioned by state socialist pasts, post-1989 transformations, and more recent processes of EU integration. To tackle this complexity, in this chapter we make use of disability studies, studies of post-socialism, content analysis of policy documents, and case studies from two post-socialist countries, Hungary and Bulgaria. The latter makes our analysis limited in its empirical scope – nevertheless, we intend to offer insights into broader trends of policy formation in the post-socialist CEE region. To this end, we have used several different research methods.

Methods

We explore the challenges of post-socialist DI by combining a macro-level, top-down study of regional policy formation with a micro-level, bottom-up investigation of local policy documents, agencies, and practices. We consider this mix of perspectives to be essential for critical engagement with disability policy reform in the CEE region because it allows us to uncover general patterns while also taking into account their specific articulations on the ground. In our macro-level analysis of policies, we consider historical and structural factors impacting on DI reform in CEE countries by referring to state socialist legacy, post-socialist neoliberalization, and EU membership. The pitfalls of deterministic thinking predating such large-scale considerations are mitigated by paying heed to local policies and agencies.

Our micro-level investigations include studying domestic policy documents and mobilizations. We apply the tools of content analysis, broadly conceived – which is a widely used method in qualitative social scientific research (Berg, 2004; Hsieh and Shannon, 2005) – to reveal ways in which general historical and structural factors have been transformed into specific policy prescriptions concerning independent living and DI in Hungary and Bulgaria. Thus, we appraise policy documents such as domestic strategies and legislation that are constantly reviewed and reflected upon by both external actors such as the EU and internal actors like civil society groups and organizations. More specifically, we analyse the content of some key provisions in the Hungarian Social Act 1993/3, the Hungarian Government's Deinstitutionalization Strategy for 2011–2041, and the Bulgarian Social Assistance Act of 1998 and the regulations regarding its implementation.

Our analysis of policy documents is complemented by case studies of domestic mobilizations in support of the right of disabled people to live independently and to be included in the community. Case study methodology allows

one to focus on a unit of data while making broader conceptual observations (Gerring, 2004), thus combining particularistic, descriptive, and heuristic approaches to a given topic (Merriam, 2009: 43–44). That said, a major limitation of case studies is their restricted generalizability (Flyvbjerg, 2006) – a limitation that, in the present analysis, is mitigated through macro-level inquiry into historical and structural forces shaping DI reform in post-socialist CEE countries.

We begin by discussing the genealogy of present-day disability policy in CEE countries, tracing its features to constructions of disability under state socialism and their subsequent modifications (rather than erasure) by the neoliberal transformations that followed the events of 1989. We then consider the mixed impact of EU accession and attendant integration on DI reform in the region over the last 15 to 20 years. In the second part of the chapter, we analyse disability policy documents from Hungary and Bulgaria and we develop case studies of domestic campaigns and other initiatives. The conclusion formulates strategies for moving ahead with DI in such a way that the provisions of Article 19 of the CRPD can effectively be realized in practice, and independent living for disabled people in CEE countries can become a reality. Drawing on Nancy Fraser (1995), we argue that such a development necessitates a shift from 'affirmative' to 'transformative' approaches to social change in the disability area.

Genealogy of disability policy in CEE countries

Present-day disability policy in CEE countries has been strongly shaped by the legacy of state socialism – a social, political, and economic system that emerged in Russia in the aftermath of the October Revolution of 1917, spread throughout Eastern Europe in subsequent decades, and disintegrated at the end of the 1980s (Lane, 1996). Although state socialism was presented by its proponents as a radical alternative to capitalism, its approach to disability was strikingly similar to the one embraced by capitalist countries in the first half of the twentieth century.[1] State socialism defined disability as a medically identifiable inability to work and, on this basis, regulated the access of disabled people to public support in cash and in services. This medical-productivist understanding of disability underpinned the proliferation of segregated facilities such as residential institutions for social care (Mladenov, 2018).

The central management of state socialist economies made it possible to allocate significant resources to the building of an extensive infrastructure of residential institutions for social care, routinely located in remote areas to hide disability from public view (Holland, 2008; Phillips, 2009). The sheer materiality of the institutional approach, buttressed culturally by its medical-productivist legitimation, made it very difficult to dismantle or reform residential institutions. This approach survived the demise of state socialism, and decades after 1989 it has continued to be a major source of injustice by channelling disability support in the post-socialist countries of the CEE region along the lines of segregation, confinement, and stigma (Mladenov, 2018).

Since the 1990s, the CEE post-socialist countries have been subjected to neoliberal reforms introduced widely but unevenly throughout the region (Dale, 2011). Neoliberal retrenchment of public services and social security, deregulation, and privatization of state enterprises have reduced many people in the region to poverty. One way to cope has been to seek help from disability benefits (it is important to note here that poverty itself produces impairments). In effect, the number of claimants has risen. For example, in Hungary during the 1990s, the number of people living on 'disability pension' (under the official retirement age) rose from approximately 240,000 in 1990 to over 460,000 in 2003, on the eve of Hungary's EU accession (Kozponti Statisztikai Hivatal, 2013). Such an increase was also seen in Bulgaria, where, between 2000 and 2010, public expenditures on 'invalidity pensions' increased more than six-fold (Aleksiev, 2012: 4). A vicious circle has emerged – the welfare state has been shrunk, and this (ironically) has forced the welfare state to spend more and more on disability benefits.

Such spending has been largely inefficient. Instead of distributing adequate amounts based on individual needs to those who are disabled while ensuring that all people (disabled and non-disabled alike) have an adequate standard of living that does not make the disability category a condition for survival, post-socialist states have distributed small amounts to an ever-increasing number of people claiming disability status, some of whom have been disabled (including by poverty) while others have been merely poor. As argued by Stone (1984), the distinction between 'disabled' and 'able-bodied' is political, economic, and historical – in times of strong welfare-state arrangements, there is less need to make recourse to the disability category in order to cope with life and to escape poverty and exploitation. However, the distinction becomes more contested and, accordingly, more violently policed in times of economic turmoil and welfare-state retrenchment (see also Roulstone, 2015).

As a result of neoliberal cuts, the living conditions of institutional residents worsened. In his analysis of disability policy in post-Soviet Russia, Fröhlich (2012: 378) observed the following:

> Over the course of the social transformations in the 1990s, the Russian social security system faced rapid changes as a result of declining financial and structural resources, and the social situation of people with disabilities became precarious. During the fall of the Soviet Union, the living conditions in state-run residential institutions collapsed.

Available evidence points towards similar patterns of degradation of the living conditions inside socialist-era residential institutions in other post-socialist CEE countries in the aftermath of 1989 (Tobis, 2000; World Bank, 2003). In the European Court of Human Rights (ECHR) case of *Stanev* v. *Bulgaria* (no. 36760/06, § 20, ECHR 2012), the description, which reflects the situation in an old-type institution for 'adults with mental disorders' in Bulgaria during the 2000s, is particularly revealing:

> [T]he buildings did not have running water. The residents washed in cold water in the yard and were often unshaven and dirty. The bathroom, to which they had access once a week, was rudimentary and dilapidated.… The toilets, likewise located in the yard, consisted of decrepit shelters with holes dug in the ground. They were in an execrable state and access to them was dangerous. Furthermore, basic toiletries were rarely available.

At the same time, disabled people living outside institutions (locked in their homes because of a general lack of community services) have been plunged, together with their relatives, deeper and deeper into poverty, which has made them seek institutional care: '[T]he extreme poverty faced by families in Eastern and Central Europe means that families are given few alternatives but institutionalisation of their family member' (Inclusion Europe and Inclusion International, 2005: 4). In the aftermath of the financial crisis of 2008, welfare budgets have been subjected to additional cuts (Hauben *et al*., 2012), which have further increased the misery of those at the receiving end of 'social care' policies. But besides neoliberal retrenchment and austerity, there have been other important external and internal factors that have impacted on contemporary disability policy in the CEE region.

The role of the EU

It was policy pressure and funding from the EU that provided the major impetus and public resources to start the process of DI in CEE countries in the late 2000s (Estonia, Latvia, Lithuania, Poland, Czech Republic, Slovakia, Hungary, and Slovenia joined the EU in 2004, Bulgaria and Romania joined in 2007, and Croatia joined in 2013). As Phillips (2012: 35) points out in her study of the implications of EU candidacy and accession on disability rights and policies in Bulgaria, Romania, Croatia, and Macedonia, '[i]n many cases, reform is not "home grown" or internally generated but rather is carried out in reaction to external expectations and funding. This means that commitment may be low and measures incomplete.' The EU's acquis communautaire influenced the adoption of new disability rights legislation across the region, while the EU's structural funds were made available to CEE members for projects aiming at the social inclusion of disabled people, which included DI and the development of various forms of support in the community.

The impact of these new legislative and financial frameworks on post-socialist disability policy has been mixed. On the ground, EU funds have often been allocated to refurbish old residential institutions or to build new ones. As we have argued elsewhere (Mladenov and Petri, under review), such outcomes of EU-promoted DI reforms have contradicted the aims formulated in official documents like the EU Disability Strategy 2010–2020 (European Commission, 2010) – and domestic efforts at DI have often generated reinstitutionalizing policies and practices (Parker *et al*., 2016, 2017). The very discourse on DI, generated by

EU bodies and international non-governmental organizations, has manifested Europe-wide power imbalances impeding the genuine transition from institutions to community living. At the EU level, DI reform has been framed by a number of policy documents whose tracking and deciphering requires proficiency in EU governance and international law, which *in itself* could be a barrier to effective engagement with EU policy-making by disabled advocates and self-advocates (Petri *et al*., 2017).

Consider this bricolage: presently, the key EU documents on DI include the European Disability Strategy 2010–2020 (European Commission, 2010), which has committed the EU to 'promote the transition from institutional to community-based care'; the EU Regulation on the European Structural and Investment Funds (ESIFs), known as *Regulation (EU) No 1303/2013*, which requires certain '*ex ante* conditionalities' to be fulfilled before the member states can receive funding through the ESIFs – with regard to DI, such a condition is that selected states (including all post-socialist CEE member states) should include in their national poverty reduction strategies 'measures for the shift from institutional to community based care'; the European Commission's *Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation – DI)* of January 2014, which clarifies the meaning of the aforementioned conditionality in the sense that the states should plan measures for the development of services in the community to enable independent living; the European Commission's *Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union* of June 2014, which states that the EU should support only those actions that help with independent living and that measures contributing to further institutionalization should not be supported by the ESIFs; and the EU Ombudsman's report *Decision of the European Ombudsman Closing Her Own-Initiative Inquiry OI/8/2014/AN Concerning the European Commission* of May 2015, which openly criticizes the use of ESIFs in support of institutionalization and provides recommendations for changes.

The content of these documents is highly specialized, privileging people who have mastered the juridical and/or administrative language of EU policy-making, thus reproducing the notorious gap between EU governance and the everyday concerns of EU citizens. In many cases, local disability rights activists have either been co-opted or estranged by what has become a legal/technocratic approach to pursuing disability rights advocacy, and particularly DI (Petri *et al*., 2017). The effect on local publics has been that DI and other disability rights reforms have been delegitimized as 'Western stuff', with such misperceptions being amplified by populist governments (Hungary being a prominent, if not an isolated, example).[2]

Domestic policy formation

Gaps between EU policies and CRPD-defined standards on DI on the one hand and domestic policy formation in post-socialist CEE countries on the other can

be exemplified by analysing changing definitions of 'supported living' in Hungary. Supported living is understood in EU policy guidelines as an important community-based service on par with personal assistance and accessible housing: '[I]n supported living people can choose who they want to live with, in housing that they own or rent. They also receive personnel support from agencies that do not control the accommodation' (EEG, 2012: 94). However, the current use of the term 'supported living' (in Hungarian: *támogatott lakhatás*) in the Hungarian Social Act 1993/3 is markedly different from this understanding. The term itself had been largely unknown in Hungary until the late 2000s when, following Hungary's ratification of the CRPD in 2008, various disability advocacy initiatives started to push for DI.[3]

It was only in 2013 that the amendment of the Social Act established 'supported living' as a new service category for disabled people, including people with psychosocial impairments. The amendment of the then 20-year-old Social Act in 2013 followed the development of the Hungarian Government's Deinstitutionalization Strategy for 2011–2041, which claimed to reflect the international 'paradigm shift' in disability policy, as represented by the CRPD:

> In this Strategy, we avoid all residential provisions that offer segregated and compound living for disabled people where they are unable to exercise control over their own lives. Supported living is a type of social service where people live in the community in a property average in its quality and size; the service must ensure that residents decide on as many aspects of their lives as possible and that they live as members of the local community.
>
> (Hungarian Government, 2011)[4]

However, a closer look at the definition of 'supported living', as set out in the Social Act itself, reveals a very different picture. Although this legislation acknowledges that such a service must be provided on the basis of a thorough 'needs assessment' to ensure that it responds to individual needs, it allows for 'supported living' to be offered in residential settings for up to 50 people. This provision is clearly a misappropriation of the term, as defined in EU policy guidelines (EEG, 2012: 94–95). Moreover, it shows how post-socialist DI has co-opted a human rights discourse 'imported' from the EU and CRPD, while maintaining the status quo of old structures.

Similarly, a content analysis of relevant Bulgarian legislation reveals that the flaws of Bulgarian DI (CIL, 2013; Deneva and Petrov, 2016) have been enabled by certain legislative provisions that have misrepresented institutional placement as support in the community. Key among these provisions is the problematic definition of 'social services in the community' included in 2002 in the Bulgarian Social Assistance Act of 1998: ' "Social services in the community" are services provided in a family environment or an environment close to the family one' (Additional Provisions, Para. 1). For one thing, this definition is too focused on the family, but the bigger issue is that, in combination with defining 'social

services in the community of a residential type' as 'services which provide an opportunity to live in an environment close to the family one' (Additional Provisions, Para. 1), possibilities are opened up to set up residential care under the guise of community services. The problem is exacerbated in Chapter III ('Social Services'), Art. 36 of the Regulations for the Implementation of the Social Assistance Act, which operationalizes the blanket definitions contained in the Act.

A closer look at the Regulations reveals a long list of services denoted as 'Social services, which are provided in the community' (Art. 36, Para. 2), encompassing subcategories such as 'social services at home', 'day care centres', and 'foster care', but also the subcategory 'social services of a residential type', under which one finds different forms of 'centres for family-type placement' (in Bulgarian: *tsentrove za nastanyavane ot semeen tip*) and 'sheltered housing' (in Bulgarian: *zashtiteno zhilishte*). The definition therefore enables policy-makers and practitioners to misrepresent small residential settings as community services ostensibly akin to home-based care or foster care, thus justifying their proliferation or else glossing it over by abusing the EU-promoted discourse on community-based services (EEG, 2012). On the other hand, the service 'personal assistant' (in Bulgarian: *lichen asistent*) is included under the subcategory 'social services at home', together with 'home care' and 'meal-on-wheels', which effectively erases the fundamental difference between these different forms of individualized support (Deneva and Petrov, 2016: 6) – and it is important here to consider the insistence of independent living advocates that '[t]he term "personal assistance" cannot be used for service delivery solutions where housing and assistance with the activities of daily living are provided in one inseparable package' (Ratzka, 2004: 3).

The provisions of the Bulgarian and Hungarian legislation, as analysed here, are of pivotal importance for DI reform. Their flaws reflect persistent difficulties with processing the legacy of state socialist constructions of disability over the decades of post-socialist neoliberalization in the aftermath of 1989. Such flaws enable the proliferation of reinstitutionalizing practices under the banner of 'deinstitutionalization' and, moreover, erect definitional barriers to the creation of possibilities for independent living and community inclusion. It is in this domestic policy context that local actors mobilize to seek social change.

Local mobilizations

It is worth remembering that before becoming an expert-centred and expert-controlled discourse, European DI was promoted at the grassroots level by disabled activists seeking independent living outside of the confines of institutional walls. For example, in his history of the independent living movement in the United Kingdom, the disabled activist John Evans (2002) recalls numerous local initiatives and international collaborations aimed to create and promote community alternatives to institutional care, and consider also Adolf Ratzka's (1996)

recollections on independent living activism in Sweden in the 1980s and 1990s. Moreover, such efforts were not limited to Western European countries, although similar initiatives in state socialist Eastern Europe were heavily repressed by the authorities:

> [I]t is important to note that the Soviet-era disability rights activism that emerged beginning in the 1960s came out of internaty (see Indolev 1998). This is evidence that, despite their many shortcomings, the internaty had a beneficial if unintended side effect: the close proximity of people with similar experiences, concerns, and grievances allowed a disability rights consciousness to foment. At the same time, however, the tight state control on internaty meant that the rights movements were also squelched there, because the state could easily move people from internat to internat to disrupt social networks.
>
> (Phillips, 2009: n.p.)

It was only after the fall of the state socialist regime at the end of the 1980s that disability rights campaigners were able to organize freely without being directly repressed or else submitted to tight control by the authorities. Some of these advocacy initiatives have promoted systemic change along the lines of independent living and DI, while others have merely attempted to humanize the mechanisms for institutional confinement and segregation inherited from state socialist disability policy.

Past mobilizations

In Hungary, parents of disabled people have put forward demands for better services in many areas including education, rehabilitation, employment, and daycare since the 1990s. These efforts have been impactful – for example, organizations of parents of autistic people have successfully lobbied subsequent governments for progressive changes in both education and autism diagnosis policies (Balázs and Petri, 2010). However, in the field of community living, parents' organizations focused mostly on the creation and funding of group homes. Indeed, according to leading advocates and government officials, one of the biggest achievements of parents' advocacy in autism in the 2000s was the establishment of several small group homes, each accommodating up to 12 adults (ibid.). Such impact was recognized by officials at the time and was explained with reference to grassroots unity:

> One of the reasons why parents' advocacy in autism has been so successful is the fact that AOSZ [Autistak Orszagos Szovetsege – Hungarian Autistic Society, the national umbrella organisation representing families of autistic people] was organised bottom-up, so parent-led organisations were more united than those in other disability groups.
>
> (Ibid.: 44)

Despite such positive appraisals, demands for personal assistance schemes or personal budgets did not feature high in parents' advocacy. Instead, parents' organizations, often allied with non-governmental organizations established by professionals, focused much of their lobbying on education and specialized services for children. When asked about services for adults in an empirical study (Kiss, 2010), parents stated that small residential settings such as group homes are appropriate – or for some even ideal – for autistic adults, provided that the residents have their own rooms and access to in-house support like in-house assistants as well as vocational and other types of rehabilitation. Notably, demands for supported living schemes were not made, with many parents stating that their adult-aged children should live with the family until the parents can no longer look after them (Kiss, 2010).[5]

In Bulgaria, the advocacy for independent living and community inclusion began in the middle of the 1990s with the founding of the Bulgarian grassroots disabled people's organization Centre for Independent Living–Sofia (CIL–Sofia). As a user-led, user-controlled, cross-disability initiative, CIL–Sofia has campaigned for more than 20 years for a complete overhaul of the national disability support system. Such campaigns, recorded in numerous reports, analyses, and publications (available at the organization's website: cil.bg), have included demands for the introduction of personal assistance, as well as advocacy for a nationwide transition from institutional to community-based services aligned with EU guidelines and the provisions of the CRPD.

Among the results of these efforts was the adoption of an 'Assistants for Independent Living' scheme by the Sofia Municipality in 2007, which has been implemented at the municipal level since then (Mladenov, 2017). More recently, CIL–Sofia has organized a number of protests, performances, and other public events criticizing domestic DI reforms as 'reinstitutionalizing' because of their over-reliance on small residential settings as substitutes for the big institutions of the past (CIL, 2013; Deneva and Petrov, 2016). However, such advocacy initiatives have remained largely isolated and marginalized because of the reluctance of other Bulgarian civil society organizations to support them, and most importantly because of the (sometimes open) hostility of nationally representative umbrella organizations of and for disabled people towards systemic change (Mladenov, 2009).

Present-day mobilizations

The strongest, most vocal, and most popular disability-related campaigns in Hungary, Bulgaria, and elsewhere in the CEE region in 2018 targeted neoliberal austerity and its pernicious effects on locally provided disability support.[6] In Hungary, a campaign was launched in 2018 by a small parental organization, with the objective to raise the allowance of informal caregivers of severely disabled children or adults. Informal caregivers often work 24/7 to support their severely disabled or chronically ill family members, mostly because there are no

support services in the community. Presently, around 12,000 caregivers work under this 'caregivers allowance' (in Hungarian: *ápolási díj*) whose monthly amount, even in the highest support category, is only HUF 52,800 (approx. EUR 160) per month. The campaign has aimed to increase this amount significantly and to acknowledge by law that this is not a welfare allowance, but is employment (with ensuing pension and other entitlements).

This initiative gained significant public support, with nearly 40,000 signatures on an online petition (aHang, 2018). An open letter to the minister of social affairs was signed by 41 non-governmental organizations, including disabled people's organizations and online collectives such as parents' online self-help groups. Several demonstrations were held in front of the Parliament building, attended by caregivers, disabled people, and supporters. The largest Hungarian disabled people's organization (core-funded by the state) also supported the campaign, openly criticizing the government's reluctance to improve the situation. Several opposition MPs, including politicians from liberal, far right, and green parties, also supported the campaign and tabled legislative proposals.

A similar campaign took place in Bulgaria, where parents of disabled children took to the streets in Sofia and other cities with demands for legislative codification and public funding for personal assistance for their children. This campaign was launched in June 2018 and, at the time of writing (late September 2018), was still ongoing (Marinova, 2018). It has included several months of protest camping in front of the Bulgarian Parliament under the slogan 'The system kills us', public demonstrations, and heated discussions on Facebook. The media presence of the protesting parents has been very strong and has initiated a nationwide debate on the need to reform disability support (Stoyanova and Stoynova, 2018).

The parents (consistently referred to in the Bulgarian media as 'the mothers') have been supported by the Bulgarian Ombudsman Maya Manolova, who has collaborated with the activists in drafting a new Personal Assistance Bill. However, the nationally representative organizations of disabled people have opposed the campaign and have proposed an alternative legislative reform that, according to the parents, is oriented towards maintaining the status quo (Stoyanova, 2018). Moreover, the Personal Assistance Bill drafted by Manolova and the parents has been criticized by CIL–Sofia because it puts assistants' wages at very low levels and does not restrict the possibility of family members to be employed as assistants. CIL–Sofia has argued that providing support in this way would reduce it to social assistance for families with disabled children (CIL, 2018).

Although anti-austerity campaigns such as those in Hungary and Bulgaria in 2018 testify to the power of local agencies to influence disability policy in post-socialist CEE countries, they are not necessarily conducive to disabled people's independent living. Of note here is that tensions between, on the one hand, the strategy of poverty alleviation and, on the other, advocacy for independent living and social inclusion have plagued the disabled people's movement from its early days. Consider, for example, the famous document 'Fundamental

Principles of Disability' – a transcript and commentary of a discussion held in 1975 between representatives of two British disability organizations, the radical Union of the Physically Impaired Against Segregation (UPIAS) and the moderate Disability Alliance.[7] In this discussion, the Alliance defended income substitution for disabled people (a kind of invalidity pension intended to alleviate the poverty of those excluded from gainful employment on the grounds of their impairments), whereas UPIAS insisted on making society (and, particularly, employment) more inclusive for disabled people so that they could gain (economic) independence:

> The Union's social theory of disability, itself a product of the technological changes in society, reflects the most advanced developments which make it clear that the alternative to an 'incomes' (or more properly, 'pensions') approach to the particular poverty in disability is to struggle for changes to the organisation of society so that employment and full social participation are made accessible to all people, including those with physical impairments. Setting 'incomes' in the context of this struggle to change the organisation of society, would help physically impaired people recognise the correct emphasis to be placed upon incomes.
>
> (UPIAS, 1976: 15)

Obviously, UPIAS's approach was strongly productivist, influenced by a specific conception of redistribution ('to each according to work contribution' as opposed to 'to each according to need'), but also inflected by the rising scepticism towards the welfare state that would, eventually, morph into the neoliberalization of the 1980s and beyond:

> [F]or people of working age financial and other forms of help must above all be geared to the retention or achievement of integrated employment: dependence on the State must increasingly give way to the provision of help so that a living can be earned through employment. Similarly, the assistance given to physically impaired children must be directed towards their progressive integration into ordinary employment.
>
> (Ibid.: 15)

Can we, as disability advocates and analysts from CEE countries, learn something from these early exchanges between Western disability organizations and grassroots activists while retaining our critical distance informed by our own experience and insight into state socialist ableism and the neoliberal dismantling of CEE welfare states post-1989? For example, would it be possible to retain UPIAS's emphasis on independent living and social inclusion while rejecting UPIAS's 'dependency' rhetoric (which eventually became a central argument of neoliberal and neoconservative reformers – see Roulstone and Prideaux, 2012: 81), as well as UPIAS's productivist assertion that for disabled people of

working age 'financial and other forms of help must above all be geared to the retention or achievement of integrated employment'?

Concluding reflections: from affirmation to transformation

It seems that recent campaigns for disability reforms in some post-socialist CEE countries have reproduced the approach defended by the Disability Alliance in Britain some four decades ago, without considering the dangers of income support highlighted by UPIAS (1976). Let us consider the cases of Hungarian and Bulgarian parents protesting in 2018 with the help of UPIAS's (1976) analysis, while bracketing the latter's productivist leanings and 'dependency' rhetoric. From such a perspective, increasing (or providing) parental allowances will make families of disabled children less poor, but will not make disabled children more independent or included in society. In the absence of (non-parental) personal assistance and other community services, cemented by legislative misrepresentation of residential settings as 'community services', both the parent (usually the mother) and the child become prisoners of their home, locked out in the realm of the private even when their basic needs such as food, clothing, and shelter are satisfied.

To better understand the situation, we might distinguish between 'affirmative' and 'transformative' redistributive measures, following Nancy Fraser (1995). Paying parents to care for their disabled children exemplifies affirmative redistribution, which amounts to a mere reallocation of resources without changing the underlying mechanisms maintaining disabled people's ableist subjugation (and women's patriarchal oppression). In contrast, developing community services such as supported living or personal assistance could have transformative effects (as far as they are not shaped according to flawed legislative definitions), making disabled children more equal to non-disabled ones (and women freer to explore life outside the home). As Fraser (1995) has suggested, it is not enough to advocate for social and economic rights, and what is needed is to advocate for *transformative* measures for the achievement of these rights.

From such a perspective, the problem with domestic disability rights mobilization against neoliberal austerity in the post-socialist CEE countries is that they aim exclusively at affirmative redistribution, which in itself is unable to cancel the subordinate position of disabled people in societies that have otherwise remained heavily ableist. Kolářová (2012), in her analysis of a protest against austerity led by disabled people in the Czech Republic in 2011, makes the point that '[n]either shaming the government for breaking the consensus of humanism that requires the society to *help* the misfortunate, nor shaming others for illegitimately claiming such social assistance, will disrupt the structural and institutionalized inequalities that produce disability'. The advantage of transformative measures is that they could potentially disrupt such oppressive structures.

While they cannot substitute income support and cover the additional costs of living with impairment, measures such as personal assistance, supported living, and accessible housing are indispensable for bringing about social transformation in the disability field. These measures, however, have been missing from existing DI programmes in the CEE region, where DI has been perceived by policy-makers largely in terms of infrastructural investments into new residential facilities without broader policy changes in community services, personal assistance, or housing (Petri and Kozma, 2017; Mladenov and Petri, under review). But without introducing such changes, the post-socialist CEE countries are bound to comply only half-heartedly with the EU's top-down pressures for DI and with the provisions of the CRPD – by refurbishing old facilities and/or building smaller replicas of the large, state socialist residential settings. Meanwhile, disabled people will remain confined in institutions or at home, while independent living will remain abstract, distant, and even menacing 'Western stuff'.

Notes

1 Besides disability policy, there were other principles, practices, relations, and institutions within state socialism that remained capitalist in their essence. This has prompted some analysts to refer to state socialist societies as 'state capitalist' ones (Tamás, 2011; Debord, 2014). In this chapter, we follow Lane (1996) in sticking to the more conventional term 'state socialism' because it emphasizes key differences from capitalism, including public ownership of the means of production, central economic planning, and an ideological prioritization of collectivism over individualism.
2 Presently, there is a strong backlash against 'human rights' in Hungary, where 'human rights' are associated with 'Western' interference in national sovereignty and are seen as a 'Western' invention intended to 'weaken' Hungary. Similar ideas have been spreading in other CEE countries as well. That said, Western European countries have also witnessed a resurgence of anti-EU and anti-UN sentiments, as exemplified most prominently by 'Brexit' events in the United Kingdom.
3 Notably, at that time DI had already been a recognized policy, set by the Hungarian Equal Opportunities of Disabled People Act of 1998, one of the first 'disability human rights' laws in Europe (Vanhala, 2015). Although this legislation set out DI as a core action, it also allowed for continuity in 'humanized' institutional care for those with high support needs and did not mention 'supported living'.
4 Most of the provisions of this strategy, including the quoted paragraph, have been retained after its partial amendment in 2017.
5 Ironically, Hungarian parents of autistic people refused to fight for the very services that they and their children would need in order to live independently and to be included in the community, demanding instead the creation of new residential settings funded by the state. However, studies also found that parents were reluctant to place their autistic children in existing residential care facilities because they saw such services as ill-prepared to meet autistic people's needs, for example by being understaffed, by requiring residents to share rooms, by lacking organized daily activities for residents, and by employing staff ignorant about the specific needs of autistic people (Kiss, 2010: 191–193). Focus group discussions revealed that most parents considered any residential services, large and small alike, only as a 'last resort' in case their own ill health would prevent them from being able to look after their autistic family member.

Moreover, the parents of 'high functioning' autistic people were the least likely to consider group homes for their children (Petri and Valyi, 2009). This meant that the higher their children's support needs, the more likely it was that the parents considered residential care as an option, revealing how the lack of alternatives in the community pushed parents in a direction in which they were essentially reluctant to go.

6 For a Polish example, see: www.france24.com/en/20180527-polish-disabled-protesters-call-off-sit-parliament.

7 The document contains the seminal distinction between 'impairment' and 'disability' subsequently used by Michael Oliver (1996) in his formulation of the social model of disability.

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