

Deinstitutionalisation of children with disabilities: Process, progress and challenges in South-East Europe

Nikolina Milić,* Gresa Rasiti,** Esmā Latić,*** Melina Kalem**** and Muamer Fazlić*****

Abstract: *More than a decade since Albania, Bosnia and Herzegovina, Bulgaria and Serbia made a commitment to gradually close their institutions for children with disabilities, the process of exchanging institutional with family-based care seems to be stalling. These countries have an immediate Socialist/Communist past where, as some authors argue, there is a legacy of heavy institutionalisation of persons with disabilities that creates one of the key challenges related to ending disability-based deprivation of liberty of children in South-East Europe. Although some progress has been made, children with disabilities are still overrepresented in institutions, sometimes due solely to poverty and limited community-based support to families who would otherwise be able to take care of their children. This article seeks to explore the root causes of heavy institutionalisation of children with disabilities in South-East Europe while discussing the key challenges in the process of managing the transition from institutional care to community living in Albania, Bosnia and Herzegovina, Bulgaria and Serbia.*

Key words: *deprivation of liberty; children; children with disabilities; institutions; deinstitutionalisation; South-East Europe*

* Research Coordinator: Nikolina Milić; Master of Laws (University of Essex), Bachelor of Arts (University of Belgrade), Children's Rights Regional Officer for South East Europe at the Global Campus of Human Rights.

** MA in Human Rights and Democratisation (GCSEE/ERMA).

*** MA in Human Rights and Democratisation (GCSEE/ERMA).

**** MA in Human Rights and Democratisation (GCSEE/ERMA).

***** MA in Human Rights and Democratisation (GCSEE/ERMA).

This article is based on a paper prepared for and presented at the 2020 Global Classroom, a project of the Global Campus of Human Rights (September 2020).

1 Introduction

For decades the isolation and segregation of children with disabilities was a common practice in South-East Europe (SEE), with parents in many cases advised by authorities that their children would be better cared for in an institution. The discovery of gross human rights violations in residential institutions in SEE countries during the 1990s led to massive injections of emergency international aid to temporarily improve the situation (Axelsson et al 2004: 15). However, in most former socialist SEE countries, deinstitutionalisation would not become a policy priority until at least by the first decade of the twenty-first century. Moreover, available data suggests that the deprivation of liberty in residential institutions was even more often exercised in the post-Socialist period, with a sharp rise in the rates of infants and toddlers with disabilities in institutions (Tobis 2000: 24). Almost 20 years later the shift towards family-based alternatives and the commitment to close down institutions have not been realised. Although the overall numbers were reduced in some states, children with disabilities continue to be overrepresented in institutions.

To understand the process, status and challenges of deinstitutionalisation, the article explores comparative case studies of four countries in the SEE region, namely, Albania, Bosnia and Herzegovina (BiH), Bulgaria and Serbia. The United Nations (UN) Global Study on Children Deprived of Liberty revealed that children with disabilities constitute 77 per cent of all children in institutions in Serbia, while the numbers are also extremely high for BiH – 58,1 per cent (Nowak 2019: 190). According to the same source, the situation in Albania and Bulgaria is somewhat improved, with the overall number of children with disabilities being 25 per cent and 10,2 per cent respectively. However, this data should be cautiously scrutinised. For instance, the backbone of Bulgaria's deinstitutionalisation efforts are so-called small group homes, introduced as a community-based model of care. Hence, children placed in these facilities are not considered by the Bulgarian authorities as being institutionalised. On the other hand, these small group homes are far from community-based in the sense of the Convention on the Rights of Persons with Disabilities (CRPD) due to their inherited institutional mindset and institution-like treatment. The situation is similar to the so-called *la casa famiglia* in Albania and other comparable solutions in Serbia and BiH.

Similar Socialist or Communist pasts as well as political and economic turmoil during the transition to democracy have created many common challenges across the states here under review that still have to be addressed. The lack of adequate and available community-based services outside large residential facilities that would enable families to take care of their children, on the one hand, and negative legal and societal attitudes towards disability, on the other, seem to be a common characteristic

throughout the region. While statistical data to measure the reach of efforts aimed at reducing the number of children with disabilities in residential institutions is incomplete, the available sources suggest that children with disabilities in SEE are more likely to be deprived of their liberty in institutions than children who do not live with disabilities. Among children with disabilities, those with mental and intellectual impairments often spend most of their lives in institutions, which usually is the only available option because of a lack of alternatives.

The article first explains the main concepts around deinstitutionalisation and disability-based deprivation of liberty, relying on international and regional human rights standards. Second, it explores the root causes of both the institutionalisation and segregation of children with disabilities by providing an insight into the socio-historical background. Third, the article provides an overview of current legislation and its implementation shortcomings in Albania, BiH, Bulgaria and Serbia. Finally, the article presents an analysis of the deinstitutionalisation processes in these countries. Deinstitutionalisation is not possible without the existence of inclusive community-based services to families in which children with disabilities live. The reach of deinstitutionalisation efforts in this article, therefore, is measured not only by the number of children who were 'removed' from institutions, but also by the availability of community-based services, the number of children placed with families and similar. The conclusions rely on relevant primary and secondary sources. Primary data was obtained from several institutions in Serbia and BiH, the Bulgarian Ministries of Health and Social Care, and the Albanian State Social Services. Information was also acquired from a variety of international and non-governmental sources.

2 Replacing disability-based deprivation of liberty with community-based support

Deprivation of liberty occurs when a person is either restricted to a confined space or placed in an institution or other setting without the ability to leave on his or her own volition, by order of a judicial, administrative or other authority (Mendez 2013: para 27; OP-CAT article 4(2)). Hence, it is closely linked to the placement and confinement of children with disabilities in institutions of a social type. Yet, in practice children are not deemed deprived of liberty if their parents or legal guardians consent to their placement in such an institution (Liefgaard 2018 in Nowak 2019: 68). Having a disability should not in itself justify deprivation of liberty (CRPD article 14), while necessity and proportionality of such deprivation has to be evaluated by a judicial authority during a periodical review process (CCPR/C/GC/35). As emphasised by Catalina Devandas Aguilar, the first UN Special Rapporteur on the Rights of Persons with Disabilities, disability-based deprivation of liberty is a product of accumulated social

discrimination, which may be traced to inaction in implementing the fundamental rights of persons with disabilities (Devandas 2019: para 86). Due to the excessive use of psychotropic medications and the complete control exercised over their movements from early childhood (Devandas 2019: para 86), children remain unaware of any alternatives and often opt to stay institutionalised – even as adults.

Spending early childhood in an institution has grave consequences for a child's well-being and development. While the authors do not disregard the fact that maltreatment can also occur in a family-based setting, research shows that children with disabilities in institutions are more prone to experience abuse and neglect, the lack of essential services, lack of access to education, and have reduced ability to form meaningful relationships with caregivers (Pinheiro 2006; UN Human Rights Council 2012; Mendez 2015; Human Rights Watch 2016; Ijzendoorn et al 2020). Repeated studies since the 1940s have shown that the disturbance of attachment to a stable caregiver has a devastating effect on children (Ijzendoorn et al 2020). Aside from attachment disorders, institutional living may cause delayed cognitive and physical development, poor cognitive processing and the development of self-harming habits (Ijzendoorn et al 2020: 709-711). Evidence also shows that children living in institutions are 2,8 times more likely to be emotionally neglected than children living with families (UN Department of Economic and Social Affairs 2019: 207). Institutions are found to aggravate or even produce disabilities, leaving numerous harmful effects on a child's mental development and motoric skills (Browne 2009), while smaller group settings also prove detrimental to a child's growth and well-being (Dozier et al 2014: 200). Recent insight into small group homes in Bulgaria showed that while physical conditions of living in smaller settings are improved, the lack of active treatment and social interaction and habilitation persisted even in the most well-equipped facilities (Disability Rights International 2019). Therefore, it is important to emphasise that 'neither large-scale residential institutions with more than a hundred residents nor smaller group homes with five to eight individuals or even individual homes can be called independent living arrangements if they have other defining elements of institutions' (CRPD/C/18/1: 5). In this regard, some of the most usual, general characteristics are isolation and segregation; the rigidity of daily routines irrespective of personal will and preferences; the inability to choose with whom to live; a paternalistic approach in service provision; the supervision of living arrangements; and the obligatory sharing of assistants.

Children who are removed from an institution and placed in family-based care demonstrate a rapid improvement in their overall health condition, intellectual functioning and ability to develop a relationship with the caregivers (Browne 2009). On the other hand, being deprived of liberty in institutions from an early age has a long-lasting impact on

children. A recent study has shown that while replacing institutions with foster or nuclear family care is associated with a significant recovery in growth and cognition, other developmental outcomes such as attention deficit persisted (Ijzendoorn et al 2020). The lack of requisite care for and the use of intrusive measures on children with disabilities in residential institutions were recently recognised by the European Court of Human Rights as contrary to the prohibition of torture, inhuman or degrading treatment or punishment (*LR v North Macedonia*, paras 72-83).

The existing international legal framework provides a solid basis for ending the deprivation of liberty of children with disabilities. The basic right of every child to live with a family and to be included in the community without discrimination based on disability is enshrined in the Convention on the Rights of the Child (CRC) and CRPD. While CRC prescribes that deprivation of liberty could be used in exceptional circumstances, as a measure of last resort for the shortest period of time (article 37), the CRPD provisions imply that no institution is suitable for children with disabilities under any circumstances (CRPD/C/18/1). Disability experts argue that article 37 of CRC provides little or no protection for children with disabilities where community services have not been created for them (Disability Rights International 2017: 3). They repeatedly stress that children are placed in institutions due to the failure of the social service system to provide a more acceptable placement as well as to the failure of the state to establish community-based services for the support of families with children with disabilities. According to Save the Children, '[t]he very existence of institutions encourages families to place their children into care and draws funding away from services that could support children to thrive within families and communities' (Save the Children 2019: 2). In this regard, it is worth mentioning that maintaining residential institutions requires large amounts of funds, whereas it has been shown that it can be up to six times more costly than supporting family-based care (Hope and Homes for Children 2016).

The most commonly used 'justification' for the institutionalisation of children with disabilities stems from the medical model of disability, which suggests the need for 'specialised care' in institutions rather than living in a community (Devandas 2019). Such arguments usually are mistaking the state's failure to establish community-based support to families for the best interests of the child. In other words, the lack of community-based support services for families with children with disabilities does not mean that institutionalisation is in the child's best interests – especially if parents are indeed able and willing to take care of their children. The separation of children from their parents should occur only in extreme circumstances and as a last and temporary resort, when the child, for example, is in imminent danger of experiencing harm by his caregivers. It cannot be a substitute for the failure of states to establish appropriate support. The

Committee on the Rights of the Child (CRC Committee) clearly states that financial reasons cannot serve as a justification for separating children from their parents (CRC/C/GC/14: para 61). However, data acquired in this research will show that poverty is the most usual reason for persisting with the institutionalisation of children with disabilities in SEE.

3 Socio-historical root causes for disability-based institutionalisation in South-East Europe

Available data suggests that the placement of children with disabilities in large residential facilities was prevalent in the SEE post-Socialist countries. As many as 10 out of 15 countries with the highest number of institutionalised individuals have a socialist background (Mladenov & Petri 2019). The reasons for this may reside in the Communist perception of social formations that for more than 45 years shaped the reality of SEE countries. With a strong emphasis on productivity, society's attitude towards persons with disabilities was closely related to their (in)ability to work. This unique past has to be considered when seeking to explain the present-day challenges faced by post-Socialist countries.

For decades Albania, BiH, Bulgaria and Serbia relied on an overprotective state system in every sphere of life, including social protection. Socialist universal welfare systems nurtured the legacy of overprotective care for persons with disabilities who were considered ill and non-able objects in need of pity and humanitarian assistance (Dixon & Macarov 1992). In this context, disability was seen as an individual medical condition or pathology which should be cured by medical professionals. Persons with severe or combined impairments needing ongoing individual support were often directed towards institutional care (Axelsson 2004: 18). The institutionalisation of children with disabilities allowed caregivers to enter the labour market and promised to ensure more efficient contributions to the collective economy, thereby fostering a spirit of collectivism more generally (Popivanova 2009). Hence, parents would regularly be 'advised' to place their disabled child in an institution as soon as the child is born, leading them to believe that the child would be better off in an institutional setting (Popivanova 2009).

However, some Socialist countries, such as Serbia and BiH (both at the time part of Yugoslavia) were different from, for instance, Bulgaria and Albania. While social protection systems in the former Yugoslav countries were largely decentralised and relatively well-developed, systems in Albania and Bulgaria were highly centralised and dominated by large residential institutions (Axelsson 2004). However, compared to Bulgaria, Albania did not experience such a high rate of child institutionalisation. For instance, at the beginning of the 2000s Albania officially had approximately 1 200 children in institutions (UNICEF 2002: 3) whereas Bulgaria had 31 102

children (1,93 per cent of the overall child population) in 332 child care institutions (Raycheva et al 2004: 482). This phenomenon seems not to be related to the quality of community-based support in Albania, which was fairly underdeveloped and almost non-existing. Its explanation should be sought rather in the cultural specificity of Albanian society, in which community and family responsibility towards the most vulnerable sections of society is highly developed (Tobis 2000: 16).

Major political changes during the 1990s led to economic collapse in SEE, which took its toll on the provisions for the most vulnerable as social protection systems which collapsed one after the other. In Serbia, a political crisis led to international sanctions and severe inflation, driving the majority of its citizens into poverty. Persons with disabilities and their families were among the worst affected groups. Consequently, children were sometimes placed in institutions solely because of poverty (Čerimović 2016: 47). The situation in BiH was further aggravated by prolonged war-induced adversities, displacement and poverty. Many children were orphaned or seriously injured by war, while poverty and undernourishment also impacted them severely. Albania and Bulgaria had to deal with both economic collapse and social unrests that marked the end of the Communist regime. Being the last in SEE to denounce Socialism, Albania was in political turmoil while also facing inflation and poverty during the 1990s. Severe economic difficulties led to financial cuts in the social care system while legislation allowed children to be separated from their parents on the grounds of poverty. In 1996 alone, 992 children were placed in Albanian institutions (CRC/C/11/Add.27: para 237) despite reduced funding. Children in Bulgaria were in an even worse situation with hundreds isolated in institutions that had less than one euro per child daily to cover the costs of food, heating, health care and clothes (*Nencheva & Others v Bulgaria* 48609/06). Fifteen deaths in a remote Dzurkovo institution for persons with disabilities during the winter of 1996/97 was a devastating example of how Bulgaria failed to protect vulnerable children from serious and immediate threats, violating the right to life enshrined in article 2 of the European Convention on Human Rights.

During the transition to democracy, social assistance services in SEE were largely transferred to municipalities while the responsibility for residential institutions remained under the authority of the central government and its budget. Ironically, such a system created a financial incentive for municipalities to reduce their expenses by placing vulnerable individuals in residential facilities financed by other levels of government (Tobis 2000: 14) rather than developing community-based services that had to be funded from the municipal budgets. This contributed to the continuation of institutionalisation even during the 2000s despite normative changes that pushed for deinstitutionalisation. Moreover, decades of neglect and segregation caused deeply-rooted discrimination and prevailing social

attitudes stigmatising disability. Due to the non-existence of community-based support coupled with poverty, it is not surprising that many parents still perceive institutions as a viable option for providing care to their children with disabilities.

4 Overview of the legal framework for deinstitutionalisation of children with disabilities in South-East Europe

Countries reviewed in this article are parties to CRPD, CRC and most other major human rights treaties, including the European Convention on Human Rights and the revised European Social Charter. These instruments put a strong emphasis on the right of the child to live in a family, since it is the natural environment for the growth and overall well-being of children. The prevention of first-time separation, therefore, should be a priority and families are entitled to support so as to fully assume childcare responsibilities. Only in cases when a family environment is endangering the rights of the child can a child be removed from the family – provided that it is in his or her best interests, a measure of last resort and for the shortest possible period of time measured in days rather than months. Institutional placement should result in more appropriate placement as soon as possible. These obligations are no different for children with existing long-term physical, mental, intellectual or sensory impairments. The constitutions of the four SEE countries reflect their international obligations with ratified international treaties while giving these instruments higher legal strength over domestic legislation.

During the European Union (EU) accession process, SEE countries were pushed to reform their legal frameworks on disability and children's rights while also showing progress in practice. As a candidate and later a member state, Bulgaria relied heavily on the EU structural funds to facilitate its ongoing transition from institutional to community-based care, while its policies were governed by the European Strategy for Persons with Disabilities (2010-2020). The other three countries are still in the accession process: Serbia and Albania are candidate countries while BiH is a potential candidate. Although some work has been done to improve legislative frameworks and bring them in line with the *acquis*, EU reports on the accession progress reveal that persons with disabilities are among the most vulnerable groups for human rights violations in SEE. While supporting the improvement of the rights of persons with disabilities and their inclusion in society, the European Commission is still to ensure that support and funding to candidates as well as member states prioritises family integration, and that funds are not used to enable placement in residential settings (which violates both CRC and CRPD).

4.1 Albania

Albania relatively recently enacted legislation on inclusion and accessibility. The country amended its Social Care Services Act in 2016 and adopted the Children's Rights Protection Act in 2017, thereby recognising a child as a rights holder and reiterating the right of every child to live in a family environment. However, both acts were criticised by the Committee on the Rights of Persons with Disabilities (CRPD Committee) for utilising outdated and derogatory language on disability, contributing further to segregation and negative perceptions about disability (CRPD/C/ALB/CO/1: para 6). Most of the secondary legislation still needs to be adopted (European Commission 2019a: 29). The disability assessment system in the country has for a long time been based on an outdated medical model perceiving disability as an illness that should be treated (CRPD/C/ALB/CO/1: para 6). Only recently the authorities initiated a switch towards a bio-psychosocial assessment. However, this is only a pilot project in the municipality of Tirana covering merely around one-third of the Albanian population (European Commission 2020a: 92).

Negative perceptions of disability paired with the non-existence of efficient early identification and support services at the local level that should prevent family separation render the CRPD provisions in Albania without tangible effect (CRPD/C/ALB/CO/1). Some of the established services for the most vulnerable groups in Albania proved to have limited reach. Underdeveloped community-based services on the local level, including the lack of financial and human resources, contribute to critically low social care coverage in the country – only about 10 000 beneficiaries or 0,35 per cent of the population in 2019 (European Commission 2020b: 92). Although the decentralisation process is ongoing, local governments proved to be ill-prepared to undertake the provision of services, which leaves children with disabilities and their families at risk of not receiving any type of service (UNICEF 2018a: 19). The Children's Rights Protection Act stipulates the right of every child to have 'a sound physical, mental, moral, spiritual and social development and to enjoy an appropriate family and social life suitable for the child' (article 6), but it places a heavy burden on parents and legal guardians to follow mandatory procedures to access basic services (article 32). Moreover, as many as one out of three children with disabilities face discrimination in public services, such as health or social services, despite the specific legislative prohibition on discrimination (World Vision Albania 2019).

On the policy level, the National Action Plan for Persons with Disabilities (2016) envisages licensing ten non-state service providers, establishing three types of government-funded services and placing 150 children with disabilities with foster families by 2020 (target 3). A significant number of targets, sadly, were not set due to the lack of baseline data. The National Agenda for Children's Rights (2017-2020) has been criticised

for the absence of a holistic approach in developing community-based services and limited focus on health and education (CRPD/C/ALB/CO/1: para 15). While the real impact of these policies remains to be assessed, the monitoring of legislation and policy implementation in general is hampered by the lack of comprehensive, timely and disaggregated data (European Commission 2019a: 30; CRPD/C/ALB/CO/1; CRC/C/ALB/CO/2-4).

4.2 Bosnia and Herzegovina

The complicated post-war political organisation of Bosnia and Herzegovina (BiH) is standing in the way of comprehensive country-level legislation on the rights of the child as well as gatekeeping and the development of community-based support services. Three administrative units (Federation of BiH, Republic of Srpska, Brčko District) have their own set of laws and policies for the realisation of children's rights, while central government only defines the main principles of protection. Although the majority of children are still being placed in institutions by their parents and legal guardians (and neither by a decision nor review of a judicial body) it is important to stress the fact that low-level legislation permits the deprivation of liberty based on impairment, leaving the door open for forced institutionalisation of children with intellectual and psychosocial disabilities (CRPD/C/BIH/CO/1: para 26).

The rights of children with disabilities in BiH to different forms of assistance and support are enshrined in the Fundamentals of Social Welfare Act and more closely regulated by the three administrative units' laws. In the Federation of BiH, the Protection of Civilian Victims of War and Protection of Families with Children offers financial support exclusively to low-income families, leaving many behind this threshold. Those who manage to battle the complicated social system usually do not receive more than €100 per month. Similarly, in the other entity, Republic of Srpska, the Social Protection Act holds the threshold at 70 per cent of minimum disability degree (according to medical assessment) which triggers entitlement to in-home support. It is not surprising, therefore, that families with children with disabilities straddle the line of poverty due to insufficient support (Somun-Krupalija 2017).

The most important policy documents at the administrative unit level are the Federation of BiH's Strategy of Deinstitutionalisation and Transformation of Social Protection Institutions System (2014-2020); the Federation of BiH's Strategy for the Promotion of the Rights and the Position of Persons with Disabilities (2016-2021); and the Republic of Srpska's Strategy for Improving the Social Position of Persons with Disabilities (2017-2026). Similar to Albania, the reach of these documents is difficult to measure due to the non-existence of proper data collection, adequate indicators and benchmarks (CRC/C/BIH/CO/5-6: paras 9-10).

Additionally, the sustainability component of a number of established policies is missing. Many social security measures are project-dependable and limited by the lack of funding, inadequate procedures and a general lack of coordination (European Commission 2019b: 139; CRPD/C/BIH/CO/1: para 34; CRC/C/BIH/CO/5-6: para 33). All strategic documents acknowledge the lack of social support services in general. Nevertheless, rather than focusing on establishing community-based support to families, the 2014-2020 Strategy, for instance, sets the priority for capital investments at the establishment of a network of institutions for 'organised living of children and youth without adequate protection, persons with disabilities and older persons'.

4.3 Bulgaria

Children in Bulgaria can be placed in institutions only as a measure of last resort and not for longer than three consecutive years (Social Assistance Act, article 16). Specialised residential institutions for children were formally abolished, but *de facto* they still exist in the form of group homes for up to 15 children with disabilities under the auspices of the Ministry of Labour and Social Policy. Moreover, a significant number of children with disabilities are being placed in 12 institutions for medical and social care for children, which are managed by the Ministry of Health. As a measure of gatekeeping, Bulgarian legislation envisages community-based services to children with disabilities, that is, financial aid and the use of day care social integration, rehabilitation and early intervention centres. The Persons with Disabilities Act (2019) and the Personal Assistance Act (2019), however, link financial support to the poverty threshold which is updated annually, while those whose disability is estimated below 50 per cent are being left behind. It does not come as a surprise that children with disabilities and their families are recognised as one of the social groups most exposed to poverty and exclusion in the country.

The most important policy document guiding the deinstitutionalisation process in Bulgaria is the National Strategy Vision for Deinstitutionalisation of Children in the Republic of Bulgaria (2009) pledging *inter alia* to remove all children from institutions by 2025. The main objectives in the Strategy are related to increasing the child protection system's capacity while establishing a wide range of community-based services, closing down 137 institutions for children below 15 years and establishing a moratorium on placements of children below three years. Measures enlisted in the accompanying Action Plan (2010-2025) aim to prevent the placement of approximately 3 000 children annually in institutions and to develop an adequate legal framework to foster this transition and improve the effectiveness of child protection services. The Plan was criticised by experts for lacking a holistic approach and insufficiency of measures for prevention of primary family separation (National Network for Children

2016). It was furthermore condemned for the lack of a sustainability component for newly-created services and focus on the improvement of infrastructure rather than building the professionals' capacities (National Network for Children 2016).

4.4 Serbia

Serbia still does not have a comprehensive children's rights act. Instead, several dozen different, sometimes contradicting, legislative acts tackle the protection of children. An umbrella act, the Social Protection Act (2011), prohibits the institutionalisation of children under three years 'except in extreme and justified circumstances' with the consent of the competent minister (article 52). This deviation leaves a large margin of assessment to the executive power and contributes to the persisting institutionalisation of children with disabilities in the first years of their lives. The same legislative document prescribes that residential institutions for children may not exceed a capacity of more than 50 residents. Yet, five of the largest residential institutions where children with disabilities are placed nevertheless deviate from this provision.

The National Strategy for the Improvement of the Position of Persons with Disabilities and the National Plan of Action for Children both expired in 2015 without new strategies being adopted for the next five years. This indicates the lack of continuity in planning and coordinating services with adequate and sustainable financial support for persons with disabilities. Moreover, available data suggests that Serbia is still unable to systematically apply legislation in protecting persons with disabilities from confinement and deprivation of liberty solely on the basis of disability (Nowak 2019; Social Protection Institute 2020). The state's commitment to preventing institutionalisation by supporting families remained declarative, as the Financial Support to Families with Children Act (2018) failed to improve the situation of, *inter alia*, families with children with disabilities. This legal document should have been the basis of social protection and support to parents of children with disabilities by enabling them to take care of their children while holding a job. In fact, it seems to rather push them deeper into poverty by failing to provide wage compensation to parents who need to take leave to care for children (Fundamental Rights Agency 2020).

5 Deinstitutionalisation process: Persisting challenges and recurring patterns

Albania, BiH, Bulgaria and Serbia formally initiated the process of replacing institutional care with community-based support during the 2000s by enacting laws and policies that should have led to the gradual deinstitutionalisation of children. During the early stages, family-based care, gatekeeping, the development of inclusive services and civil society

participation were listed as priorities in this process. At the time there were officially 432 children with and without disabilities in institutions in Albania (CRC/C/11/Add.27: paras 237-239), 927 in BiH (CRC/C/RESP/85: 6), 12 612 in Bulgaria (CRC/C/BGR/2: para 66), and 2 175 in Serbia (CRC/C/SRB/Q/1/Add.1: para 37). The majority were children with disabilities; around 57,9 per cent in Albania (CRC/C/11/Add.27: para 313); 64 per cent in BiH (CRC/C/11/Add.28: para 207); and 54,1 per cent in Serbia (CRC/C/SRB/Q/1/Add.1: para 42). These numbers should, however, be taken tentatively. Due to inconsistent data collection, it is reasonable to assume that there were considerably more children in institutions. For instance, it is estimated that in 2004 alone, the numbers in Bulgaria were even three times higher with approximately 31 000 children placed in institutions (Save the Children et al 2004).

5.1 Albania

Statistical data provided by many different sources implies that the number of children living in institutions in Albania is the lowest in the region for years, largely owing to the cultural specificity of Albanian society. Non-consistent data collection and the lack of disaggregated data on the residential institutions' transformation process (piloted in 2015) hampers monitoring and the evaluation of guiding legislation and policies. According to some sources, the share of children with disabilities in Albanian institutions increased from 8,8 per cent in 2017 (CommDH(2018)15: para 26) to 10,2 per cent in 2019 (Nowak 2019). According to other sources, the number of children with disabilities in residential care in 2017 was even higher, at 19 per cent (Rogers & Sammon 2018: 58), thereby significantly decreasing by 2019. Nonetheless, all sources imply that children with disabilities are much more likely to end up in residential care and less likely to be deinstitutionalised to family-based care, usually remaining in institutions for the rest of their lives.

Albania opted to transform existing residential institutions to 'community services', which are simply smaller residential homes for up to ten children (*casa famiglia*) located sometimes within the same institutions that are being transformed. Although the physical conditions in which children reside are indeed improved, *casa famiglia* replicate institutional culture and contribute to the overall failure of closing down the institutions. The experience from other countries implies that such solutions, seen initially as temporary, most often become the ultimate solution and that children eventually do not end up living with their families or in their communities. Children residing in *casa famiglia*, however, are not officially considered institutionalised by authorities and the placement is also usually long-term.

The impact of the strategic documents on actual improvement of the community-based support to both children with disabilities and their families proved to be rather limited in Albania. It has been observed that 'the existing services and structures do not constitute a child protection system, but a *patchwork* of services and dispersed action' (Lai 2016: 11; CommDH (2018) 15: para 12). Poor inter-sectoral cooperation and inadequate financial resources planned for the established services, as well as the lack of clear leadership in the process, are some of the main reasons behind it (Lai 2016: 11; CommDH (2018) 15: para 12). Although foster care and kinship care services were progressively developed since 2012, children with disabilities represent only 4 per cent of children in this kind of alternative care, which constitutes a reduction of half compared to 2015 (Rogers & Sammon 2018: 57). In the period from 1 July 2019 to 1 July 2020, only five children were placed in family-based care, that is, returned to their biological families (State Social Services 2020).

While increasing the number of community-based services, the country failed to make it adequate and available to families and children. One of the main issues is the concentration of services mainly in large cities. The needs assessment in 2019 revealed that 34 per cent of all municipalities provide no social care services and 61 per cent of municipalities do not provide services for persons with disabilities (European Commission 2020: 93). At the same time, only around one-third of municipalities approved and budgeted for social care plans outlining the needs of vulnerable communities and the services that need to be established in response (European Commission 2020: 93). It is, therefore, not surprising that more than half of parents with children with disabilities report that the costs of accessing the services are 'unaffordable' or 'absolutely unaffordable' (World Vision Albania 2019).

The lack of financial and other support continues to be the determinative factor for persisting institutionalisation amidst normative changes. Compared to the EU average, the number of children under three years of age who grow up in formal care is significantly worse in Albania (European Commission 2020b: 24). The majority of children with disabilities in residential institutions in Albania still have one or both living parents. The reason behind their placement in institutions often is due solely to poverty and inadequate support (CommDH(2018)15; CRC/C/ALB/5-6: para 148). Studies have shown that the vast majority of families with children with disabilities (96 per cent) in Albania are generating a low or medium income, with many being near or below the poverty line (Voko & Kulla 2018: 48). Moreover, almost half of the country's population is at risk of poverty or social exclusion, which is more than double the EU average and the highest of any Western Balkan country and Turkey (European Commission 2020: 93).

Access to existing services continues to be a burden for families in the context of limited service provision, extreme poverty, vulnerability, discrimination and stigma (UNICEF 2018a: 108). Persons with disabilities and their families either believe that social protection services in their communities are missing or insufficient to meet their needs, whereas only 28 per cent are satisfied with these services (World Vision Albania 2019: 11). Only 7,8 per cent of children with disabilities benefited from social services, mainly in the cities, while 86,9 per cent of parents find official state support insufficient to meet the basic needs of their children with disabilities (Voko & Kulla 2018: 43). Ironically, the amended Children's Rights and Protection Act places the responsibility on parents and guardians to follow complex legal procedures assisted by (unspecified) child protection bodies only to then access the most basic services (Network of Disability Organisations 2019: 15). Tackling this issue seems to be the unavoidable link towards successful deinstitutionalisation and a family-based life of all children with disabilities.

5.2 Bosnia and Herzegovina

The situation in BiH is similar with regard to the availability and adequacy of social services. The country, however, has an even larger backlog in the deinstitutionalisation process due largely to a complicated political structure standing in the way of the successful implementation of its international obligations. Deinstitutionalisation in BiH seems to be a matter of verbal rather than actual commitment. It has been more than a decade of promises resulting only in the expansion of existing institutions some of which commit serious children's rights violations. The blatant example is the Pazarić institution for children with psycho-social and intellectual disabilities. Shocking photos were released showing children being tied to the furniture and radiators as a part of the established procedure at Pazarić (N1 BiH 2019). The public exposure of the case caused wide-range condemnation by both experts and the public (Council of Europe Commissioner for Human Rights 2019; *Sarajevo Times* 2019) although children's rights violations in the same institutions were not a novelty. Over the past ten years, the Ombudsperson's Office in BiH repeatedly stressed that the conditions in residential institutions throughout the country are below the standard of human dignity (Džumhur 2018).

Rather than moving children to family-based care, the number of children in institutions in BiH remained very high, implying systemic problems on many levels. According to the official statistics for 2016 and 2017, there were 1 079 and 1 018 children with disabilities in institutions respectfully (CRC/C/BIH/Q/5-6/Add.1: para 79). By 2018 there were 1 045 children with disabilities in institutions (Agency for Statistics 2019: 20), constituting 58,1 per cent of all children living in institutional settings in BiH (Nowak 2019: 190). The official statistics, however, do not cover

children with disabilities residing in institutions governed by religious and non-governmental organisations, making it impossible to get a clear image of the situation.

Similar to other countries in SEE, the majority of children with disabilities living in institutions in BiH are not orphans. Studies show that 72 per cent of children in institutions in the country have at least one living parent and that 40 per cent are institutionalised solely due to poverty (UNICEF 2017a: 27). Poverty is the most persisting social characteristic that fuels institutionalisation and hampers gatekeeping policies. The poverty rate in the country officially stands at 16,9 per cent (World Bank 2015) whereas even families with higher monthly incomes would find it challenging to cover all expenditures to care for their children with disabilities. Persisting institutionalisation, therefore, is a matter of inadequate or non-existent community-based support to families with children with disabilities. Investments in community-based services, thus, are the key for preventing separation and ending over-reliance on institutional care.

It cannot be said that BiH did not establish community-based services at all, but rather that these are not adequate to meet the basic needs of families and, in most cases, they are not available. For instance, in the two administrative units (Federation of BiH and Republic of Srpska) financial assistance for home-based care is 'reserved' for children whose disability is estimated at more than 70 and 90 per cent. This is according to the outdated medical assessment still in place. In the overall BiH budget for social assistance benefits, only one-quarter is granted based on needs assessment (that is, to persons with disabilities) while others are status-based benefits, reserved mainly for veterans with war-related disabilities (European Commission 2019b: 139). Long-term institutional 'care' for children with disabilities thus remains prevalent in the country. The CRC Committee has stated that the placement of children in institutions is being done without giving primary consideration to the child's best interests despite legislative obligations (CRC/C/BIH/CO/2-4: para 31). Moreover, the prospects for leaving care seem to be extremely low. In most cases, children would be erased from the statistics upon reaching the age of maturity. They are then considered adults and included in the adult statistics despite the fact that they often never leave institutional care despite a reduction in official statistical data.

Essentially, the system seems to leave children with disabilities and their parents without adequate support for community-based living. Without support, gate-keeping policies of preventing children with disabilities from being institutionalised in the first place are not conceivable. National legislation at all levels continues to utilise terminology that is not in line with CRPD, namely, treating disability as an illness requiring medical care. It lacks a human rights-based approach to disability and no efforts

are made to bring the legislation into full compliance with CRPD and CRC (CRPD/C/BIH/CO/1: para 9; CRC/C/BIH/CO/5-6). Furthermore, it aggravates discrimination and segregation in society. Universal and equal access to early childhood recognition and intervention services is not available to children with disabilities (CRPD/C/BIH/CO/1: para 14).

5.3 Bulgaria

Of all countries in the region for which data are available, Bulgaria had the highest number of infants in institutional care in 2009 (UNICEF 2012: 24). A series of systemic changes both in legislation and practice was initiated after the country was shamed into action by both media reports documenting serious human rights violations in institutions even during the 2000s. Relying heavily on EU structural funds, by June 2016 the country managed to reduce the number of residential institutions for children by nearly two-thirds (137 to 91). At the same time, the official number of children in institutional care decreased nearly six-fold, from 7 587 in 2010 to 1 232 (Kukova 2019), further decreasing to 633 at the end of 2018 (UNICEF 2018b). This is the reason why Bulgaria is often referred to as an example of good practice with regard to the deinstitutionalisation of children, not only in SEE but also wider. However, these numbers should be carefully scrutinised. While it is beyond doubt that Bulgaria made an enormous effort to close down large residential institutions, often called 'old orphanages', the number of group homes for up to 15 children in turn was sharply increasing. In only six years (2007 to 2013) 140 group homes for up to 12 children were built for 1 845 children with an inadequate effort to place them in family care (ENIL et al 2018). By 2015, 113 new homes were built to make a total of 253 facilities (Child Pact 2016). Similarly, around 65 per cent of children that were moved from institutions in the 2013-2015 period were placed in group homes and only 7,2 per cent were reintegrated into families or placed in foster care (Spirov et al 2015).

Group homes have similar characteristics to institutions despite not being considered by Bulgarian authorities as such. Although the conditions are much better than in large residential institutions, the quality of life of children remain unchanged as they still are not in control of their day-to-day activities and decision making, even when they reach adolescence and despite their capabilities. There is no prospect for them to move to the community and family-based arrangements (Rosenthal et al 2019). The dehumanising and dangerous conditions of children placed in group homes expose them to emotional neglect and physical dangers. This came to the public attention after a Disability Rights International report was published following the visit to several care homes in Bulgaria (Rosenthal et al 2019). The most consistent observation of the expert team in different facilities were the lack of active treatment, social interaction and habilitation even

in the cleanest and most well-staffed facilities. In 2018 the Human Rights Committee expressed its concern about 'continuing reports of violence against children living in institutional care and, in particular, about the 292 deaths of children between the ages of 0 and 7 during the period 2010-2014, which have reportedly not been investigated' (CCPR/C/BGR/CO/4: para 39).

By the end of 2018 there were 2 887 children with disabilities in small group homes (National Network for Children 2019: 37) or approximately 80 per cent more than the number of children with disabilities that Bulgarian authorities consider 'institutionalised' at the time. The official rhetoric is that there are no specialised institutions for children with disabilities in Bulgaria since 2015. Social services, including group homes, are deemed to have a significant role 'in supporting children and families, as well as in realising the process of deinstitutionalisation' (Social Assistance Agency 2020). Increasing numbers of children in group homes, paradoxically, caused the government to negotiate and plan their expansion. In September 2019, for the first time in history, three disability rights organisations initiated the proceedings before the EU Court of Justice against the European Commission for failing to halt funding being used by Bulgarian authorities for building institutions for persons with disabilities instead of financing community-based services (Case T-613/19).

What is more, mostly due to poverty and unavailability or inadequacy of community-based support, 3 800 children in Bulgaria continue to be separated from their families every year, with one-third being below three years old (Kukova 2019: 3). Families of children with disabilities often feel under pressure to place their children in institutions primarily due to economic reasons (Rosenthal et al 2019: 34). Even when children can access the support of a personal, social or domestic assistant, the provision of such services is limited in the sense of project-dependant financing and uneven availability throughout the country. Decisions on the admission often are not based on the individual needs of the child, but on the care that is or is not available in the service system (Rosenthal et al 2019: 27). The prospects of leaving residential care are low for children with disabilities. During the last decade, the number of institutions for medico-social care for children (IMSCC) within the Ministry of Health were reduced from 32 to 12. However, 406 children with disabilities remained in such residential care on 1 July 2020 (Ministry of Health 2019). More than 600 children under three years of age are being placed in IMSCC every year with 90 per cent being children with disabilities and one-fourth being younger than 12 months (Ministry of Health 2019). The National Association for Foster Care stated that at the end of 2018 there were 23,7 per cent of officially-approved foster families that did not have a child accommodated in it (Kukova 2019: 37). Among children in foster care, only 9,3 per cent were children with disabilities (Kukova 2019: 38). In the first six months

of 2020, only 46 children under three years of age were removed from IMSCC (Ministry of Health 2020). However, there is no information on whether they were placed in family-based care or other institutions.

5.4 Serbia

As previously stated, incomplete statistical data undermine the possibility to accurately assess the situation in Serbia. However, available data suggests that the country has a significant backlog in deinstitutionalisation, especially with regard to children with disabilities. They are among the most represented groups of children in institutions throughout the country despite efforts made. Serbia initiated the process of deinstitutionalisation in 2009 when the competent authorities, supported by UNICEF and other partners, developed the Comprehensive Social Protection Institutions for Children Transformation Plan (2009-2013). Strategic goals and benchmarks enlisted therein were later incorporated in the legislation governing social protection. Moreover, the Serbian Ombudsperson prepared a Deinstitutionalisation Roadmap in 2014, proposing nine stages for gradual deinstitutionalisation of persons with disabilities generally, including public awareness raising, legislative changes, monitoring as well as results evaluation.

In the initial phase, the overall number of children in institutions was significantly reduced. In 2011 there were 63 per cent fewer children in institutions compared to 2000 (UN Department of Economic and Social Affairs 2019: 207). By 2018 there were 50 per cent fewer children in Serbian institutions compared to 2009 (Social Protection Institute 2019: 14). However, a closer look at the statistical data reveals that children with disabilities were not deinstitutionalised at the same pace as children without disabilities. In 2011 the percentage of children with disabilities in institutions was reduced by only 37 per cent compared to 2000. In 2014 there were 837 children in Serbian institutions (Social Protection Institute 2014: 10) whereas 79,9 per cent of these were children with disabilities (Social Protection Institute 2019: 56). Six years later, at the end of 2019, although the overall numbers were reduced, 73 per cent of 647 children in 17 residential institutions were children with intellectual or physical impairments (Social Protection Institute 2020).

The evidence suggests that children with disabilities are disproportionately institutionalised and appear far less likely to benefit from efforts aimed at the transition from institutional to family-based care than their non-disabled peers. This is a common characteristic throughout the region. The average stay of 131 children with disabilities in one of the largest institutions in Serbia is 12 years, whereas in the last year no child was deinstitutionalised to family-based care (Kolevka 2020). Disability advocates are repeatedly stressing that even when numbers are reducing, this is not due to successful deinstitutionalisation but rather

as a consequence of reaching 18 and becoming a part of adult statistics (MDRI-S 2018). Some even continue to live in the same institutions, often life-long. According to the same source, this life path of persons with disabilities is a result of a poor normative framework, of the preservation of old and outdated attitudes among social care professionals and legislators, as well as low investments in the social protection system (MDRI-S 2018). Once institutionalised, 71 per cent of adults and 40 per cent of children continue to live in an institution for the rest of their lives without any serious review, in clear contradiction of international standards (MDRI-S 2019; A/HRC/40/59/Add.1: para 44).

Looking at the past 20 years, it seems that the achievements are limited and that residential care remains prevalent over family-based care. Similar to other observed countries, many children become separated from their parents and placed in institutions simply because of the lack of community-based support and services by families who are prepared to take care of their children born with disabilities (A/HRC/40/59/Add.1: para 45). During his recent visit to Serbia, the UN Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment observed that children with disabilities spend most of their time lying in cribs or metal beds with little or no human contact, except feeding, changing and weekly showering (A/HRC/40/59/Add.1: para 41). He also observed the lack of oversight and enforceable regulations regarding the use of physical restraints in institutions which might be used unnecessarily or disproportionately. A high number of cases of inhuman or degrading treatment in residential institutions indicates that children with disabilities, particularly those with intellectual impairments, are more likely to be victims of physical and sexual violence (CRC/C/SRB/CO/2-3: para 32).

Research into alternative care practices shows that, before separation, in half of the cases, no preventive gatekeeping measures whatsoever were taken (Petrušić 2019: 85). Although it should be the backbone of deinstitutionalisation, community-based support for people with disabilities in Serbia remains inadequate (CRPD/C/SRB/CO/1: para 13), lacking necessary funding and expertise to be effectively implemented (A/HRC/40/59/Add.1: para 46) even in cases when it is envisaged in legislation. In 2019 children constituted only 0,6 per cent of total beneficiaries of home assistance service (Social Protection Institute 2020). On the other hand, the use of personal assistants' service, which is rated as one of the best examples of community-based support, is increasing. Only in 2019, 1 328 children benefited from this service, presenting an increase of 49,7 per cent compared to 2018 (Social Protection Institute 2018: 53; Social Protection Institute 2020). However, community-based services often remain unavailable or insufficient at the local and municipal level (CRPD/C/SRB/CO/1: para 13) with the majority of services being offered exclusively in large cities.

6 Conclusion

Although some progress has been made, children with disabilities continue to be disproportionately represented among children in institutions in Albania, BiH, Bulgaria and Serbia. The UN Global Study on Children Deprived of Liberty revealed that Serbia still needs to do much given that children with disabilities constitute 77 per cent of all institutionalised children in the country. The other three countries analysed in this article, based on the Global Study findings, are doing somewhat better, with numbers being reduced to 10,2 per cent (Bulgaria); 24 per cent (Albania); and 58 per cent (BiH). A year since the publication of the Study, none of these countries, however, seem to have managed to significantly reduce the number of children with disabilities in the formal care system, thus depriving them not only of their liberty but also of their childhood and family life. Although overall numbers have decreased in Serbia, BiH and Albania, available data suggests that it was because the majority of children with disabilities simply became adults, thus excluding them from the official statistics on children. They often remained in institutions, usually even in the same institutions.

A common inherited Socialist legacy, political upheavals and economic and social adversities during the 1990s provide a socio-historical context that explains why deinstitutionalisation was so difficult in Albania, BiH, Bulgaria and Serbia. Moving from the legacy of a social welfare system that relied extensively on segregated and protective care system to a system promoting community-living and inclusion proved to be a fairly complex one. While legally committed to deinstitutionalisation, these countries often used funds to maintain or renovate institutions rather than to establish community-based support measures to families in order to efficiently prevent separation and institutionalisation. Moreover, despite the ratification of major international treaties for the protection of children, it seems that all of the observed countries continue to disregard these obligations – a fact that has also been acknowledged by the UN treaty bodies and special mandates, as well as watchdog organisations. The lack of high-quality, timely and reliable statistical data makes the situation even more disturbing.

The variety of both primary and secondary data presented in this article suggests that Albania, BiH, Bulgaria and Serbia have yet to establish adequate mechanisms to prevent the abandonment and institutionalisation of children with disabilities. An extremely high number of children with disabilities in institutions who still have one or both living parents willing to take care of them proves that poverty and inadequate support are among the main reasons behind persisting institutionalisation. Moreover, the lack of resources in the community and family support services seems to be a common characteristic throughout the SEE region. While some

community-based services have been established over the past years, they remain poorly funded, limited and concentrated in the large cities. The segregation and societal discrimination is another pressing issue, which is why these countries still need to engage in wide-range public awareness raising to combat rooted discrimination and stigma around disability in general.

Even though it might seem that Bulgaria is a pioneer in the deinstitutionalisation of children in SEE, available data suggests that the decrease in the number of children in institutions does not necessarily mean that children were placed with families. It rather suggests that they were placed in smaller group institutions that are wrongly presented as community-based formations. To that end, simultaneously with the reported decrease in numbers of children with disabilities in Bulgarian institutions, the numbers of children in group homes rose almost at the same pace. The fact that thousands of children continue to be separated from their parents every year bears evidence to the inefficiency of gatekeeping strategies in the country. The Bulgarian example shows that rather than solely closing down the institutions, the state must eliminate the need for institutions by investing in a family support network. Otherwise, large institutions will be replicated in smaller institution-like settings, failing to respect, protect and fulfil the rights of children with disabilities to live in a nurturing and loving family-based environment in line with their best interests.

Several studies reveal that the institutionalisation of children with disabilities in SEE countries often is not a measure of last resort, but the only option families have. The placement in institutions predisposes children with disabilities to specific forms of violence, and one of the best ways to prevent harm is to do everything possible to ensure that every child is supported to live with a family. In order to prevent initial family separation, targeted support must be given to those families most at risk of being unable to afford health care expenses and manage the constant assistance needed for a child with a disability. This is crucial for preventing institutionalisation, especially because the majority of children with disabilities in SEE countries, in fact, are not orphans. In addition to preventing initial family separation, it is crucial to also enhance the capacity of foster care for children whose best interests are not to remain in the nuclear family. If this is done, Albania, BiH, Bulgaria and Serbia could indeed successfully end institutional caring for children with disabilities. Otherwise, institutions will always remain the most common and optimal option and deinstitutionalisation will remain a never-ending process.

References

- Agency for Statistics of Bosnia and Herzegovina (2019) *Bosnia and Herzegovina in numbers 2019*, available at http://bhas.gov.ba/data/Publikacije/Bilteni/2020/NUM_00_2019_TB_0_EN.pdf (last visited 17 August 2020)
- Axelsson C, Granier P & Adams L (2004) *Beyond de-institutionalisation. The unsteady transition towards an enabling system in South East Europe* Belgrade: Disability Monitor Initiative South East Europe
- Browne K (2009) *The risk of harm to young children in institutional care* London: Save the Children UK
- Bulgarian Helsinki Committee (2017) *Alternative report about the rights of persons with disabilities in Bulgaria under the Convention on the Rights of Persons with Disabilities* Sofia: Bulgarian Helsinki Committee
- Bulgarian Helsinki Committee (2018) *Alternative report on the implementation of the International Covenant on Civil and Political Rights in Bulgaria* Sofia: Bulgarian Helsinki Committee
- Ćerimović E (2016) *It is my dream to leave this place: Children with disabilities in Serbian institutions* New York: Human Rights Watch
- Child Pact 'Bulgaria: Country Fact Sheet' (2016), available at <https://www.openingdoors.eu/wp-content/uploads/2016/12/country-fiche-Bulgaria-2016.pdf> (last visited 18 August 2020)
- Council of Europe Commissioner for Human Rights *Report by Dunja Mijatović following her visit to Albania* CommDH (2018)
- Council of Europe Commissioner for Human Rights 'Commissioner urges authorities of Bosnia and Herzegovina to investigate abuses in the Pazaric institution for children with disabilities' Statement 20 November 2019, available at <https://www.coe.int/en/web/commissioner/-/commissioner-urges-authorities-of-bosnia-and-herzegovina-to-investigate-abuses-in-the-pazaric-institution-for-children-with-disabilities> (last visited 19 August 2020)
- Crowther N, Quinn G & Hillen-Moore A (2017) *Opening up communities, closing down institutions. Harnessing the European structural and investment funds* Galway: Community Living for Europe Structural Funds Watch
- Devandas CA 'Rights of persons with disabilities: Report of the Special Rapporteur on the Rights of Persons with Disabilities (2019) A/HRC/40/54
- Dimitrov M 'Bulgaria still failing isolated disabled children report (2019), available at <https://balkaninsight.com/2019/11/21/bulgaria-still-failing-isolated-disabled-children-report> (last visited 25 February 2020)
- Disability Rights International (2017) *Comments and suggested revisions to the UN Committee on the Rights of Persons with Disabilities, Draft General Comment No 5: On the right of people with disabilities to live independently* Washington: Disability Rights International
- Dixon J & Macarov D (1992) *Social welfare in Socialist countries* Abingdon/New York: Routledge
- Doichinova M (2018) *From institutions to community living. Drivers and barriers of deinstitutionalisation. Case Study Report Bulgaria 2018* Vienna: European Union Agency for Fundamental Rights
- Dozier M et al 'Consensus statement on group care for children and adolescents: A statement of policy of the American Orthopsychiatric Association' (2014) 84 *American Journal of Orthopsychiatry* 3
- Džumhur J et al (2018) *Special report on the status of persons with intellectual and mental disabilities in Bosnia and Herzegovina* Banja Luka: Ombudsman for Human Rights in Bosnia and Herzegovina

- ENIL, Validity Foundation, Centre for Independent Living, Bulgarian Helsinki Committee 'Petition to the European Parliament concerning the use of the European Structural and Investment Funds to support deinstitutionalisation of people with disabilities in Bulgaria' (2018), available at https://enil.eu/wp-content/uploads/2019/04/CILPetiton_Fin_200918.pdf (last visited 13 August 2020)
- European Commission (2019a) *Albania 2019 report accompanying the document Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions 2019 Communication on EU Enlargement Policy* Brussels: European Union
- European Commission (2019b) *Bosnia and Herzegovina 2019 Commission staff working document: Analytical report accompanying the document Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions 2019 Communication on EU Enlargement Policy* Brussels: European Union
- European Commission (2020a) *Albania 2020 report accompanying the document Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions 2020 Communication on EU Enlargement Policy* SWD(2020)354 final Brussels: European Union
- European Commission (2020b) *Commission staff working document: Economic reform programme of Albania (2020-2022) Commission Assessment* SWD(2020) 70 final, 21 April 2020, Brussels: European Commission
- Fundamental Rights Agency of the European Union 'National contribution to the Fundamental Rights Report 2020' (2020), available at https://fra.europa.eu/sites/default/files/fra_uploads/serbia-frr2020_en.pdf (last visited 13 August 2020)
- Haxhiymeri E (2018) *Community-based services for children with disabilities: Best practices analysis* Tirana: Save The Children
- Hope and Homes for Children (2017) *Ending institutional care: Questions and answers* Wiltshire: Hope and Homes for Children
- Human Rights Council Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment on his visit to Serbia and Kosovo (2019) A/HRC/40/59/Add.1
- Human Rights Watch 'Children behind bars: The global overuse of detention of children' (2016), available at <https://www.hrw.org/world-report/2016/children-behind-bars> (last visited 13 August 2020)
- Ijzendoorn MHV et al 'Institutionalisation and deinstitutionalisation of children 1: A systematic and integrative review of evidence regarding effects on development' (2020) *The Lancet* DOI: [https://doi.org/10.1016/S2215-0366\(19\)30399-2](https://doi.org/10.1016/S2215-0366(19)30399-2)
- Kilkelly U & Liefwaard T (2019) *International human rights of children* Singapore: Springer Publishing
- Kolevka Home for Children with Developmental Disabilities Reply to the GCSEE/ERMA questionnaire, received on 9 July 2020 via electronic mail (2020)
- Kukova S (2019) *Country report on living independently and being included in the community Bulgaria* Brussels: Academic Network of European Disability Experts
- Lai A (2016) *Future of an integrated child protection system in Albania* Strasbourg: Council of Europe
- MDRI-S 'The recently reported deaths in social care institutions in Serbia are not isolated cases' 11 March 2019, available at <https://www.mdri-s.org/press-releases/the-recently-reported-deaths-in-social-care-institutions-in-serbia-are-not-isolated-cases> (last visited 18 August 2020)
- MDRI-S 'The situation of children and youth with disabilities in the social protection system. Challenges and opportunities' 21 August 2018, available

- at <https://www.mdri-s.org/press-releases/the-situation-of-children-and-youth-with-disabilities-in-the-social-protection-system-challenges-and-opportunities> (last visited 13 May 2020)
- Mendez J Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E Méndez (2013) A/HRC/28/68
- Mendez J Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (2015) A/HRC/28/68
- Mendez J (2017) *Protecting children against torture in detention. Global solutions for a global problem* Washington: Centre for Human Rights and Humanitarian Law Anti-Torture Initiative
- Ministry of Health of the Republic of Bulgaria Reply to the GCSEE/ERMA questionnaire, received on 30 July 2020 via electronic mail
- Ministry of Social Welfare of the Republic of Bulgaria (2020) Reply to the GCSEE/ERMA questionnaire, received on 23 July 2020 via electronic mail
- Mladenov T & Petri G 'Critique of deinstitutionalisation in post-Socialist Central and Eastern Europe' (2019), available at <https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1680341> (last visited 13 August 2020)
- Mulheir G 'Deinstitutionalisation: A human rights priority for children with disabilities' (2012) *The Equal Rights Review* 9
- N1 BiH 'Zastupnica objavila šokantne detalje o tretmanu štíćenika u Pazariću' (Parliamentary representative revealed shocking details on the treatment of Pazarić residents) 20 November 2019, available at <http://ba.n1info.com/Vijesti/a392432/Zastupnica-objavila-sokantne-detalje-o-tretmanu-sticenika-u-Pazaricu-FOTO-VIDEO.html> (last visited 29 March 2020)
- National Network for Children 'Bulgaria updates its Action Plan on Deinstitutionalisation' (2016), available at <https://www.openingdoors.eu/bulgaria-updates-its-action-plan-on-deinstitutionalisation> (last visited 18 August 2020)
- National Network for Children (2016) *Report card 2016: What is the average government score for childcare?* Sofia: National Network for Children
- National Network for Children (2019) *Report card 2019: What is the average government score for childcare?* Sofia: National Network for Children
- National Statistical Institute of the Republic of Bulgaria 'Homes for medico-social care for children' (2019), available at <https://www.nsi.bg/en/content/5606/homes-medico-social-care-children> (last visited 10 August 2020)
- Network of Disability Organisations Alternative Report to the UN Committee on the Rights of Persons with Disabilities on Albanian Government's Initial Report on the Convention on the Rights of Persons with Disabilities (2019), available at https://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/ALB/INT_CRPD_ICO_ALB_33892_E.docx (last visited 24 August 2020)
- Nowak M (ed) (2019) *United Nations global study on children deprived of liberty* New York: United Nations
- Ombudsman of the Republic of Serbia (2014) *Roadmap to deinstitutionalisation in the Republic of Serbia: A possible way of implementing the process of deinstitutionalisation* Belgrade: Ombudsman of the Republic of Serbia
- Ombudsman of the Republic of Serbia (2020) *Regular annual report of the Protector of Citizens 2019* Belgrade: Ombudsman of the Republic of Serbia
- Petrušić N (2019) *Special report of the ombudsman: Status of children's rights in the Republic of Serbia* Belgrade: Ombudsman of the Republic of Serbia
- Pinheiro PS (2006) *Report of the Independent Expert for the United Nations study on violence against children A/61/299*

- Popivanova CI 'Changing paradigms in child institutionalisation: The case of Bulgaria' (2009) 48 *Journal of the American Academy of Child and Adolescent Psychiatry* 10
- Rama R (2017) *Evaluation report: The rights of the child with disabilities and social inclusion* Tirana: Albanian Disability Rights Foundation
- Raycheva L, Hristova K, Radomirova D & Ginev R 'Bulgaria: Childhood in transition' (2004) II *Children's Welfare in Ageing Europe* 469 Trondheim: Norwegian Centre for Child Research
- Rogers J & Sammon EM (2018) *We all matter! Situation analysis of children with disabilities in Albania* Tirana: UNICEF in Albania
- Rosenthal E, Ćirić Milovanović D & Ahern L (2019) *A dead end for children: Bulgaria's group homes* London: Disability Rights International
- Sarajevo Times* 'Council of Europe Commissioner for HR Dunja Mijatović condemned the way children are treated in the institution for the care of children with mental disabilities' Pazarčić' 3 December 2019, available at <https://www.sarajevotimes.com/council-of-europe-commissioner-for-hr-dunja-mijatovic-condemned-the-way-children-are-treated-in-the-institution-for-the-care-of-children-with-mental-disabilities-pazaric> (last visited 29 March 2020)
- Save the Children (2019) *Family strengthening: A collection of best practices from Eastern Europe* Tirana: Save the Children in Kosovo
- Save the Children, Inter-Ethnic Initiative for Human Rights, Every Child Bulgaria, Bulgarian Helsinki Committee, Centre for Independent Living NGO Alternative Report on Bulgaria's Progress Towards EU Accession (2004), available at https://issuu.com/bghelsinki/docs/2004_ngoalternativerreport_en-1- (last visited 6 August 2020)
- Social Assistance Agency of the Republic of Bulgaria (2020) Reply to the GCSEE/ERMA questionnaire, received on 23 July 2020 via electronic mail
- Social Protection Institute of the Republic of Serbia 'Children in the social protection system (*Deca u sistemu socijalne zaštite*)' Belgrade: Social Protection Institute of the Republic of Serbia (2014), available at <http://www.zavodsz.gov.rs/media/1284/deca-u-sistemu-socijalne-zastite.pdf> (last visited 24 August 2020)
- Social Protection Institute of the Republic of Serbia Work of institutions for accommodation of children and young people in the Republic of Serbia for 2017 (2019) Belgrade: Social Protection Institute of the Republic of Serbia
- Social Protection Institute of the Republic of Serbia (2020) Reply to the GCSEE/ERMA questionnaire 340/20, received on 8 July 2020 via electronic mail
- Somun-Krupalija L (2017) *Children with disabilities in Bosnia and Herzegovina: I don't think I am different* Sarajevo: World Vision Bosnia and Herzegovina
- Spirov B et al (2015) *Ending institutionalisation. An assessment of the outcomes for children and young people in Bulgaria* London: Lumos
- State Social Services of the Republic of Albania (2020) Reply to the GCSEE/ERMA questionnaire, received on 14 July 2020 via electronic mail
- Tobis D (2000) *Moving from residential institutions to community based social services in Central and Eastern Europe and the former Soviet Union* Washington: The World Bank
- UN Committee on the Rights of Persons with Disabilities (2016) Concluding Observations on the Initial Report of Serbia CRPD/C/SRB/CO/1
- UN Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of Bosnia and Herzegovina CRPD/C/BIH/CO/1

- UN Committee on the Rights of Persons with Disabilities General Comment on article 19: Living independently and being included in the community (2017) CRPD/C/18/1
- UN Committee on the Rights of Persons with Disabilities Concluding Observations on the initial report of Bulgaria (2018) CRPD/C/BGR/CO/1
- UN Committee on the Rights of Persons with Disabilities. (2019) *Concluding Observations on the Initial Report of Albania*. CRPD/C/ALB/CO/1.
- UN Committee on the Rights of the Child Consideration of reports submitted by States Parties under article 44 of the Convention, Initial report of States parties due in 1994: Albania, CRC Committee (2004) CRC/C/11/Add.27
- UN Committee on the Rights of the Child Consideration of reports submitted by States Parties under article 44 of the Convention, Initial report of States parties due in 1999: Bosnia and Herzegovina (2004) CRC/C/11/Add.28
- UN Committee on the Rights of the Child Written Replies by the Government of Bosnia and Herzegovina Concerning the List of Issues (CRC/C/Q/BIH/1) Received by the Committee on the Rights of the Child Relating to the Consideration of the Initial Report of Bosnia and Herzegovina (CRC/C/11/Add.28) (2005) CRC/C/RESP/85
- UN Committee on the Rights of the Child Consideration of reports submitted by States Parties under article 44 of the Convention, Second periodic reports of States parties due in 1998: Bulgaria CRC/C/BGR/2 (2007)
- UN Committee on the Rights of the Child Written replies by the Government of Serbia to the list of issues (CRC/C/SRB/Q/1) prepared by the Committee on the Rights of the Child in connection with the consideration of the initial report of Serbia (CRC/C/SRB/1) CRC/C/SRB/Q/1/Add.1 (2008)
- UN Committee on the Rights of the Child Concluding Observations on the consolidated second to fourth periodic reports of Bosnia and Herzegovina, adopted by the Committee at its sixty-first session 17 September–5 October 2012 CRC/C/BIH/CO/2-4
- UN Committee on the Rights of the Child Concluding Observations the combined second to fourth periodic reports of Albania, adopted by the Committee at its sixty-first session 17 September–5 October 2012 CRC/C/ALB/CO/2-4
- UN Committee on the Rights of the Child Concluding Observations on the consolidated second to fourth periodic reports of Bosnia and Herzegovina, adopted by the Committee at its sixty-first session 17 September–5 October 2012 CRC/C/BIH/CO/5-6
- UN Committee on the Rights of the Child General Comment No 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (Art 3, para 1) CRC/C/GC/14
- UN Committee on the Rights of the Child (2017) Concluding Observations on the Combined Second and Third Periodic Reports of Serbia CRC/C/SRB/CO/2-3
- UN Committee on the Rights of the Child (2019) Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Bosnia and Herzegovina CRC/C/BIH/CO/5-6
- UN Committee on the Rights of the Child (2019) List of issues in relation to the combined fifth and sixth periodic reports of Bosnia and Herzegovina: Replies of Bosnia and Herzegovina to the list of issues CRC/C/BIH/Q/5-6/Add.1
- UN Department of Economic and Social Affairs (2019) *Disability and Development Report: Realising the Sustainable Development Goals by, for and with Persons with Disabilities* New York: UN
- UN General Assembly (2010) Guidelines for the Alternative Care of Children, Resolution adopted by the General Assembly on the report of the Third Committee (A/64/434) A/RES/64/142

- UN Human Rights Committee (2018) Concluding Observations on the Fourth Periodic Report of Bulgaria CCPR/C/BGR/CO/4
- UN Human Rights Council (2012) Joint report of the Office of the High Commissioner for Human Rights, the United Nations Office on Drugs and Crime and the Special Representative of the Secretary General on violence against children on prevention of and responses to violence against child juvenile justice system A/HRC/21/25
- UNICEF (2002) *MONEE Country Analytical Report 2002: Children and disability in Albania* Tirana: UNICEF
- UNICEF (2012) *Children under the age of three in formal care in Eastern Europe and Central Asia: A rights based regional situational analysis* Geneva: UNICEF
- UNICEF (2017a) *Annual Report 2017 Bosnia and Herzegovina* Sarajevo: UNICEF Bosnia and Herzegovina
- UNICEF (2018a) *Everybody counts: A situation analysis of the inclusion of children with disabilities in the Western Balkans and Turkey* Geneva: UNICEF
- UNICEF (2018b) 'Data on the children with disabilities in Bulgaria and around the world: How to overcome the challenges', available at <https://www.unicef.org/bulgaria/en/data-children-disabilities-bulgaria-and-around-world> (last visited 13 August 2020)
- Voko K & Kulla F (2018) *Child disability in Albania: Disability prevalence, access to services and quality of services study report* Tirana: Save the Children, World Vision
- World Bank 'Poverty headcount ratio at national poverty lines (% of population) - Bosnia and Herzegovina' (2015), available at <https://data.worldbank.org/indicator/SI.POV.NAHC?locations=BA> (last visited 29 October 2020)
- World Vision Albania, Albanian Disability Rights Foundation (2019) *Monitoring the National Disability Action Plan (2016-2020) Summary* Tirana: WVA/ADRF

2020

Deinstitutionalisation of children with disabilities: Process, progress and challenges in South-East Europe

þÿ F a z l i , M u a m e r

Global Campus of Human Rights

<http://doi.org/20.500.11825/2039>

Downloaded from Open Knowledge Repository, Global Campus' institutional repository