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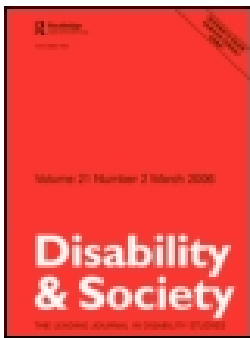
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## Critique of deinstitutionalisation in postsocialist Central and Eastern Europe

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To cite this article: Teodor Mladenov & Gabor Petri (2019): Critique of deinstitutionalisation in postsocialist Central and Eastern Europe, *Disability & Society*, DOI: 10.1080/09687599.2019.1680341

To link to this article: <https://doi.org/10.1080/09687599.2019.1680341>



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## Critique of deinstitutionalisation in postsocialist Central and Eastern Europe

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### ABSTRACT

In this paper, we explore critically deinstitutionalisation reform, focusing specifically on the postsocialist region of Central and Eastern Europe (CEE). We argue that deinstitutionalisation in postsocialist CEE has generated re-institutionalising outcomes, including renovation of existing institutions and/or creation of new, smaller settings that have nevertheless reproduced key features of institutional life. To explain these trends, we first consider the historical background of the reform, highlighting the legacy of state socialism and the effects of postsocialist neoliberalisation. We then discuss the impact of 'external' drivers of deinstitutionalisation in CEE, particularly the European Union and its funding, as well as human rights discourses incorporated in the UN Convention on the Rights of Persons with Disabilities. The analysis is supported by looking at the current situation in Hungary and Bulgaria through recent reports by local civil society organisations. In conclusion, we propose some definitional tactics for redirecting existing resources towards genuine community-based services.

### ARTICLE HISTORY

Received 23 May 2018  
Accepted 8 October 2019

### KEYWORDS

residential institutions;  
Independent Living;  
European Union; state  
socialism; postsocialism;  
neoliberalism

### Points of interest

- This paper looks at efforts to help disabled people in Central and Eastern Europe to live outside institutions, in the community.
- We argue that some countries in Central and Eastern Europe only pretend to help disabled people live in the community.
- In reality, these countries repair existing institutions or build new ones.
- The reasons for this are found in the history of these countries and in more recent policies such as cuts to social support.

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- We give examples by looking at the current situation in Hungary and Bulgaria.
- We conclude that it is important to create true community services instead of building more institutions pretending to be community services.

## Introduction

A report published in 2007 estimated that nearly 1.2 million people, including children and adults with psychosocial impairments, lived in residential institutions for disabled people in 25 European countries. This data, presented by Mansell et al. (2007, 25), also showed that the rate of institutionalisation in large institutions (with over 30 places) was higher in the postsocialist region compared to the rest of the European sample, with ten of the fifteen top-ranked countries being former socialist states (Mladenov 2018, 38). Since then, deinstitutionalisation reform has progressed, but with uneven and re-institutionalising results. The reform has been supported by the European Union (EU) through its Structural Funds. In addition, a number of Central and Eastern European (CEE) countries, including Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, North Macedonia, Romania, Serbia and Slovakia have developed laws and policies aiming at closing down residential institutions and replacing them with various new services (Phillips 2012; Turnpenny et al. 2018).

Reports on deinstitutionalisation (for example, Mansell et al. 2007; EEG 2012; Kozma and Petri 2012; Turnpenny et al. 2018) repeatedly note the lack of data about the number of residents living in different settings – or about the exact number of those receiving community-based services – which makes it difficult to track the actual progress countries have made. However, certain trends can still be observed. For example, a recent international report, based on data drawn from over 30 countries, asserted that ‘the transition from institutional to community-based services has been uneven and has stalled’ and that in CEE countries, implementation ‘has been slow’ (Turnpenny et al. 2018, 52). Evidence also shows that, whilst legally committing to deinstitutionalisation, several CEE countries, including the Czech Republic, Bulgaria, Hungary, Romania, Latvia, Lithuania and Slovakia have used domestic or EU Structural Funds to maintain and renovate institutional settings (Parker and Bulic 2016). Elsewhere, for example in Bosnia and Herzegovina, legislation on deinstitutionalisation has not been followed by actual implementation (Turnpenny et al. 2018).

In this paper, we explore critically these processes and outcomes of deinstitutionalisation in CEE. Our contribution helps fill a gap in academic research on institutional treatment of disabled people in postsocialist societies – as also pointed out by Sumskiene and Orlova (2015, 371), existing

information and analyses on this topic have predominantly been produced by non-governmental organisations, complemented by occasional reports on abuses and violence published in the media. The article builds on the authors' nearly two decades-long involvement in disability advocacy in the CEE region and reflects their shared concerns about contemporary trends in postsocialist disability policies. It also echoes the growing unease among both disability activists (Parker and Bulic 2016) and international organisations (Quinn and Doyle 2012) about the lack of political commitment to develop community services that can effectively replace residential institutions across the CEE region. Drawing on civil society reports, academic analyses, policy documents, historical research and observations of the situation on the ground, we explore the mechanisms that have directed the reform of deinstitutionalisation in the postsocialist CEE towards re-institutionalising processes and outcomes.

We first provide a historical overview of deinstitutionalisation reforms. We pay particular attention to the ways in which the legacy of state socialism and processes of postsocialist neoliberalisation have shaped institutional confinement and deinstitutionalisation efforts in present-day CEE. We then discuss the role of the European Union as an 'external' driver of deinstitutionalisation in the region. We also pay heed to the significance of human rights discourses, and particularly of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). In the second part of the paper, we consider the situation 'on the ground' and review some critical analyses of deinstitutionalisation in Hungary and Bulgaria, formulated in recent reports by grassroots disabled people's organisations. We conclude with a discussion of definitional struggles in deinstitutionalisation efforts. It is hoped that this critique of deinstitutionalisation in the postsocialist CEE will support European disability advocates by strengthening their arguments for the need to reform the reform – in other words, to reclaim deinstitutionalisation by redirecting EU funding towards genuine community-based services.

### **Historical background**

Historically, the reform of deinstitutionalisation gained momentum in the 1960s and 1970s, first in North America and later in Europe. One of the drivers of this shift from institutional to community living has been the Independent Living movement (DeJong 1979; Ratzka 1996). John Evans (2002, 1), the British Independent Living pioneer, recounts how disabled people in the United Kingdom in the late 1970s were dissatisfied with the services they received because these services were 'paternalistic, institutional, second class, too medically orientated and out of touch with their real needs. As a result of this [disabled Britons] looked elsewhere for solutions to

overcome their restricted predicament and living conditions.’ This activism articulated with the influential critiques of residential institutions elaborated by social thinkers such as Goffman (1974), Foucault (2006) and the anti-psychiatrists (see Mansell et al. 2007, 1). There was also a (partial) convergence between disabled people’s resistance to institutional living and the ideas and practices of ‘normalisation’ (DeJong 1979, 441 and 442; Duffy 2010, 258) that focused on integrating people with intellectual and psychosocial impairments into societal ‘mainstream’. In addition, the critiques of residential institutions converged with neoliberal and neoconservative critiques of the ‘nanny state’ (Mladenov 2015).

Such trends, ideas and advocacy efforts exposed traditional institutions as sites of segregation and confinement which deprived their residents of choice and control over their lives and subjected them to degrading treatment, restraint, neglect, overmedication, physical violence and sexual abuse. The horrors of traditional institutions in CEE have been well-documented:

In one [postsocialist] European country, a recent investigation conducted by a non-governmental organisation with the Prosecutor’s Office revealed that 238 children died in institutional care in a ten-year period. According to the report, 31 children died of starvation through systematic malnutrition, 84 from neglect, 13 due to poor hygiene, six in accidents such as hypothermia, drowning or suffocation, 36 died because they were bedridden and two deaths were caused by violence. It was also found that violence, binding and treatment with harmful drugs were widespread in institutions for children. (EEG 2012, 43)

It is hard to remain analytical in the face of such abuse. However, the shocking cases of manifest violence in residential institutions – and the ones that usually attract the attention of the courts (e.g. *Stanev v. Bulgaria*, no. 36760/06, ECHR 2012) or the media (e.g. Angelova 2008) – are underpinned by less spectacular relations of devaluation, dispossession and disempowerment. The current features of institutional treatment of disabled people in CEE are shaped by the legacy of state socialist disability policy and by the neoliberal reforms which followed the collapse of state socialism. This history may also explain the flaws of reform efforts in CEE, which have focused overwhelmingly on renovating existing institutions and/or on building new, smaller ones.

### **State socialist legacy**

The state socialist system in CEE disintegrated at the end of the 1980s, but its legacy has continued to shape disability policy over the following decades of postsocialist ‘transition’. State socialism defined disability as inability to work caused by medically identifiable bodily or mental deficiencies (Mladenov 2018, Ch. 2). This medical-productivist framework was incorporated in disability assessment systems that governed the access of disabled

people to public support in cash and in kind (Phillips 2009). It also underpinned the proliferation of segregated facilities such as residential institutions for social care (Tobis 2000).

To be sure, state socialism did not 'invent' institutional segregation of disabled people – the new system merely reproduced principles and practices traceable to the asylums and workhouses, conceptualised by Foucault (2006) as hallmarks of European modernity and by disability scholars (Oliver and Barnes 2012) as offshoots of industrial capitalism. Indeed, state socialism was billed as a radical alternative to capitalism, yet it did not depart substantially from the latter's approach to disability (Hartblay 2014). The difference was in degree rather than in kind – the enhanced industrialisation sought by the state socialist regime conditioned a greater emphasis on the productivity-enhancing functions of segregated provision (see Mladenov 2018, Ch. 1). The social policy pundits of the time provided as rationale for confining disabled people to residential institutions the release of their relatives from care obligations so that the relatives could (re)join productive labour (e.g. Golemanov and Popov 1976, 32).

The central management of national economies under state socialism made it possible to allocate significant resources for the building of a massive infrastructure of residential institutions for social care in CEE countries (Holland 2008, 545), sending to the public the message that the regime cared for its population. However, these segregated facilities were routinely built in remote and isolated areas because one of their (unstated) functions was to hide disability from public view (Angelova 2008; Phillips 2012, 30 and 31), thus maintaining the illusion of mass physical prowess and social homogeneity (Fröhlich 2012, 377; Phillips 2009), arguably generated by the newly created 'classless society'. In some cases, the initial stages of confinement utilised existing buildings in remote locations. In Hungary, for example, most of the institutions were set up in the 1950s in former mansions of the aristocracy, old warehouses, and barracks. Initially, various groups (people with physical, sensory and intellectual impairments, psychiatric patients, elderly people) were mixed together. In the 1970s, the Hungarian government implemented a 'profile cleaning' and some institutions specialised in people with intellectual impairments, others – in elderly people, and so forth. This 'profile cleaning' came with capital investments as well – some new buildings were built, while the number of residents increased significantly till the late 1980s and 1990s (Turnpenny 2011).

Beside inherited material infrastructures, the segregation and confinement of disabled people in postsocialist CEE has also been perpetuated by legal capacity provisions received from state socialist legal systems. Many 'inmates' have been kept in institutions against their will through guardianship arrangements 'whereby a court removes, or restricts, the legal capacity of

individuals (so that they are not recognised in law as being able act on their own behalf, such as entering into contracts, getting married or voting in parliamentary elections)' (Parker and Bulic 2016, 22). The mechanism of confinement through guardianship in its postsocialist form has been exposed in minute and troubling details in the case of *Stanev v Bulgaria* (no. 36760/06, ECHR 2012). Only recently, in response to advocacy efforts of civil society organisations and in order to comply with the CRPD, have some postsocialist countries revised their legal capacity provisions (Turnpenny et al. 2018). For example, a new Civil Code in Hungary has made it possible to get supported decision making, and similar legislative reforms are currently underway in Bulgaria. The translation of these legislative changes into actual policies and practices remains to be seen.

The impact of the state socialist approach of segregated provision on disabled people's social standing and participation was pernicious (Mladenov 2018). According to Tobis (2000, 10-11), the legacy of state socialist residential care in the postsocialist region of CEE and the former Soviet Union included 5 500 large residential care facilities hosting approximately 820 000 children with and without impairments, in addition to 1 392 care homes for disabled adults and old people in the former Soviet Union alone (data for institutionalisation of disabled adults in CEE is not provided). The cultures and practices in these facilities resembled the features of Goffman's (1974) 'total institutions' by subjecting residents to surveillance, constant control, depersonalisation and bloc treatment (Tobis 2000, 11). This coercive, marginalising, over-controlling, patronising and degrading system proved very difficult to dismantle or reform. It survived the demise of state socialism and decades after 1989, it has continued to be a major source of injustice by shaping the organisation, culture and policy of disability support in the postsocialist countries of CEE along the lines of segregation, confinement, subjugation and stigma (Holland 2008; Mansell et al. 2007; Phillips 2012). In a recent critique of post-Soviet institutions, Šumskienė and Orlova (2015, 383) have emphatically linked cases of sexual violence, forced sterilisations and involuntary abortions to unreformed treatment regimes dating back to state socialist times:

The inherited norms of the system of Soviet psychiatry ('drugging people', 'isolating, segregating', 'staff corruption' and stigma) are described as the most powerful factors. These constantly reproduce the existence of 'dehumanized people', extreme cases of human rights abuse (forced abortion, sterilization, rape), and general tendencies to isolate the 'unwanted people'.

### **Postsocialist neoliberalisation**

Since the 1990s, the postsocialist countries in CEE have been subjected to neoliberal reforms including privatisation, deregulation, decentralisation,



fiscal austerity, and welfare-state retrenchment (Dale 2011; Ferge 1997a; Mladenov 2015; Smith and Rochovská 2007). Such reforms had a negative impact on the living conditions of institutional residents and the working conditions of their carers (Tobis 2000, 31 and 32; World Bank 2003, 24). Insider accounts of life in residential institutions during the years of post-socialist 'transition' often amount to horror stories – consider this description taken from the landmark case of *Stanev v Bulgaria* that depicts the conditions in a Bulgarian institution for people with intellectual and psychosocial impairments during the 2000s:

the 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. (*Stanev v. Bulgaria*, no. 36760/06, § 20, ECHR 2012)

Rusi Stanev, the applicant in the case, was placed in this institution against his will, on the basis of unreformed guardianship legislation – another element of the state socialist legacy that, as we already pointed out, has continued to shape disability policy under postsocialism, facilitating institutionalisation. The institution where Stanev spent involuntarily many years of his life was located in an isolated mountainous region, 8 km from the nearest village and some 400 km from Stanev's home town.

Considering the CEE region as a whole, diminishing welfare services were unable to tackle the social crisis arising from new market rules (Szikra and Tomka 2009), characterised by, among others, surging unemployment and falling household incomes. Standards of living underwent 'unprecedented peacetime deterioration' (Tobis 2000, 20). In many postsocialist countries of CEE, cuts to public services and welfare benefits have been systematically imposed since the 1990s (Ferge 1997b; World Bank 2003). Over the decades of 'transition', such cuts have been justified not only by economic necessity but also by the neoliberal ideology of the 'minimal state' – for example, unemployment benefits have been reduced to incentivise people to return to work, and social assistance has been retrenched to encourage self-reliance and eradicate 'dependency culture' (Ferge 1997b; Grigorova 2016). Furthermore, disabled people and their families experienced even lower living standards than the general population, which additionally pressurised them to seek institutional care – 'the 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; see also Tobis 2000, 23). Similarly affected were older people (a group overlapping to some extent with the one of disabled people), who:

have traditionally relied on family support, which has diminished following the breakup of the Soviet Union. As a consequence, and also because of falling pension rates, many older people have been left without income or support. This has led to an increase in the number of older people being institutionalised. (EEG 2012, 33)

Ideologically and politically, postsocialist neoliberalisation did little to change the approach of segregated provision and the associated attitudes and practices. Indeed, the convergence between key principles of neoliberal marketisation – to wit, consumer empowerment through privatisation of services and competition among service providers – and the Independent Living movement’s advocacy for choice and control through monetisation of support facilitated important gains for disabled people in Western Europe in the 1990s, including the adoption of landmark personal assistance/direct payments legislation in Sweden in 1994 and in the United Kingdom in 1996 (Mladenov 2016). Thus:

The campaign for deinstitutionalization converged with the neoliberal critique of centralised, one-size-fits-all, state-administered social care and the concomitant promotion of flexible, localised (decentralised), market-based and individually tailored social policy solutions. Neoliberals and the DPM [disabled people’s movement] were in agreement on several important points (Roulstone and Prideaux 2012, 46): that institutions had a disabling influence on the people accommodated in them; that institutions provided poor value for money; that individuals should have more opportunities for self-determination, choice and control; and that the state should interfere less with disabled people’s lives. (Mladenov 2015, 452)

Although such a convergence was not complete – neoliberals, for example, favoured informal care in the family, whereas disabled activists criticised it as enhancing dependence (Roulstone and Prideaux 2012, 46) – it nevertheless enabled reform in Western Europe. However, the postsocialist countries of CEE remained reluctant to launch deinstitutionalisation programmes until the late 2000s and in the rare cases when direct payments legislation was actually adopted (as, for example, in the Czech Republic in 2006), the funding provided for personal assistance was insufficient, prompting many disabled people to stick to traditional, segregated services (Šiška and Beadle-Brown 2011: 129).

The ‘privatization by NGO [non-governmental organisations]’ (Harvey 2005, 177) – another aspect of neoliberalisation that shaped social transformations in the postsocialist CEE – had a meagre effect on the development of community-based services as alternatives to the state-run facilities inherited from socialist times. Indeed, many service-providing NGOs emerged in CEE in the aftermath of 1989, introducing more person-centred and inclusive disability support, as compared to the old, segregated options. Although such initiatives were beneficial to some disabled people, they remained small-scale and unsustainable due to their dependence on external, project-

based and/or decentralised funding (Mladenov 2018, 90–93). On its behalf, the Independent Living movement in CEE remained weak and isolated from broader disability coalitions at home, while the latter often failed to meaningfully challenge the status quo (Mladenov 2009; Fröhlich 2012; Holland 2008).

Following the financial crisis of 2008, welfare budgets were subjected to additional cuts in most CEE countries, which severely worsened the access to social and health services for disabled people and further diminished their already low disability-related social security benefits (Hauben et al. 2012). As an example, the dismantling of the Hungarian welfare-state accelerated in 2010, when a new right-wing government was elected. Here, neoliberal retrenchment included the centralisation of social services, upward redistribution to the middle and high income households, and the introduction of a new workfare regime with curbed disability benefits and pensions (Scharle and Szikra 2015). Harsh sanctions were imposed – social assistance was tied to participation in public work programmes and those who failed to fulfil these criteria could be excluded from certain social benefits for up to 12 months (Scharle and Szikra 2015: 315 and 316). Post-2008 austerity, regarded by many as intensification of neoliberal governance (Konings 2018), has contributed to continuing institutionalisation, including through direct and indirect cuts to personal assistance schemes where such had been available (for a Bulgarian example, see Mladenov 2017).

In the postsocialist CEE, these negative effects of austerity have to some extent been offset by EU funding. However, such resources have often been channelled along the familiar lines of institutional care rather than used for strengthening or setting up of community-based alternatives such as personal assistance. We discuss these trends in the next section.

### **The European Union and deinstitutionalisation in the postsocialist CEE**

Reports and analyses often showcase as leaders in deinstitutionalisation reform in Europe the Nordic countries, particularly Sweden, as well as the United Kingdom (EEG 2012, 22). There, deinstitutionalisation has been systematically pursued since the 1980s, driven by the factors mentioned at the beginning of the preceding section, including disabled people's activism, critical social science, normalisation and neoliberalisation. As a result, major legislative achievements in the 1990s have provided disabled people with community-based alternatives to institutional care, including user-led personal assistance (Mladenov 2015, 2016). After the fall of the Berlin Wall in 1989, the former state socialist countries of CEE gradually opened up to the values, visions and practices that had already enabled deinstitutionalisation

in some of their Western European counterparts. However, the decisive boost for the reform came with the accession of CEE countries to the EU (Phillips 2012), with Estonia, Latvia, Lithuania, Poland, Czech Republic, Slovakia, Hungary and Slovenia joining in 2004, Romania and Bulgaria in 2007, and Croatia in 2013.

The policy of deinstitutionalisation has been promoted by the European Commission since the early 2000s (Mansell et al. 2007, 3). Initially created in response to lobbying and advocacy on behalf of pan-European disability organisations such as the European Network on Independent Living, the European Disability Forum, and Inclusion Europe, deinstitutionalisation has later been advanced in order to conform to international disability rights legislation such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD), ratified by the EU in 2010 (Parker and Clements 2012; Quinn and Doyle 2012). As a recent pinnacle of these policy developments, the EU Disability Strategy 2010–2020 has committed the EU to:

promote the transition from institutional to community-based care by: using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people. (European Commission 2010, 6)

In parallel with their economic integration into the EU, most CEE countries have also made their legislation increasingly compatible with the EU legal order or *acquis communautaire*, which meant that new non-discrimination laws and other policies have been adopted across the region (Lewis 2002; Wiener and Schweltnus 2004). EU's cohesion and pre-accession funds have also been made available for projects targeting disabled people, including deinstitutionalisation programmes and initiatives. Over the last decade or so, it is these new legislative and financial frameworks that have been shaping disability policies and services in the region. On the one hand, some countries have been developing and implementing deinstitutionalisation strategies and progressive legal capacity legislation (Kozma and Petri 2012). On the other hand, evidence has demonstrated that merely symbolic legal adaptations have repeatedly failed to realise meaningful changes in actual policy and practice (Kozma and Petri 2012; Phillips 2012; Turnpenney et al. 2018; Walker 2011).

Currently, a key resource for the process of deinstitutionalisation in CEE are the European Structural and Investment Funds (ESIFs). According to official regulations, guidelines and reports, ESIFs should not be used for building new residential institutions or renovating the existing ones, except in extraordinary, life-threatening circumstances and in the context of ongoing efforts at deinstitutionalisation (Parker, Angelova-Mladenova, and Bulic 2016, 43). Instead, these resources should be used to promote independent living and

inclusion in the community, as stipulated in Article 19 of the CRPD. The measures envisioned by the EU for this transition to community-based services include ‘training human resources and adapting social infrastructure, developing personal assistance funding schemes, promoting sound working conditions for professional carers and support for families and informal carers’ (European Commission 2010, 6). EU funds could be particularly helpful for covering heightened ‘transition’ costs – such as capital investment and double running costs – that characterise the initial stages of deinstitutionalisation (EEG 2012, 102 and 103).

Given the abundance of various legislative texts including EU and member state laws and policies, and further UN and civil society guidelines, it is not surprising that the understanding and interpretation of these quasi-regulations is problematic. The scope of this article does not allow us to review the plethora of documents that inform policy-makers and advocates in how they plan, implement and monitor deinstitutionalisation programmes in the CEE region. However, it must be noted that the tracking and deciphering of various legal texts 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. As noted in an earlier report on disability advocates’ engagement with human rights texts:

if special expertise or highly educated ‘experts’ are needed to even talk about human rights then emancipatory knowledge may remain inaccessible to those who most need it (Petri, Beadle-Brown, and Bradshaw 2017a, 11).

Against this complex legislative background, EU and public funds have in practice often been allocated to refurbish old and/or to establish new residential institutions in a number of CEE countries (Human Rights Watch 2016; Kozma et al. 2016; Parker 2010; Šumskienė et al. 2015). In effect, the results of EU-driven deinstitutionalisation programming have been different and sometimes antithetical to the ones anticipated in official documents such as the EU Disability Strategy 2010–2020, with many efforts at deinstitutionalisation eventually ending up with re-institutionalising policies, cultures and practices (CIL 2013; Deneva and Petrov 2016; Phillips 2012, 31; Kozma et al. 2016).

### **A closer look at the current situation ‘on the ground’**

Mediated by the two historical factors of state socialist legacy and postsocialist neoliberalisation, deinstitutionalisation reform in CEE has proceeded with great difficulty. It has been estimated that during EU’s 2007–2013 programming period, at least 150 million Euros were spent for maintaining or expanding institutional care for disabled people in Hungary, Latvia, Lithuania, Romania and Slovakia (Parker and Bulic 2013, 11 and 12). In 2012,

the Open Society Foundations submitted a petition to the European Parliament complaining about the ‘illegal use of EU Structural Funds (principally the European Regional Development Fund) by some Central and Eastern European (CEE) Member States that have invested the funds in long-stay residential institutions which perpetuate the unjust, inappropriate and long-term social exclusion of people with disabilities’ (Open Society Foundations 2012, n.p.). Another widespread practice in the CEE region – and one that has similarly fed on EU funds – has been to move people from large to small residential institutions (Parker, Angelova-Mladenova, and Bulic 2016).

Let us emphasise that although scaling down of residential settings and relocating them towards community centres could potentially humanise them, this does not (in itself) eliminate relations of devaluation, dispossession and disempowerment embedded in institutional practices or cultures. Small settings often reproduce institutional ills such as surveillance, rigid routines, bloc treatment, objectivation of service users, social isolation and stigmatisation. According to the European Network on Independent Living (ENIL), a leading critic of this process of re-institutionalising deinstitutionalisation in the EU, ‘[t]he overreliance on “small group homes”, “family-type homes” and “protected housing” is likely to lead to the continued segregation of people with disabilities from the community’ (Parker, Angelova-Mladenova, and Bulic 2016, 49). In its review of the EU-funded Operational Programmes developed by Bulgaria, Estonia, Hungary, Latvia, Lithuania and Slovakia for the current 2014-2020 programming period, ENIL has exposed plans to renovate existing institutions or to develop smaller ones (Parker, Angelova-Mladenova, and Bulic 2016, 35). On the other hand, neither personal assistance, nor development and/or adaptation of social housing have been prioritised.

### **Hungary**

The current plans for further deinstitutionalisation in Hungary, funded by the EU Structural Funds with a staggering 250 million Euros (Magyar Kormány 2018), have been criticised by both Hungarian and international NGOs for issues such as the remote and isolated locations and size of new residential facilities which will likely maintain institutional culture. In a press release issued in late-2017, ÉFOÉSZ, the national umbrella organisation representing people with learning impairments and their families, asked the government to withdraw and redesign the whole programme:

Analysis of the [present] project plans reveal, without doubt that these investments do not aim at developments that allow the full and meaningful participation of people with learning disabilities in society. Rather, [the investments] aim to

preserve the former system of large institutions and other services. (ÉFOÉSZ 2017, n.p.)

Deinstitutionalisation was launched by the Hungarian government as late as 2012. Throughout the 1990s and 2000s, residential institutions remained the dominant type of disability services. Government policies of the time aimed at modernisation of institutions and recognised ‘small group homes’ as modern or ‘new’ types of services (Hungarian Parliament 1998). NGOs of parents of people with intellectual impairments and/or autism successfully acquired (both public and private) funding in the late 1990s and 2000s to build group homes, usually for 8 to 12 residents. Similar group homes were also built within the grounds of institutions. By 2013, around 10% of all residential beds were found in such smaller settings, while people living in the community had little to no access to support services (KSH 2015). Despite the fact that parents’ NGOs successfully lobbied for policy changes in other areas – such as better education for autistic children (Balázs and Petri 2010) – the government’s reluctance to launch deinstitutionalisation received only sporadic criticism throughout the 2000s. Meanwhile, the Hungarian government continued to fund occasional renovation projects of institutions.

Hungary’s ratification of the CRPD in 2007 opened up an opportunity for concentrated lobby for deinstitutionalisation and for the development of community-based services. In 2008, when the government published the draft of an EU-funded programme that aimed at large-scale investment into existing institutions (including renovation, extension and the development of new buildings), the proposal met vocal criticism by various NGOs and academic bodies. Critiques cited Hungary’s obligations to comply with Article 19 of the CRPD. As a result, the government withdrew the proposal (Bugarszki et al. 2010). Government experts and civil society actors also used the CRPD as a ‘lobby tool’ in inter- and intra-ministerial negotiations during the planning of the EU Structural Funds programming period 2014–2020, to commit to deinstitutionalisation (Kozma et al. 2016). Eventually, the country’s first deinstitutionalisation programme was launched in 2012 aiming at the partial closure of six residential institutions, effectively moving out 600 residents to smaller settings, and the government also set out plans for a 30-year deinstitutionalisation strategy.

However, the first projects between 2012–2015 resulted in mixed outcomes. Here, both legal frameworks and programme implementation resulted in redirection of EU funds towards the development of institutionalised structures. For example, a new legislative category was created by an amendment of the Social Act of 1993 that was supposed to develop a new form of community service named ‘supported living’ (in Hungarian: *támogatott lakhatás*). However, under the amended legislation, ‘supported

living' services include living arrangements such as 'houses and flats for seven to twelve people' and 'compound settings of flats or buildings for up to 50 people' (Social Act of 1993, 75(5)). Consequently, most of the new residential settings (called 'supported living' in government papers) that opened after 2015, are typically for 6, 8 or 12 people, with most of the residents sharing a room with another person (Nagy et al. 2017). Parallel to building these facilities, so-called 'living centres' for up to 25 residents were also established. These centres became responsible for service delivery for the new residential settings, thereby maintaining structures largely similar to the institutional ones: both support services and living space were run and maintained by staff of the former institutions. Furthermore, programme implementation was accompanied by watchdog reports on overestimated infrastructural costing that favoured profit-making over careful planning based on residents' needs (Verdes 2015).

Monitoring revealed only symbolic and tokenistic involvement of disabled people's organisations in the deinstitutionalisation process (Kozma et al. 2016). When choosing their place of living in the new facilities, residents' preferences were often displaced by other considerations such as type of disability, level of support need, age, gender or the opinions of guardians (Nagy et al. 2017). Studies suggest that the newly established small group homes maintain elements of both institutional culture and community-based services – although many residents enjoy relatively greater degrees of freedom (e.g. several new settings have an 'open door' policy) and more opportunities for contact with the community, the lack of services such as personal assistance and employment in local communities seriously limits their options to meet others, eventually isolating them (Nagy et al. 2017).

Importantly, the Hungarian deinstitutionalisation programme, despite all its references to the implementation of the CRPD, does not include investments into community-based services. This results in a narrowly-understood approach focusing mostly on the reorganisation of selected institutions and delivering no improvement in the lives of disabled people and their families living in the community. As one government official stated, '[we are] chopping up one big cube into several small cubes' (Petri and Kozma 2017b). Therefore, the first phase of the Hungarian deinstitutionalisation reform was more akin to a large-scale infrastructural investment aiming at the exploitation of available EU-funding while making no impact on community support services.

This contradiction also means that some residents in group homes may get more support or opportunity to form peer relationships than either those in large institutions or disabled people living with their families, simply



because support services outside residential settings such as personal assistance are scarce. As one study observed:

Those with a learning disability or with severe and multiple disabilities who live in the community with their families are far the most disadvantaged – not because of the support they get from their families, but because both the availability and the content of available support services are unsatisfactory. (Bernát et al. 2017, 34)

## **Bulgaria**

Recent reports produced by the Bulgarian disabled people's organisation Centre for Independent Living – Sofia (CIL – Sofia) corroborate the Hungarian findings and trends, adding disturbing details. The process of deinstitutionalisation in Bulgaria commenced in the late 1990s – early 2000s, prompted by EU accession efforts, but received a real boost in 2007, with the airing of a BBC 4 documentary about the inhuman and degrading treatment of children in a social care institution in the Bulgarian village of Mogilino (Angelova 2008). Since then, a number of new facilities such as 'centres for family-type placement' and 'small group homes' mushroomed around the country, ostensibly as alternatives to traditional residential institutions.

However, CIL – Sofia's researchers Deneva and Petrov (2016) have characterised the practices and cultures within these new settings as approximating those in the old facilities they were supposed to replace. Examples include: staff members making unilateral decisions for the residents, including about activities, rooms and roommates; the residents not being provided with (copies of) signed contracts, needs assessments, individual plans and other personal documents; residents rarely making contacts with people outside the premises; guests needing to sing in; leaving the premises being allowed only after approval from a member of staff and for a set period of time; CCTV cameras being used (even in bedrooms) to keep residents under surveillance; staff members discussing residents in the latter's presence; and so forth. Deneva and Petrov (2016) have also identified a lack of community services such as personal assistance (preventing those who need it from engaging in individual activities in the community), peer support, social and/or accessible housing, and integrated employment opportunities. In effect:

The large institution in the small village turns into a small institution in the big town; the space of the large institution (bedrooms, kitchen, dining room, living rooms) turns into the same rooms but within two separate buildings – the bedrooms, kitchen and dining room, into the CFTP [centre for family-type placement], the living room and another dining room – into the day-care centre [DC]. The users are 'socially included' by being moved in the morning from the CFTP into the DC, and back in the evening – that is, if there are transport and attendants available. (Deneva and Petrov 2016, 20)

An earlier report published by CIL – Sofia (CIL 2013) highlighted similar problems, including paternalistic attitudes of the staff, bloc treatment of residents, top-down decision-making, lack of choice on the everyday level, and isolation from the larger community. The corollary is that ‘comfortably hidden under the camouflage of “deinstitutionalisation”, behind the back of the European observers and beyond the scope of the media interest, *reinstitutionalising models get cloned in Bulgaria*’ (CIL 2013, 1, original emphasis). The report also emphasises that the Bulgarian legislation enables re-institutionalising deinstitutionalisation by defining the new residential settings as ‘services in the community’ – a category that the Regulations for Application of the Social Assistance Act (Article 36) apply both to new residential settings and to personal assistance, which undermines the essential difference between these two modes of public support (CIL 2012, 17 and 18). Such blurring of categorical boundaries has been a major barrier before the efforts at reforming the deinstitutionalisation reform in Bulgaria, despite the country’s ratification of the CRPD in 2012.

Thus, the channelling of EU funds towards institutional care ‘on the ground’ (instead of using the funds to set up community services such as personal assistance, to provide accessible and affordable housing, etc.) has been enabled by flawed definitions included in domestic legislation. Such definitional deficiencies are linked to a general lack of understanding of independent living, itself rooted in unreformed state-socialist approaches to disability – consider that, similarly to the situation in Hungary, the new institutions are usually staffed by people who had worked in the old institutions (CIL 2013, 11 and 12). The profit-making imperative has also been a key driver, with ‘bricks and mortar’ generating highest return on investment and therefore attracting most interest – developers have reported net profits in the range of 40–50 percent per year on investments worth up to half a million Euro (CIL 2013, 17).

## Discussion

To recapitulate, our analysis has suggested that deinstitutionalisation reform in the postsocialist CEE has been driven by legislative, political and funding agendas set by EU bodies and supported by human rights discourses, particularly the CRPD. However, these ‘external’ forces have been mediated by two ‘internal’ historical factors characterising the current situation in the CEE region – state socialist legacy and postsocialist neoliberalisation. As a result of such mediation, deinstitutionalisation reform has produced re-institutionalising outcomes, whereby refurbished and/or smaller residential settings have been posited as the default alternative to traditional institutional care. Institutional residents (often disabled children and young people during the

still unfolding initial phase of postsocialist deinstitutionalisation) have been re-accommodated in outwardly improved settings which, despite their arguably safer treatment regimes, better living conditions, reduced size and, in some cases, more central geographical location, have nevertheless reproduced key characteristics of institutional life such as depersonalisation, rigid routines and bloc treatment.

Re-institutionalisation is certainly not specific to the CEE region. Many Western European countries have been experiencing similar processes – for example, an analysis of statistical data from six countries (England, Germany, Italy, Netherlands, Spain and Sweden) has argued that a drop in the number of beds in residential psychiatric institutions may be followed by a slight rise in beds elsewhere in services systems, such as in forensic care, supported housing arrangements or even in prisons (Priebe et al. 2005). A more recent British report has asserted that despite decade-long efforts to personalise community support through various measures including personal assistance, direct payments, individual budgets etc., welfare systems can easily ‘slip back’ to institutional culture when welfare benefits and other means of social support are weakened due to neoliberal retrenchment (Duffy 2011). However, what differs in CEE countries is that systems of community support have never developed fully across the region, which still relies heavily on its state socialist heritage. Indeed, while re-institutionalisation in many Western European countries may be seen as taking steps away from previously developed systems of community-based services, re-institutionalisation in CEE is more akin to a failed effort to leave behind institutions themselves. The key stakeholders in the process have dismissed such re-institutionalising trends by focusing on superficial differences and disregarding internal commonalities between ‘new’ services and ‘old’ institutions.

The last point suggests that definitions of key terms such as ‘residential institutions’ and ‘community-based services’ are pivotal. Re-institutionalising processes and outcomes have been justified by defining residential institutions in terms of overt characteristics such as size (traditional institutions are large facilities confining tens to hundreds of residents) or physical location (usually, in the periphery, built in the outskirts of small towns and villages). However, reducing the size or changing the physical location of institutions has not been enough for effective deinstitutionalisation. Moreover, defining institutions by their overt characteristics has enabled the reproduction of institutional practices and cultures in smaller and less manifestly damaging settings located closer to community centres. It is therefore crucial to define institutions by focusing on more covert, mundane, internal features such as surveillance, deprivation of personal possessions, rigidity of routine, bloc treatment of the residents and so forth (CIL 2013; Deneva and Petrov 2016; EEG 2012).

As far as 'community-based services' are concerned, here the definitional struggle is deployed on the boundary between these services and 'residential services in the community', as demonstrated in the Bulgarian case discussed earlier (CIL 2013). The advocates of deinstitutionalisation emphasise that community-based services should, in principle, enable equal participation in the community and independent living; they should be person-centred (rather than service-centred or provider-centred) and continuous (delivered for as long as there is a need rather than for as long as there is a budget); they should separate housing from support (i.e. support should not be attached to a specific residential arrangement and should follow the person); and whenever housing is provided, it should be dispersed (i.e. scattered throughout neighbourhoods) rather than clustered to avoid bloc treatment, segregation and stigma (EEG 2012, 83 and 84).

## Conclusion

Can the reform of deinstitutionalisation in the postsocialist CEE be reformed? Can the gap between the disability rights agenda promoted by the EU and the agendas of its member-states, or between abstract international human rights instruments and concrete national policies, be bridged? Based on our foregoing analysis, several points need to be taken into account in answering this question. On the one hand, we highlighted the historically contingent structural forces blocking or diverting the efforts at deinstitutionalisation in CEE. We mentioned the patterns and mechanisms of paternalism, medicalisation, productivism and maldistribution, and we explored their genealogy by looking at state socialist legacy and postsocialist neoliberalisation. On the other hand, by drawing on reports produced by Hungarian and Bulgarian disabled people's organisations, we highlighted critical responses to flawed postsocialist deinstitutionalisation reforms generated by local actors, in defiance of structural determinations.

We also highlighted the top-down character of the pressures at deinstitutionalisation that have tended to flow from the EU bodies and international human rights instruments towards national and local constituencies in the postsocialist member-states. Such pressures may be welcomed by local actors – particularly by those critical of national policy frameworks and developments – but they may also be experienced as disempowering by the grassroots. Research has shown that 'some advocates and self-advocates feel they are "not competent" to talk about human rights because of the level of expertise it requires, which implies that they feel disempowered when they are expected to use human rights as an advocacy tool' (Petri, Beadle-Brown, and Bradshaw 2017a, 16-17). Professionalisation and specialisation alienate EU bodies and human rights discourses from their social bases and need to

be countered by re-energising the grassroots in order to preserve the legitimacy and efficacy of international agreements.

As suggested in the 'Discussion' section, one prominent aspect of deinstitutionalisation reform that could potentially reconcile the two levels is the ongoing struggle over the definitions of 'residential institutions' and 'community-based services'. When such definitional struggles are waged at the domestic level (e.g. CIL 2013; Deneva and Petrov 2016), this could potentially translate top-down pressures for deinstitutionalisation into bottom-up mobilisations to change the terms of the debate or to establish control over its framing. However, the historical factors of state socialist legacy and post-socialist neoliberalisation have erected a number of structural barriers before the transposition of EU-level guidelines (EEG 2012) into effective domestic practices in the postsocialist countries of CEE. It may be the case that only a profound societal transformation could dismantle these barriers. From such a perspective, domestic definitional struggles may seem like a weak tactic – however, it is also a tactic that provides important clues about the strategies needed and the agencies involved.

## Acknowledgements

The authors would like to thank the two anonymous referees of the journal for their feedback which helped us improve the article.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 747027. This document reflects only the author's view. The Research Executive Agency of the European Commission is not responsible for any use that may be made of the information it contains.

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