VALIDITY

Deinstitutionalisation and Life in the Community in Bulgaria

A Three-Dimensional Illusion

The Validity Foundation – Mental Disability Advocacy Centre is an international non-governmental human rights organisation which uses legal strategies to promote, protect and defend the human rights of persons with intellectual disabilities and persons with psychosocial disabilities in Europe and Africa. Validity holds special consultative status with the United Nations' Economic and Social Council (ECOSOC) and participatory status at the Council of Europe. www.validity.ngo.

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A report by
Validity Foundation

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Acronyms

Acronym	Stands for
ASA	Agency for Social Assistance
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CPT	Council of Europe's Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee on the Right of Persons with Disabilities
DI	Deinstitutionalisation
EC	European Commission
ERDF	European Regional Development Fund
ESIF/ESI Funds	European Structural and Investment Funds
IBRD	International Bank for Reconstruction and Development
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
NGO	Non-Governmental Organisation
SACP	State Agency for Child Protection
UDHR	Universal Declaration of Human Rights
UNICEF	United Nations Children's Fund

Instead of foreword – A personal story

I am in my 30's and I was first diagnosed with Paranoid Schizophrenia and then with bipolar syndrome, Type 1. In the text that you are reading, I describe the experience that I had in so-called "small group homes". In my case, we are talking about a "Protected House" for persons with psychosocial disabilities. My intention is to show how my stay in such an institution did not help me to become more independent, but on the contrary, I had to live in a way that did not allow me to exercise my right to free choice.

I have been living with my grandmother for 18 years, near my biological parents. In January 2000, I was mistakenly diagnosed with Paranoid Schizophrenia. Unofficially, I was diagnosed with this condition at the age of 17 after a private check-up. However, my first stay in a psychiatric facility was in January 2000, and I mention this for a specific reason. I was 19; going to reviews and taking psychoactive drugs had become a routine, and the bullying and the stigma that all mental illnesses carry was a banal part of my everyday life. Over the past 15 years, to this day, I have been admitted and discharged from such hospitals a total of 35 times. During one of the last three admissions, caused by an extremely severe psychotic crisis, an open session was organised in the hospital. Open sessions are interviews where all employees are present, the attending physician asks questions, and the rest listen to the answers, discuss, and make a decision. With mine, it was confirmed that I had never had schizophrenia, but bipolar syndrome, Type 1.

I will start my story with my experience in the first family-type accommodation center (a protected house, which is a type of group home), where I lived for about 2 months. The purpose of my stay was to get me out of the traumatic situation in my home, which is very bad for my mental health.

The living conditions in the protected house were better than those in my home - there was a microwave and a washing machine, which I was allowed to use. In my home it is prohibited by my parents. As a rule, 50% of the benefits of all residents had to pay for rent and overheads, and the condition of staying in the protected house was to have a recognised disability status. Since I didn't yet have an allocated disability pension, I was allowed to use without payment.

For each one of us (5 women) who lived there, food was provided three times a day, along with a bed, access to a bathroom, and the opportunity to learn how to cook during kitchen duty. We had a hygienist who took care of cleanliness. Smoking inside was allowed when everyone living was a smoker, but when there were those who did not smoke (as in my case), it was mandatory to smoke on the terrace.

The daily routine at the facility was as follows:

We all got up at 6am, and between 6 and 7am we did our private toilette, had breakfast, and tidied our lockers and beds. There were 3 beds in both rooms. Between 7 and 8am, we put on clean, good clothes in order to look good, as far as our conditions allowed (because of the strong medications, some patients did not even comb their hair, while others showed their vanity and put on gloss or lipstick), and gathered to go together to the "Equal chance" center for labour and art therapy. That was obligatory. This center was the best we had. While I was still living in the apartment, there were already rumours of its closure, but by the time I left, it was still functioning.

The members of the staff were assigned to this center. None of the users knew what qualifications the employees had, or whether they had any. These people helped us use our free time by doing embroidery, knitting, drawing, colouring, and découpage.

At lunchtime, we would have our lunch at the centre. We took turns shopping and receiving help from the staff to learn how to allocate our budgets. Again, under the supervision of the staff, we prepared our meals, and had it in a separate corner for this purpose, and then took turns at doing the dishes, drying them, and putting them in their cabinets. At 2 or 3pm, we were released after having cleaned up everything.

At the protected house, we had the right to go out only after we had informed the nurse who handed out our medications and let her know where we were going to go, who we would be with and when we would come back. If my memory is right, it was forbidden to go outside the city. The staff took upon themselves the duty to assess whether our current mental health condition allowed it. An example from my personal experience: I had a planned stay at the clinic of a doctor and I had made all the arrangements, but just as I was about to call a taxi, the nurse on duty literally stopped me at the door, even though I had explicit permission from the doctor. The reason for the ban was that I was on too strong medication and, according to her, I was going to "experience a new crisis". This I did not take emotionally, because if the patient who asks for permission seems confused, upset, or affected, they would call the doctor on duty to officially refuse the leave request.

Despite these rules, there was a patient who was sent for treatment to a hospital and who managed to escape, get money from someone and return to the apartment in semi-consciousness.

One of the minor problems that I considered normal and didn't even consider a problem was that none of us was given a choice about who to live with or spend our free time with. We had no one to talk to about the incompatibility of our temperaments or conflicts when they occured, which were not unusual. If we tried to talk to the nurse who handed out the medicine, or to the psychologist who came from time to time, the answer was that we were being "cranky", that we were "ungrateful", that we had "somewhere to live", and so on.

It was because of conflicts at the small group home, which I had no real opportunity to resolve, that things for me started going badly in this house; and gradually went from bad to worse. The conflict arose because the housing hygienist (a female staff member) allowed herself to arrange our clothes, evaluating, without asking us, which clothes belonged to whom. So, she took someone else's clothes and put them into my things, which led to accusations and tension. It was extremely ugly - a member of staff had interfered so violently with my personal space, by deciding instead of me what things were mine, when to collect them, and where to put them. This was against any rules (in my opinion), but it was also something I didn't realise was particularly problematic. After all, the staff knows best - it's the staff! None of us knew where the boundaries were - what they could make us do and what they couldn't, and consequently what they could do and what they couldn't. We didn't know our rights. The case I told you about upset me very much. When I am unfairly accused, and there is no one to protect me, I get very upset, and then show pronounced physical auto-aggression. It happened then, too. In short, this "protected" housing put my safety at a great risk.

Meal times were predetermined during the daytime, and washing the dishes was on a rotating principle. We went to bed within a certain hour, got up within a certain hour, and it was forbidden to get out of bed between bedtime and getting up. With the benefit of hindsight it now occurs to me that we had no chance of becoming independent and free in that place. Of the many things I remember, in every respect, the decision was not ours, but that of the staff. Visiting the day centre was a duty, walks were allowed or, alternatively, refused by the staff, inviting outsiders was more than absurd, expenses were carried out under supervision, there was one TV, and conflicts were inevitable, and I don't remember if we had any books at all, but I clearly remember that we were forbidden to introduce religious literature.

Freedom of decisions, I think, were restricted to what clothes to wear.

As a result of my stay in this small group home, my condition deteriorated. I was admitted to a clinic for treatment. After I was discharged, I went back to my hometown. I came home very upset and with even lower self-esteem. I admit that I blamed myself for having been unable to adapt, to live independently, to learn new skills, to budget the time and money I have. I criticised myself for not having become responsible enough for myself and others, for not realising that none of us were given the opportunity to learn responsibility, independence, and to achieve personal growth.

The decision to go there was mine, as I found no other way out of the traumatic environment at my parents' house, but all the while I felt depressed, controlled, guilty, annoyed, obstructed, intruded upon, and like I should apologise for being there. I didn't dare complain because I had showed a desire to get away from the nightmare at home, and things went from bad to worse. Instead of helping me, being in this safe place actually hurt me a lot.

In 2019, there was a risk of going back to a similar housing or a small group home, and because of this, I was admitted to a psychiatric hospital and kept there so that I could start fulfilling the conditions of accommodation. I experienced a lot of unpleasant things in the psychiatric hospital, including being placed (incorrectly) in a closed ward. In the end, it didn't lead to me moving back into a small group home. The story of my stay in a psychiatric hospital is a separate story, which I will tell on another occasion. I know the stories of many people who have gone through small group homes and those that haven't had my (rather controversial) luck of getting back into the family environment. Despite my return to my parents' home, I can't use any meaningful services that I really need so that I can organise my life independently. I don't have a home of my own, and I can't use public services due to a number of restrictions. With the pension I get, I can't afford a place to live. Because of my diagnosis, I am not employed, and my pension is extremely insufficient and controlled by my family, although I am not placed under guardianship. There are a number of skills that I feel I need so that I can be on my own, but support for acquiring them is not available.

Acknowledgements and Contributor Biographies

This report was put together by Nadezhda Toteva Deneva. Much of the information on deinstitutionalisation and group homes presented in this report is based on her personal experiences and knowledge. Contributions to this report were also made by Aneta Genova Mircheva, Steven Allen, Ann Campbell, Sándor Gurbai, and Palik Taslakian.

Nadezhda Toteva Deneva has unique experience and knowledge about the Bulgarian deinstitutionalisation process. She personally took part in the closure of the Mogilino institution and worked as an expert in social services and child protection at the deinstitutionalisation unit at UNICEF Bulgaria from May 2007 to December 2010. She was the Head of the Unit of deinstitutionalisation at the Bulgarian branch of the Lumos Foundation from December 2010 to June 2013. Currently, she is working as a freelancer, consultant, researcher and trainer in the area of social services and deinstitutionalisation. She did fieldwork during the initial stage of and has been constantly involved in the deinstitutionalisation process in Bulgaria. Much of the information on deinstitutionalisation and group homes presented in this report is based on her personal experiences and knowledge.

Aneta Genova Mircheva has been working in the areas of mental health and human rights as a lawyer since 2005. Aneta worked for the Bulgarian Helsinki Committee and the Mental Disability Advocacy Centre until 2013, since then she has been an independent lawyer cooperating closely with Validity Foundation. She represented clients in the cases of *Stanev v. Bulgaria and Stankov v. Bulgaria* before the European Court of Human Rights. Aneta has been involved in the monitoring of institutions across Bulgaria, researching the rights of persons with disabilities, and delivering training sessions. Aneta leads a group of lawyers working in the fields of mental health and human rights and together they are litigating cases to ensure access to fundamental rights for persons with disabilities, including the right to justice, right to freedom from inhuman and degrading treatment, right to family, right to education, right to property, right to health. Aneta is also a clinical social worker and an art therapist and developed a method for human rights education with elements of art therapy.

Steven Allen is a social justice activist. He joined the Validity Foundation in 2013 and was jointly appointed as Co-Executive Director in 2018, where he leads the organisation's advocacy and research initiatives. He holds an LLB (Law) from the University of London and has a postgraduate research interest in systems which restrict and/or deny legal agency for members of historically marginalised populations. Before this, Steven was a senior trainer in conflict transformation for a decade, leading programmes for young people in conflict with the law in the UK, the Middle East and India. He served on the independent monitoring board of a young offenders' institution in London for five years, and previously worked at a charity that successfully campaigned to establish the first Children's Commissioner for England. Along with Ann Campbell, he was jointly named as a recipient of the Open Society Foundations New Executives Fund in 2019.

Ann Campbell is the Co-Executive Director at Validity. She has three years of experience litigating as a barrister at the Irish Bar and, since then, has worked with several national and international NGOs in Europe, Asia and Africa. Ann brings practical experience and knowledge in the areas of asylum law, women's rights, and LGBTQ rights in addition to her work on disability rights. She has an LLM in International Human Rights Law and over 14 years in national and international law and litigation, litigating at the European Court of Human Rights, the UN Treaty Bodies, the European Committee of Social Rights and, most recently, the European Court of Justice. She is keenly interested in how people's different identities affect their experience of discrimination, and determine the appropriateness of remedies.

Sándor Gurbai is a disability rights lawyer and holds a PhD from Pázmány Péter Catholic University, Hungary in law and political sciences. Sándor is an Impact Manager for Validity Foundation – Mental Disability Advocacy Centre, where he leads Validity's advocacy strategies to improve human rights protections for persons with psycho-social and intellectual disabilities in Central and Eastern Europe and takes part in Validity's specific litigation activities. Sándor is a fellow affiliated with the Human Rights Centre, School of Law at the University of Essex, UK, and a researcher affiliated with the Essex Autonomy Project at the University of Essex, UK. He is an external lecturer on disability rights at ELTE Eötvös Loránd University, Hungary.

Palik Taslakian is a former Litigation Manager at Validity Foundation in charge of managing the litigation strategy in a number of European countries. Palik has a Masters in comparative criminal law and a Maîtrise in International Law from the University of Paris 1 Pantheon Sorbonne, focused on international crimes, specifically the crime of genocide. Palik has been working in the humanitarian sector since 2009 and started her journey providing legal support to families of autistic children. She has focused ever since on promoting and defending the rights of vulnerable populations in Europe and the Middle East, working for international human rights organisations and United Nations agencies.

Introduction – Why we wrote this report and why now?

Growing up in a family is fundamental for all children. Making decisions about where to live and with whom to live with is essential for all adults. These are both related to the right to live in the community to which all persons, children and adults, with and without disabilities, are entitled to, regardless of how intensive the support they may need. However, children with disabilities are often denied the possibility to live in a family and they are placed in so-called alternative care settings, while adults with disabilities are often not allowed to choose their place of residence and those people with whom they would like to share their lives.

Unfortunately, institutionalisation of children and adults with disabilities is still widespread in Bulgaria.

During the period in which this report was compiled (2018-20), many legislative changes took place in Bulgaria. A new Persons with Disabilities Act was adopted and entered into force on 1 January 2019. At the same time, the Personal Assistance Act also came into force. Moreover, a new Social Services Act entered into force on 1 July 2020.

Besides these legislative changes, political promises have been made that policies and practices that isolate persons with disabilities and result in violations of their human rights will be ended.[1] However, the situation on the ground remains worrying. Persons with disabilities continue to be segregated in institutions, big and small, and they continue to face serious human rights violations on a daily basis. These problems must be addressed systematically. In short, promises need to be translated into reality.

Within professional social services discourse, there was no debate on institutions, institutionalisation, institutional culture, or life in the community prior to the initiation of deinstitutionalisation (DI) in Bulgaria. And while there were no discussions about what an *institution* actually was, everyone seemed to be aware of what *deinstitutionalisation* was.

> "An institution is any place in which people who have been labeled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size."[2]

Besides this lack of knowledge within professional social services, persons with disabilities and human rights organisations have not been involved meaningfully in the DI process. Even where persons with disabilities and human rights organisations could participate in meetings, their expertise was overlooked, and their views were ignored.

DI has been on the political agenda in Bulgaria since 2010. Although deinstitutionalisation is a process that holds great promise, it is a risky one as well. DI can easily result in trans-institutionalisation, meaning that

[1] See more about the plans for reforms in the 'Action Plan containing measures for bringing regulations and policies in the field of people with disabilities in the Republic of Bulgaria into accordance with the provisions of the Convention on the Rights of Persons with Disabilities (2013-2014)', available at: http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=784.

[2] European Coalition for Community Living (without date) What Does Exclusion From Society Mean? p. 7. Available at: https://fliphtml5.com/qcfn/ejtg/basic.

individuals who are moved out from institutions end up in other types of institutions. This report investigates whether the current DI process in Bulgaria can actually achieve its purpose: realisation of the right to live in the community for those persons with disabilities who are currently living in large-scale and smaller institutions. The report also focuses on whether EU funding has been used in line with Bulgaria's obligations under international and EU law.

The DI process is still in process; nevertheless, the early results are clear enough to publish this report. These preliminary results are alarming since the implementation of the deinstitutionalisation process seriously violates the human rights of persons with disabilities. This fact makes this report timely and extremely important.

Section 1 of this Report summarises relevant standards in relation to the right to independent living and being included in the community for persons with disabilities under international human rights law.

Section 2 sets out the background and context for our Report by giving a general overview of the history of the deinstitutionalisation process in Bulgaria to the present day.

Section 3 provides information about how 'group homes' have become a predominant model deployed under the Bulgarian DI process, and why these settings are not be compliant with the right of persons with disabilities to live independently and to be included in the community.

Section 4 describes the current situation concerning access of persons with disabilities to general public services, arguing that access to these services should be an essential component of a successful DI process.

Section 5 briefly reflects on the impacts of COVID restrictions on persons with disabilities in institutions, including group homes.

Section 6 shows how EU funds have been misused to create new forms of institutionalised settings, namely group homes, across the territory.

Finally, in **Section 7**, conclusions and recommendations are provided to relevant stakeholders including the European Commission, the Bulgarian Government, the Ministry of Labour and Social Policy, the Agency for Social Assistance, the Ombudsman, the Audit Office of Bulgaria and the Chief Prosecutor.

1. The right to independent living and being included in the community

The right to independent living and being included in the community of persons with disabilities is a fundamental right guaranteed by international human rights law. It is an important right at both European Union and Member State levels. Bulgaria signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 17 September 2007 and ratified it on 22 March 2012, thereby making it part of its national legal framework. As the Constitution of the Republic of Bulgaria highlights:

> International treaties which have been ratified in accordance with the constitutional procedure, promulgated and having come into force with respect to the Republic of Bulgaria, shall be part of the legislation of the State. They shall have primacy over any conflicting provision of domestic legislation.[3]

1.1 Relevant international hard law in a nutshell

Article 19 of the CRPD represents the same paradigmatic shift which is evidence in all other articles of the CRPD. While Article 12, for example, calls for abolishing substituted decision-making and introducing support to exercise legal capacity, Article 19 requires States parties to close institutional settings for persons with disabilities and instead ensuring their full inclusion and participation in the community. Core components of Article 19 require duty bearers to ensure (1) that persons with disabilities have the opportunity to choose their place of residence and where and with whom they want to live, and (2) that they have access to a range of services to facilitate their inclusion in the community, and (3) that all forms of isolation or segregation are avoided. These paradigmatic changes are based on the respect for inherent dignity of persons with disabilities, acknowledging their individual autonomy, and including the freedom to make their own choices, and to exercise their independence.[4]

The UN Committee on the Right of Persons with Disabilities (CRPD Committee) is the authoritative oversight body of the Convention. According to the CRPD Committee, the right to independent living and being included in the community is deeply rooted within other sources of international human rights law, especially in Article 29(1) of the Universal Declaration of Human Rights (UDHR), Article 12 of the International Covenant on Civil and Political Rights (ICCPR), Article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), Article 15(4) of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and Article 23(1) of the Convention on the Rights of the Child (CRC).[5]

1.2 Immediately or progressively applicable?

Article 19 of the CRPD contains a combination of (1) civil and political rights, and (2) economic, social and cultural rights. In other words, it means that the right to independent living and being included in the community has a mixed nature. Some of the aspects are immediately applicable, and others are subject to progressive realisation. This distinction of rights and nature of their implementation can be found in Article 4(2) CRPD, according to which:

> With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of

[3] Constitution of the Republic of Bulgaria, Article 5(4).

[4] Article 3(a) of the CRPD.

[5] CRPD Committee (2017) *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, paras 9-12.

> international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.

While Article 19(a) on the right to choose one's residence and where, how and with whom to live, is *immediately applicable*, Article 19(b) on the right to access individualised, assessed support services and Article 19(c) on the right to access service facilities are progressively realisable. However, *progressive realisation* does not mean that States can wait with the implementation of economic, social and cultural rights. It rather "entails the immediate obligation to design and adopt concrete strategies, plans of action and resources to develop support services as well as making existing, as well as new, general services inclusive for persons with disabilities."[6] Furthermore,

> States parties have the immediate obligation to enter into strategic planning, with adequate time frames and resourcing, in close and respectful consultation with representative organizations of persons with disabilities, to replace any institutionalized settings with independent living support services.[7]

1.3 Intersection with the right to equality and non-discrimination

Human rights are interrelated, interdependent and indivisible, and people are all equally entitled to human rights without any discrimination. Equality and non-discrimination are principles, and also, they are substantive and cross-cutting rights. These rights are clearly subject to immediately applicable.[8] In relation to Article 19 of the CRPD, this means that States parties must

> repeal or reform policies, laws and practices that prevent persons with disabilities from, for example, choosing their place of residence, securing affordable and accessible housing, renting accommodation or accessing such general mainstream facilities and services as their independence would require. The duty to provide reasonable accommodation (art. 5 (3)) is also not subject to progressive realization.[9]

When it comes to the intersection of Article 19 and the right to equality and non-discrimination, States have two types of obligations: (1) negative obligations, which require states 'not to do' something, and (2) positive obligations requiring them 'to do' something. The CRPD creates negative obligations for States parties by requiring them not to discriminate persons with disabilities by, for example, segregating and isolating them in institutional settings, and this includes refraining from creating smaller facilities that are nevertheless institutions. The Convention includes positive obligations too; for example, persons with disabilities must be provided with access to the support they may require in exercising their legal capacity, including making decisions on where, how and with whom to live, access to individualised support services, and reasonable accommodations that suit their needs and enable them to live independently in the community.

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[6] Ibid, para 39.

[7] Ibid. Para 42.

[8] Cf. CRPD Committee (2018) *General comment No. 6 (2018) on equality and non-discrimination*, CRPD/C/GC/6, Para 12.

[9] CRPD Committee (2017) *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, para 46.

1.4 Council of Europe – What does the European Court of Human Rights say?

The European Court of Human Rights has delivered several judgments related to the right to independent living and being included in the community of persons with disabilities, and has held that placement of persons with disabilities in social care institutions results in violation of the European Convention on Human Rights. That was the case in *Stanev v. Bulgaria,*[10] *D.D. v. Lithuania,*[11] *Kędzior v. Poland,*[12] *Mihailovs v. Latvia,*[13] *and in Stefan Stankov v. Bulgaria*.[14] In the case of *Kocherov and Sergeyeva v. Russia*,[15] the Court said that it is better for a child to live with their parents with disabilities than to be brought up in an institution.

In the case of *Stanev v Bulgaria*, an important aspect was that the will and preferences of persons with disabilities must be respected concerning decisions on where, how and with whom persons with disabilities want to live. Mr. Stanev claimed he had been placed against his will in a 'home for adults with psychiatric disorders' *(Дом за възрастни с психични разстройства)* for nine years. In January 2012, the Grand Chamber found that there had been: a violation of Article 5(1) (right to liberty and security) of the European Convention on Human Rights, in that the applicant was illegally detained in the psychiatric social care institution; a violation of Article 5(4) of the Convention, concerning the impossibility for him to bring proceedings to have the lawfulness of his detention decided by a court by virtue of his placement under guardianship; a violation of Article 5(5), concerning the impossibility for him to apply for compensation for his illegal detention and the lack of review by a court of the lawfulness of his detention; a violation of Article 3 (prohibition of degrading treatment), concerning the conditions in which he was forced to live; a violation of Article 13 (right to an effective remedy), concerning the impossibility for him to apply for compensation regarding his degrading living conditions; and, a violation of Article 6(1) (right to a fair hearing), in that he was denied access to a court to seek restoration of his legal capacity.

In the case of *Kocherov and Sergeyeva v. Russia*, the message of the decision of the European Court of Human Rights was twofold: (1) it is better for adults with disabilities to live in the community than in a social care institution, and (2) it is better for a child to live in family environment than in a childcare institution. Mr. Kocherov was living with his wife in a social care institution which was known as a neuropsychological care home. Mr. Kocherov's wife, who was deprived of her legal capacity on account of her mental disability, gave birth to a baby girl. Since Mr. Kocherov, at that time, was not recognised as the child's father, the baby was placed in a children's home as a child without parental care. Mr. Kocherov managed to be registered as the father of her daughter and gave his consent for her to stay at the children's home until it became possible for him to take care of her. In the meantime, a case was initiated to restore the legal capacity of Mr. Kocherov's wife, but the court refused to do so on the basis of a psychiatric examination report which stated that, among others, there were conflicting, aggressive and emotionally inadequate tendencies in her behaviour. Soon after, the marriage between Mr. Kocherov and his wife was declared void because of the latter's legal incapacity. Following a claim by Mr. Kocherov acting on his own behalf and on behalf of his daughter, they were provided with a flat under a social tenancy agreement. Mr. Kocherov was then discharged from the institution and moved into his flat. However, the Russian authorities thought that it was better for his daughter to grow up in an institution instead of with her mother who was under guardianship and her father who had a mental disability. The European Court of Human Rights unanimously found a violation of Article 8 of the European Convention on Human Rights, which sets out the right to respect for family life. Finally, the family were reunited.

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[10] *Stanev v. Bulgaria* (Application no. 36760/06, Judgment of 17 January 2012).

[11] *D.D. v. Lithuania* (Application no. 13469/06, Judgment of 14 February 2012).

[12] *Kędzior v. Poland* (Application no. 45026/07, Judgment of 16 October 2012).

[13] *Mihailovs v. Latvia* (Application no. 35939/10, Judgment of 22 January 2013).

[14] *Stefan Stankov v. Bulgaria* (Application no. 25820/07, Judgment of 17 March 2015).

[15] *Kocherov and Sergeyeva v. Russia* (Application no. 16899/13, Judgment of 29 March 2016).

These decisions provide clear recognition that life in an institution can and does result in serious violations of a range of connected rights. Collectively, decisions to place adults or children in institutions on the basis of disability amount to long-term forms of isolation and social marginalisation, violating the core right of persons with disabilities to exercise their independence and be fully included in the community.

1.5 European Union – For what (not) to use European Structural and Investment Funds?

According to Article 32 of the CPRD, States parties to the Convention, within their obligation to facilitate international cooperation, must ensure that international development programmes are inclusive and accessible to persons with disabilities. In its General Comment No. 5, the CRPD Committee highlighted that:

> International cooperation (art. 32) must be conducted in a way which ensures that foreign aid is invested in support services in local communities that respect the will and preferences of persons with disabilities and foster their right to choose where, with whom and under what living arrangements they will live, in line with Article 19. Investing money obtained within the framework of international cooperation in development of new institutions or places of confinement or institutional models of care is not acceptable, as it leads to the segregation and isolation of persons with disabilities.[16]

The Committee took the same position regarding European Union funds which have been used to maintain residential institutions for persons with disabilities, especially for persons with intellectual and/or psychosocial disabilities, instead of investing in the development of support services for persons with disabilities in local communities. The Committee called on the European Union to:

> develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions. The Committee also recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.[17]

The use of European Union funds to establish new types of institutional settings, including group homes, which do not respect the will, preferences and choices of persons with disabilities, but rather segregate and isolate them, is not only in breach of international human rights law, but also in violation of so called 'ex ante conditionalities' which were introduced under regulations concerning European Structural and Investment Funds for the 2014-20 period, with a view to ensuring the effective and efficient use of these funds. Ex ante conditionalities include, for example, in the area of anti-discrimination, which is a core obligation both in the Treaty[18] and in the Charter of Fundamental Rights.[19]

In the next section, the Report provides an overview of the history of the deinstitutionalisation process in Bulgaria up to the present day.

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[16] CRPD Committee (2017) *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, para 96.

[17] CRPD Committee (2015) *Concluding observations on the initial report of the European Union*, CRPD/C/EU/CO/1, para 51.

[18] Treaty on European Union, Article 3; Treaty on the Functioning of the European Union, Article 10.

[19] Charter of Fundamental Rights of the European Union, Article 21(1).

2. The history of the deinstitutionalisation process in Bulgaria

The child protection system currently in operation in Bulgaria was established with the adoption of the Child Protection Act which entered into force in 2001.[20] At that time, approximately 30,000 children lived in a variety of types of institution, including boarding schools.[21] According to the Bulgarian Government's *'Strategy and action plan for the protection of children's rights 2000 – 2003'*, the "number of children living in institutions as at the end of 1999 is 35,123."[22] This represented an exceptionally high level of institutionalisation, reflecting a long-history of reliance on institutional forms of care for children with disabilities, setting many on lifetime paths of segregation.

During the process of Bulgaria's accession to the European Union, the European Commission compiled annual reports to the European Council on progress made to achieve the necessary conditions for membership. In 2004, a coalition of Bulgarian NGOs highlighted in an alternative report to the European Commission that

> The Bulgarian Government now claims there are 11,384 children in institutional care. Child rights NGOs in fact believe that there are still some 31,000 children living in institutions, the same estimate made by the European Commission in its 2003 Regular Report. These NGOs understand the new, lower, figure to be a manipulation of the statistics based on a very narrow definition of what an 'institutionalised' child is: the new total excludes all children who were not placed in institutional care on the basis of the Child Protection Act. This means that children placed in institutions under the Public Education Act (some 16,000 children) are no longer counted. Children placed in institutions under the Law for combating anti-social behaviour of minors and juveniles (some 2,000) are also missed out.[23]

The same NGO alternative report pointed out the consequence of playing with statistics.

> As a result of this, over 16,000 children who are placed in Special Schools under the Public Education Act are excluded from the deinstitutionalisation plan. This is justified on the grounds that these children are not intended to be permanently resident in these schools. In practice however, the majority of these children do live in the schools for at least 5 days per week.[24]

DI started within this context and was focused on the closure of the largest institutions for children, so-called 'specialised institutions' *(Специализирани институции)*. Initial efforts were unsuccessful.

> In 2006, the process of closing 'specialised institutions' for children began with an assessment carried out by experts from the State Agency for Child Protection (SACP, *ДАЗД*). At this stage, DI was understood as a reform that should take place *inside the institution,* through the development of additional services in the institution or in close proximity to it or on the grounds of the institution.

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[20] The Child Protection Act published in State Gazette № 48/13.06.2000 and entered into force on 1 January 2001. The Act is available in Bulgarian at: https://www.lex.bg/laws/ldoc/2134925825.

[21] The information is published in the Alternative Report of NGOs about the progress of Bulgaria in the joining process to the EU. The document is available in Bulgarian at: https://issuu.com/bghelsinki/docs/ngo_alternative_report-2004/23, p. 10., and in English at: https://issuu.com/bghelsinki/docs/2004_ngoalternativereport_en-1- , p. 9.

[22] Ibid.

[23] Ibid. pp. 9-10.

[24] Ibid. p. 10.

> Financial resources were therefore secured and allocated for repair works to existing buildings, improved furnishings, recruitment and education of personnel and the provision of additional services.[25]

In fact, the process of closure of large institutions for children included an assessment of the institutions themselves, so that they could be placed within one of three categories: (1) those to be restructured, s (2) those to be reformed, and (3) those to be closed. This plan was later on replaced by the idea to completely close all large institutions.

During the first decade of the 21st century, institutions were closed only following national and international scandals exposing the horrific abuse, ill-treatment and inhumane conditions in which children lived.[26] However, the residents of such institutions, whether children or adults, were not provided with support and rehabilitation, nor were they reunited with their families. Rather, they were simply relocated to other institutions. In some cases, institutions for children were later re-named as institutions for adults – such as in the cases of *Fakia and Dzhurkovo* – meaning that their residents disappeared from the statistics recording overall numbers of children institutionalised in the country. In this manner, the number of institutions and children placed in them could be reported to have decreased, but the children concerned were still there. They were simply considered as adults within official figures.

In 2007, the BBC documentary *Bulgaria's Abandoned Children* was broadcast. The film presented the everyday life of children housed in an institution in the village of Mogilino. The international scandal and national pressure from non-governmental organisations in Bulgaria placed the problems with the DI process on the public and political agenda. Eventually, the State was forced to accept that all large institutions for children must be closed.

The dire situation in which children and young persons in the institution in Mogilino found themselves was a catalyst for NGOs and UNICEF to consolidate their efforts towards DI. More precisely, their aim was to bring about the closure of the Mogilino institution by using new innovative methods. The first step was conducting physical health assessments and addressing urgent matters of survival of the children.[27] Psychological assessments were also conducted. The second step was to assess each resident's family situation with a view of reconnecting children with disabilities with their parents or finding alternative placements for them where reintegration was not deemed to be in the best interests of the child.

Mogilino was eventually closed in October 2009, and the majority of the children and young people[28] were moved to five 'small houses' *(малки къщички)*.[29] It was precisely at this time that UNICEF was developing and experimenting with the use of the term of 'Family-Type Placement Centres'. The initial approach was to limit the number of children placed in these centres to eight children: six children without disabilities and a maximum of two children with disabilities. Initially, these types of group homes

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[25] Know How Centre for Alternative Care for Children (2013) Research on the process of DI: the case "Bulgaria" – 2013. p. 9.

[26] For example, Nencheva and Ors v Bulgaria (Application no. 48609/06, Judgment of 18 June 2013) concerned deaths in Dzhurkovo institution in the winter of 1996-97; Lora's story from 1998 is available only in Bulgarian at: https://www.capital.bg/politika_i_ikonomika/obshtestvo/2005/12/24/234336_domut_koito_ubiva/; the Fakia scandal from 2003 available in English at: https://www.amnesty.org/download/Documents/108000/eur150112003en.pdf; BBC (2007) Bulgaria's abandoned children.

[27] For example, many children suffered from malnutrition and because of this they were in a life-threatening situation.

[28] At the beginning of the process of moving out children into small institutions, there were approximately 65 children placed in Mogilino.

[29] The concept of 'small houses' was used by UNICEF during this time as part of the communication strategy.

were to be temporary solutions for children with disabilities.[30] These types of group homes were to become dominant within the ensuing DI process, this model is now being promoted in numerous other countries.

At the same time as the initial steps to close the institution in Mogilino were underway, work began on the preparation of a political document entitled the *Vision for Deinstitutionalisation of the Children in Bulgaria*. This was officially adopted on 24 February 2010. In November 2010, the Bulgarian Council of Ministers adopted an *Action Plan for the Implementation of the Vision for De-instututionalisation of the Children in Bulgaria* ('Action Plan').[31]

As a consequence of misinterpretation of statistical data, and moving children from one institution to another, the official numbers of children living in institutions in Bulgaria dropped from 35,123 (1999) to 11,384 (2004), and then further to 7,587 (2010).[32] The latter was the official number of children living in institutions when the national process of DI officially began.

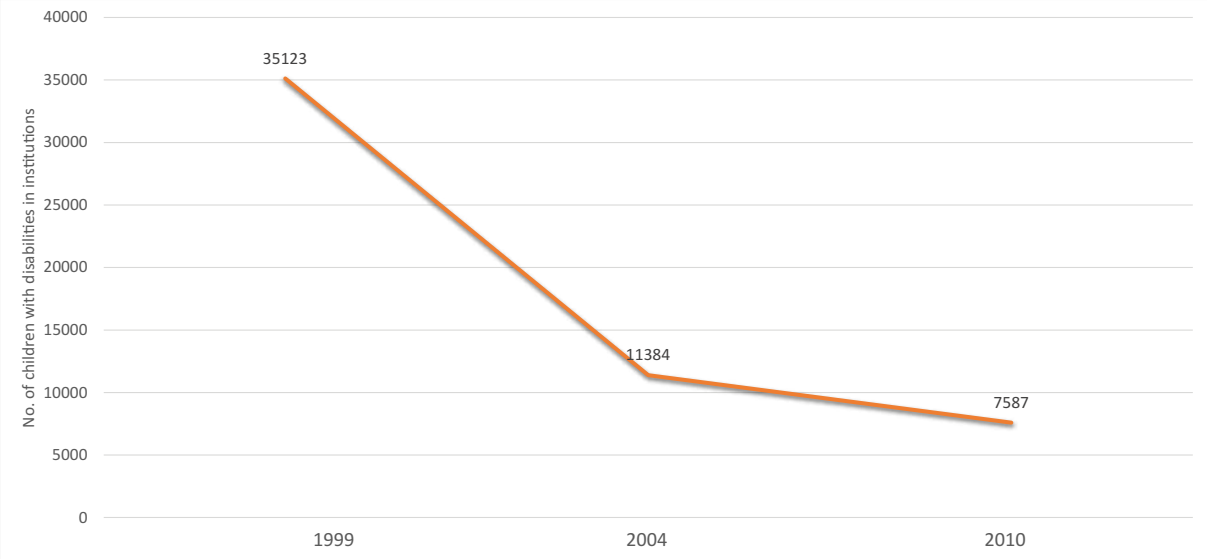

Table 1. Decreasing number of children with disabilities in institutions due to misinterpretation of statistical data and trans-institutionalisation.

In the framework of the 'official DI process', a crucial decision was taken to replace large institutional settings with small group homes for children with disabilities. In general, these new settings were physically located in urban settings but were cut off from the life of the community.

The DI process has resulted in similar consequences for adults with disabilities who were also moved from big institutions to smaller ones. Around these smaller settings, a 'ring of services' was to be provided, which means some services were physically located in different places, however in practice residents are bussed between these locations and never have real opportunities to engage with the community. The experience of persons with disabilities in such settings is limited to seeing local streets through the windows of a bus. Very often, even these rings of services are not available to average citizens since they target persons with disabilities only.

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[30] Center for Independent Living (without date) *The De-institutionalization is expensive but it doesn't worth*, Sofia, pp. 11-12.

[31] The Action Plan was adopted with Protocol 42.22/24.11.2010.

[32] Council of Ministers (2010) National Strategy "Vision for deinstitutionalization of children in the Republic of Bulgaria.", p. 2. Available in Bulgarian at http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=601.

Note on terminology – "A golden cage is still a cage"

"Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. 'Family-like' institutions are still institutions and are no substitute for care by a family."[33]

In everyday Bulgarian, 'group homes' or 'small group homes' are often referred to as 'institutions' *(институции)*, 'small houses' *(малки къщички)* or simply 'homes' *(домове)*. The key characteristics are that they are congregated residential settings which restrict or deny residents' choice and control over how they live. Regardless of their name, these services are not a family.

We use the term 'group homes' throughout this report to refer to these small institutions which include for example 'Family-Type Placement Centres', 'Centres for children and young people who need permanent medical care', 'Residential-type social services in the community', 'protected homes', and 'residential centres'.

Bulgaria continues investing substantial amounts of national and European Union (EU) money to build this new infrastructure, which ultimately results in further segregation and isolation of persons with disabilities and is in fact expanding the institutional model of service provision for persons with disabilities in the country. **At their core, group homes are discriminatory and violate human rights, regardless of their level of "quality".**

There is a strong tendency to assess the effectiveness of the DI process against the backdrop of the changing definitions instead of focusing on real change on the ground. Progress is instead recorded now based on the transformation of institutional care from large-scale to small-scale institutions, namely group homes, with no substantial change in the institutional culture, nor any genuine movement towards inclusion in the community.

[33] CRPD Committee (2017) *General comment No. 5 (2017) on living independently and being included in the community*, CRPD/C/GC/5, para 16(c).

3. Group homes: New types of institutions

One of the main conclusions that can be drawn from the lead author's ten years of experience and the field research conducted for this report is that two central characteristics remain unchanged within group homes as compared with the old system and large-scale institutions. First is the continuing existence of an institutional culture based on control of the residents and restrictions imposed by personnel. Second is the complete denial of personal choice for those placed in these new services when it comes to deciding on matters concerning them, nullifying any real chance for residents therein to exercise their autonomy and independence.

Usually, employees in group homes are required to strictly follow pre-existing guidelines for work in the field of social services which applied, *mutatis mutandis*, within large-scale institutions, as well as the same pre-existing methodology for the provision of social services. This means the same rules, practices and procedures have simply been transferred into smaller group homes, replicating the old institutional culture. The way each service functions is set out in specific legislative acts regulating different aspects of the provision of social assistance.[34] Over the lead author's years of observing the reality in social services for children and adults with disabilities, it is clear that there is no substantial difference between the criteria and standards for institutions and those applied in other types of services defined as 'based in the community', including group homes.

In concrete terms, the difference between the former large institutions and most of the new, smaller residential social services "based in the community" (group homes) is little more than formalistic. The names of the services, the numbers of residents and the numbers of personnel may be different. Sometimes group homes are located in populated areas, whereas the majority of larger institutions were previously located in rural areas, and often in areas that were difficult to access.

Beyond these characteristics, in a substantial number of cases, group homes are almost entirely the same as the previous large-scale institutions. Residents continue to be kept within the premises of the service provider and have no right to leave on their own without special permission and/or without being accompanied by a member of staff. Daily routines remain strict and identical for all residents. People are not provided with personal space or the right to make choices about their daily life, including the physical environment of their place of living. Their personal preferences are afforded little to no importance, and their inter-personal contacts are limited exclusively or primarily to engagements with personnel and other residents. The timing and subjects of their curricular activities are exclusively determined by the personnel and their behaviour is strictly controlled by staff on a daily basis through psychological (and sometimes physical) force, punishment, partiality, and administration of medications. They are provided with no support to access mainstream employment, no meaningful training for independent living, no support to overcome the trauma and vulnerability caused by institutionalisation, and no skills or support to make independent decisions, nor are they provided healthy exposure to the risks and opportunities of living in the real world, outside the institution. The attitude towards residents is indulgent, rooted in the stereotype that they will never "grow up" and be able to make their own choices. Their personal will and preferences are considered irrelevant.

The daily routine in these institutions, either large or small, is organised in such a way as to prioritise convenience for the personnel, on the one hand, and to respond to the perceived or alleged "deficits" of residents on the other hand. There is no space for adoption of progressive approaches or to explore developing practices. In other words, these services are entirely based on outdated medical and paternalistic

[34] These include the Social Assistance Act, the Health Act, and the Social Services Act which entered into force on 1 July 2020.

approaches. Bulgarian regulations stipulate that group homes can house up to 15 persons who can access other specialised social services through their placement in these centres. Notably, this stigmatising notion concerning persons with disabilities are evident even within the regulations, which specify that persons "dependent on care" can be placed in group homes.

According to official data published by the Agency for Social Assistance (*АСП* - ASA) in 2019, there were 268 small group homes for children and young people operating in the country, with a total capacity 3,338 children and young people. Eight institutions for children deprived of parental care *(Домове за деца, лишени от родителски грижи)* continue to operate and the number of children who reside in them has reduced to 117. New admissions were halted on 9 March 2018.[35]

While children with disabilities can no longer be placed into large residential institutions, statistics also show that 13 'Homes for Medico-Social Care for Children' *(Домове за медико-социални грижи за деца)* remain in operation under healthcare legislation and house 482 young children who have chronic conditions.[36] These institutions are managed by the Ministry of Health and the available information about them is scarce and inadequate. The institutions are completely closed to human rights organisations as well, and so gathering independent information is impossible. The State has declared that all new-born children without disabilities deprived of parental care are placed in foster families, which means that only children with disabilities are placed in these facilities.

There are 161 large institutions for adults still operating in Bulgaria which house a total of 10,866 people.[37] Only ten of these are closed to new admissions. Most continue to accept new residents. More recently, 68 new group homes are under construction with a view to housing 3,060 adults.[38]

This information provides only a partial picture of the extent of institutionalisation and the lack of support to enable inclusion of persons with disabilities in the community in Bulgaria. These numbers do not take into account the numbers of people housed in 'homes for temporary placement' (Домове за временно настаняване) or 'crisis centres' *(Кризисни центрове)*.

Another element to be considered is that there remains high demand for new placement of persons with disabilities in institutions. According to the most recent figures available, in 2017 there were 3,600 people on waiting lists for admission to institutions.[39] There were also nearly 900 people waiting for accommodation in group homes.[40]

While people without disabilities can cultivate a broad social circle of friends, acquaintances, colleagues and family, 'deinstitutionalised' people with disabilities are entirely restricted in their social interactions to the small circle of other residents of the group home (and, potentially, a day-care service or centres for social rehabilitation and integration) and the staff working at these places. People with disabilities living in

[35] Data mentioned in this paragraph was available on the Agency for Social Assistance webpage in 2019. At the end of 2019, these data disappeared from the Agency's website and now are on file with the authors of this Report.

[36] See further details at: https://www.nsi.bg/en/content/5606/homes-medico-social-care-children. These services are established to provide medical and other care for children between 0 and 3 years of age, however children with moderate or profound disabilities and those children whose adoption is pending can be kept in these settings up to 7 years of age, according to the regulations: Rules on the Establishment and Activities of Homes for Medico-Social Care for Children 2000 : www.lex.bg/bg/laws/ldoc/-12557311/ (available only in Bulgarian).

[37] Cf. footnote 36.

[38] Ibid.

[39] Government of Bulgaria (2017) Action Plan for the 2018-2021 period on the Implementation of the National Strategy for Long-term Care, p.3, available in Bulgarian at: http://www.strategy.bg/FileHandler.ashx?fileId=11376.

[40] Cf. footnote 36.

'deinstitutionalised settings' are also severely restricted in terms of opportunities to enjoy intimate relationships or a family. In some cases, upon the good will of personnel, a couple may be allowed to share one room. This is, however, only possible where the couple already lives in the same group home. Having a family and raising children within a group home is banned.

The absurd irony is that, under the existing legislation, the main purpose of these new type of institutions is the 'social integration' of the residents, but the 'services' are clearly not capable of fulfilling this express purpose. This is because 'social integration' for people with disabilities is understood differently and in a way that is contrary to human rights standards, including the CRPD: within the Bulgarian DI process, 'social integration' is understood as providing services such as the day-care centres and the Centres for Social Rehabilitation and Integration,[41] which offer only organised living, controlled according to the will of the staff working there.

'Social integration' for people living in any type of group home is understood to include constant surveillance by the staff, including by CCTV.[42] People in these group homes are generally treated as children and this is reflected throughout the overall approach, organisation, decoration, and regime of these 'services'. It is also heavily reflected in the language of the staff and the manner in which they think of and communicate with the residents. Often-heard phrases are:

> "But he is like a child, he cannot do anything"; or
>
> "He is 21 but he has the perceptions of a 5-year-old."

Staff do not acknowledge the real ages and needs of the residents.

This protective and infantilising attitude means that everyone involved in the DI process, from staff to policymakers and lawmakers, focus predominantly on concepts of 'care' and 'assistance' instead of the right to support and 'accompaniment'.[43] This paternalistic approach manifests in all contexts, from the direct work carried out with people with disabilities to the drafting of governing political documents.[44]

The use of the words 'care' and 'assistance' illustrate who initiates, manages and controls the DI process. Where these terminologies predominate, it is the service provider that is at the centre of the process and the resident is an object of their activities. When DI is understood as requiring support and 'accompanying', persons with disabilities can be the agents of their own lives.

The legislation and policies establishing the existing system of social services requires that 'protected' environments be created where residents' perceived need can be catered for in the same place. This is a

[41] Both Day-care Centers and Centers for Social Rehabilitation and Integration are segregated facilities where only persons with disabilities are placed. People's lives at these facilities are organised in the same way as it is in group homes: strict rules, daily routine, control by the personnel. Residents of group homes are spending their days in such services, which are technically closely related to group homes, but physically separated from them.

[42] Bulgarian Helsinki Committee (2016), "Not happening de-institutionalisation in Bulgaria", p. 65. Available in Bulgarian at: https://www.bghelsinki.org/media/uploads/documents/reports/special/2016_nesluchvashtata_se_deinstitucionalizacia_na_licata_s_umstveni_zatrudnenia_v_bulgaria_[978-954-9738-37-7].pdf. In a new group home, researchers from the Bulgarian Helsinki Committee noticed cameras "everywhere". The manager of the group home explained that using CCTV forms an element of the pilot project. Researchers indicated in that Report that they visited other group homes where the same system was operating.

[43] According to the new Social Services Act (in force from 1 July 2020), 'accompaniment' is a part of the individualised support which may be provided for person with disabilities based on their concrete needs and abilities. See Article 5 of the Social Services Act.

[44] See National Strategy for Long-Term Care.

medical, needs-based approach that ignores the rights-based model under which services should provide support for people to exercise their rights. This same medical, protective approach applies both to large institutions and to so-called 'services in the community' such as group homes and day-care centres.[45] The primary purpose of these 'services' is to satisfy the perceived medical or educational 'deficiencies' of people with disabilities, organise their free time, and maintain contact with the residents, and this is reflected in the main standards by which these services are evaluated and form the central work duties of staff.[46] Precisely, this merging of otherwise separate and different aspects of a person's life is in itself a core characteristic of institutionalisation, premised on the basis of defectology, taking us right back to the old attitudes which gave rise to mass institutionalisation in the country.

Numerous international experts have criticised these forms of forced group cohabitation,[47] as they do not ensure life in the community for people who are placed there.

In 2012, the Commissioner for Human Rights of the Council of Europe listed numerous problematic characteristics of group homes. In his Issue Paper, the Commissioner outlines that group homes do not significantly differ from institutions, as they do not allow residents full control of their own lives, and isolate them from the community, even when they are physically located in the community. The concentration of children and adults with disabilities in one place draws attention to them as a group, not as individuals. This separates them from the rest of the neighbourhood. Besides, conditioning the provision of support on placement in a group home limits the opportunity for a person with a disability to choose where and with whom to live.[48]

[45] See for example, Article 41 of the 'Regulation on the Implementation of the Social Assistance Act.' For example, para (4) calls on specialised institutions and services in the community to "provide opportunity for users of social services to organise their free time independently," however, the duty to provide support and reasonable accommodation if needed by persons with disabilities are not mentioned at all.

[46] See the 'Regulation on the Implementation of the Social Assistance Act', Articles 40-40 g and 41.

[47] For example, the European Expert Group on the Transition from Institutional to Community-based Care (2012) *Common European Guidelines on the Transition from Institutional to Community-based care*. Brussels, Belgium.

[48] Council of Europe Commissioner for Human Rights (2012) *The right of people with disabilities to live independently and be included in the community*. Council of Europe Publishing. See especially p. 40.

4. Access to general public services: Essential for deinstitutionalisation

The CRPD enshrines the right of people with disabilities to live in the community by ensuring, inter alia, that:

(i) general public services and facilities are available on an equal basis to persons with disabilities and are responsive to their needs; and

(ii) a range of support services, including personal assistance necessary to support living and inclusion in the community, are available to persons with disabilities based on their choice.[49]

The CRPD is based on the human rights model of disability which recognises that social and environmental barriers must be removed so that people with disabilities can exercise their rights on an equal basis with others. This entails the provision of an accessible physical environment, such as designing buildings and the areas around them so that they can be used by everyone. If the entrance into a building contains a ramp, then the ramp must be designed in harmony with everything else in the building, or the area around. The design of the building should not contribute to stigma or prejudice by singling out the accessible features as different. In general, the design must be in line with an approach which accepts disability and difference, not as a problem, but rather as part of rich, human diversity.

> "For deinstitutionalisation to be successful, children and adults with care and support needs, who are living or moving into the community from an institution, should have access to mainstream services and facilities. This includes, for example, access to social housing, education, employment, health care, transport, sports and cultural facilities, childcare facilities and any other services from which the community benefits. Relevant anti-discrimination legislation is therefore necessary to ensure that different groups (such as children placed in alternative care, children and adults with disabilities and older people) are not discriminated against in terms of their ability to access mainstream services and facilities."[50]

The terms 'mainstream services' and 'universal services' are rarely used in the professional context in Bulgaria, except in translated texts, despite the existing legislative framework which indicates that all services are supposed to be used by everyone without any restriction.[51]

The existing policies in Bulgaria concerning people with disabilities, including the Persons with Disabilities Act,[52] are entirely based on the old medical model of disability, implying that disability is a deviation from the norm and is a problem caused by the individual's characteristics, not the way that we structure our society. Existing policies and practices are instead geared towards getting the person concerned 'healed', 'rehabilitated', and 'adjusted' to the world of persons without disabilities. If this 'adjustment' of the person is not considered

[49] Article 19 of the CRPD.

[50] European Expert Group on the Transition from Institutional to Community-based Care (2012) *Common European Guidelines on the Transition from Institutional to Community-based care*. Brussels, Belgium, p. 77.

[51] According to Art. 5(2) of the People with Disabilities Act, one of the areas of support for persons with disabilities is universal design.

[52] The People with Disabilities Act entered in force on 1 January 2019 and was amended in March 2019, amendment entered in force on 1 January 2020.

possible, the overriding impulse remains to place the person with disability in a separated, 'protected' environment designed especially and exclusively for people like them. In this regard, the decision to place someone in an institution is the same decision, in substance, as the decision to place them in a group home.

The attempt to change the situation by closing the big institutions does not change the fact that policies and practices on the ground are fundamentally based on the medical approach to people with disabilities. The result of this approach is simply to give rise to a new type of social isolation which continues to deny people with disabilities the use of public and universal services – the services all other people use.

> "Services should enable individual users and families to participate in the community on an equal basis with others. Sometimes the principle of community living is understood narrowly as being resident in the community. This may lead to a model of service provision which perpetuates the isolation of users from the community by focusing, for example, on developing residential services (such as 'group homes') as the main alternative to the system of institutional care. Instead, a wide range of services should be developed which will remove barriers to participation and ensure access to mainstream services, thus contributing to social inclusion. For children this would mean being able to go to mainstream kindergartens and schools, to take part in sports activities etc.; for adults, examples include having access to continuing education and meaningful employment opportunities."[53]

The relationship between universal services available to the general public and specialised, disability-specific services is traditionally illustrated with a pyramid, where all public sector services accessible to all people are the foundation, while specialised services, at a higher level of the pyramid, are designed to support people with particular needs to enable them to access generalised services.

Table 2. Relationship between universal services available to the general public and specialised, disability-specific services.

[53] European Expert Group on the Transition from Institutional to Community-based Care (2012) *Common European Guidelines on the Transition from Institutional to Community-based care.* Brussels, Belgium, p. 83.

It is important to maintain the balance between the different levels of the pyramid, as society´s perception of solidarity and fairness is affected by the amount of funds allocated to each segment. In recent years, Bulgaria´s investment in these services has begun to resemble an inverted pyramid, where services provided to people with disabilities attempt to encompass every possible service in a 'protected' environment, instead of making general services available to all people, including people with disabilities. Rather than enabling people with disabilities to access general services, the specialised services have become an end in themselves and pull specialists from general services under the pretence of providing 'integrated services'. The place where people with disabilities access services matters, and currently persons with disabilities are overwhelmingly required to access general services in the same place as the segregated specialised services. This situation raises the following concerns:

– Persons with disabilities 'have access' to mainstream services without any support or reasonable accommodation; and
– Persons with disabilities can practically have access only to services which separate them out from the society.

The current developments in the provision of social services, both day-care and residential services, in reality perpetuate the social isolation of people with disabilities.[54] The services were initially designed as alternatives to institutions, but in the end, they maintain all the characteristic elements of institutions, including the prevailing attitudes of rejection and isolation of people with disabilities. There is no understanding that social services can be a tool, a bridge to accessing other public services. There are no plans or efforts towards building accessible social housing or providing effective support to people with disabilities to access general public services.

[54] The exception is those few services which provide support and accompaniment for people with disabilities to use general public services.

5. Impacts of COVID restrictions on persons with disabilities in institutions, including group homes

Community-based services (e.g. day-care centers, rehabilitation centres) were not available for persons with disabilities during the first and second waves of the COVID-19 pandemic. This situation automatically resulted in higher levels of isolation of persons living in all forms of residential care. However, the same was experienced by persons with disabilities living in the community, since community-based services were not available to them either.

As a response to the pandemic, the Government introduced restrictions on the right to liberty of persons with disabilities. Residents of institutions for persons disabilities were restricted or banned from leaving institutions, and the Government decided to ban visits from family members, friends or others. Furthermore, many residents with disabilities were isolated in their rooms without having any contact, even with their fellow residents. Persons with psychosocial impairments kept in psychiatric hospitals were not allowed to leave the healthcare facility, purportedly in order to 'protect' them from getting infected. These persons with disabilities were considered not to be able to protect themselves from being infected outside of the hospital.

In December 2020, the Council of Europe's Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) published its report on the Committee's ad hoc visit to Bulgaria, which took place from 10 to 21 August 2020. The CPT noted:

> In Byala [State Psychiatric Hospital], patients on the male and female acute wards could go outside for an hour per day but only after a few weeks or, in some cases, a few months had passed, following their admission. Patients on the male and female chronic wards were, allegedly, not allowed to go outside at all, apparently due to the Covid-19 pandemic, despite there being no apparent increased risk in so doing.[55]

Furthermore, the CPT highlighted:

> With regard to contact with the outside world, in all three [psychiatric] hospitals there were many complaints that access to a telephone was very limited; this is particularly concerning given the fact that all visits to patients in the psychiatric hospitals in Bulgaria have been forbidden since March 2020 due to the Covid-19 pandemic.[56]

The CPT recommended, inter alia, that:

> the Bulgarian authorities review the total ban on visits to patients in the psychiatric hospitals, instituted in response to the Covid-19 pandemic, and take steps to ensure that patients can receive such visits in safe conditions, respectful of requirements for physical distancing and with the deployment of PPE as indicated.[57]

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[55] CPT (2020) *Report to the Bulgarian Government on the visit to Bulgaria carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 10 to 21 August 2020*, CPT/Inf (2020) 39. Strasbourg, para 34. Available at: https://rm.coe.int/1680a090b7.

[56] Ibid., para 52.

[57] Ibid., para 54.

On 20 April 2020, a coalition of seven disability rights organisations launched a major global initiative, the COVID-19 Disability Rights Monitor,[58] under which testimonies were collected on state measures concerning the impact of COVID-19 on persons with disabilities. According to a response from a Bulgarian organisation of persons with disabilities, "eight people living in [a]residential service were suspended from work and only by a separate order of the mayor they were allowed to leave the facility."[59]

The right to health of persons with disabilities was also violated in residential settings, since regular medical check-ups for people in residential care were suspended. Persons with disabilities were not admitted to hospitals and did not receive appropriate medical assistance, even when they received positive COVID-19 test results.

A respondent with disabilities shared their concern with the COVID-19 Disability Rights Monitor: "I am afraid that I will not be treated if I become sick from the COVID-19 because I will be considered insignificant."[60]

The right to access to justice of persons with disabilities living in institutional settings was significantly hindered, since access to lawyers was impossible and independent monitoring of residential care facilities was suspended. Due to restrictions imposed, persons with disabilities felt more dependent on the residential services they used and were less willing to report violations of their rights and were less motivated to seek change.

At the end of 2020, during the pandemic and during the cold wintertime, several 'homes for medical and social care for children' were emptied, and children (all of them children with disabilities) were transferred into four institutions of the same type without any preparation and absent any logical reasoning. Civil society organisations informed the Ombudsperson about this and the Ombudsman, acting as National Preventive Mechanism, carried out inspections and found serious violations of the rights of the children concerned.[61]

The CPT also pointed out in the executive summary of its 2020 report concerning Bulgaria:

> "The Committee notes the steps taken in response to the Covid-19 pandemic in the psychiatric hospitals and social care institutions visited by the CPT's delegation and acknowledges that it certainly remains a serious risk to vulnerable patients and residents."[62]

Furthermore, the CPT stressed that "[c]learly, Covid-19 remains a serious risk for the vulnerable residents in social care establishments."[63]

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[58] See: www.covid-drm.org.

[59] On file at the COVID-19 Disability Rights Monitor.

[60] Ibid.

[61] Ombudsman of the Republic of Bulgaria (2020) *Annual Report of the Ombudsman Acting as National Preventive Mechanism*, p. 9. Available in English at: https://www.ombudsman.bg/pictures/Annual%20Report%20NPM%202020%20-%20SUMMARY_EN_.pdf.

[62] CPT (n 56). p. 4.

[63] Ibid., para 76.

6. EU funds: Misused resources

This section provides information on EU funds spent on based on a highly faulty conception of deinstitutionalisation of children and adults with disabilities in Bulgaria.

6.1 Children with disabilities

Prior to receiving EU funding, Bulgaria had already been engaged in a complex process of reform of social services for persons with disabilities. In 2003, group homes were first established as a specific form of social service.

The *Vision for Deinstitutionalisation of the Children in Bulgaria and the Action Plan for the Implementation of the Vision for Deinstitutionalisation of the Children in Bulgaria* (Action Plan) envisaged closure of all 'specialised institutions' for children with disabilities through implementing five distinct projects. The project that focused on closing the large-scale institutions was entitled *Childhood for All*[64] and was completed at the end of April 2015.

Implementation of the Action Plan has been carried out primarily through using financial resources from the EU 2014-2020 funding period and a loan from the International Bank for Reconstruction and Development (IBRD). Execution of each project was defined within parameters necessary to secure financial support from the following EU Operational Programmes: 'Human Resources Development', 'Regional Development', 'Program for Development of the Rural Regions' and 'Technical Support'. The total budgeted financing for the projects was BGN 285,624,085 (approx. EUR 146.2 million), of which BGN 255,744,557 (approx. EUR 130.9 million) was spent, inclusive of national co-funding.[65]

The Action Plan envisaged a minimum level of service provision in every region: services for prevention of institutionalisation, urgent protection measures for children at risk,[66] foster care and residential care. According to the Action Plan, residential care was to be provided only for a small number of children with "extremely complex disabilities, or older teenagers with deviant (antisocial) behaviour who do not want to live in a family".[67]

In addition to *Childhood for All* and the other four projects, the Action Plan envisaged administrative and legislative changes to ensure that new social services would be grounded in a different philosophy and context from that in which the large institutions operated. The aim had been "to develop the legislative and regulatory framework necessary to ensure the transition towards care in the family and community".[68]

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[64] Information on the project is available on the website of the State Agency for Child Protection, available in Bulgarian at: https://sacp.government.bg/%D0%BD%D0%BE%D0%B2%D0%B8%D0%BD%D0%B8/%D0%BF%D1%80%D0%BE%D0%B5%D0%BA%D1%82%D1%8A%D1%82-%E2%80%9E%D0%B4%D0%B5%D1%82%D1%81%D1%82%D0%B2%D0%BE-%D0%B7%D0%B0-%D0%B2%D1%81%D0%B8%D1%87%D0%BA%D0%B8%E2%80%9C-%E2%80%93. According to the Agency, the execution of the project is "the first fairy tale with a happy ending". The Agency goes on to say that "the deinstitutionalisation has been carried out following an individual plan which has taken into account the needs of every child and young person".

[65] Audit report for the implementation of the *Action Plan for Vision of Deinstitutionalisation,* p. 31. Available in Bulgarian at https://www.bulnao.government.bg/bg/articles/download/12630/od-deinst-deca-070819.pdf. The Audit Report was approved as final as a result of the Decision 202/18.07.2019 issued by the National Audit Authority.

[66] According to the Child Protection Act, Additional Provisions Article 1 para 11 "d", children with disabilities are considered as children at risk.

[67] Action Plan, p. 28.

[68] Ibid. p. 4.

This would have given life to the commitment that group homes would only have been a temporary solution and not result in long-term placements. The planned legal amendments were not completed, as was pointed out in a 2019 Bulgarian National Audit Office report.[69]

> Certain legislative changes laid down in the Action Plan for the Implementation of the National Strategy entitled "Vision for De-Institutionalization of Children in the Republic of Bulgaria" for the period 2009 – 2015 still have not been implemented. Commitments of the executive branch to change the legal framework and bring about positive change in the area of childcare in Bulgaria were implemented according to the concept set out in the Action Plan and, in part, in accordance with deadlines set out in the appended timetable. A significant portion of the planned legislative changes were not made within the stipulated deadlines. As a result of not meeting the timelines originally envisaged, the timely implementation of some of the measures laid out in the Action Plan has been undermined (…)
>
> During the audited period, a draft Law on children's rights and the then draft Social Services Act (which entered into force on 1 July 2020), as well as draft changes to the Family Code, were developed, which at the time of the audit had not been considered or adopted by Parliament. The required changes to the legal regulation of the DI process were made by adapting existing laws, including the Law for Child Protection, Social Assistance Act, Family Allowances for Children Act, and the Health Act. Furthermore, these legislative changes were accompanied by ministerial decisions concerning implementation of the respective laws and through adoption of new regulations, as well as amendments to already-existing regulations, according to the readiness of the relevant authorities for the implementation of the reforms of the system. **As a result, the planned modification to ensure support for all children, not only those at risk, has not been fully completed in the period 2009 – 2015.**[70]

Failure to adopt the necessary legislation envisaged in the Action Plan has led to the result of **emergence of new forms of institutional care. Regardless of how they are named, what matters is that the new group homes continue to have the same institutional characteristics, in part as a result of the incomplete process of reform**.

According to official statistics of the Ministry of Labour and Social Affairs, the number of institutionalised children in Bulgaria decreased by 87%, from 7,587 to 906 during the *Children for All* project.[71] In fact, these statistics exclude the 'deinstitutionalised' children and young people who were in fact transferred to group homes throughout the country.

Many of the children and young people who were previously located in the old large-scale institutions were placed with foster families and were adopted. However, the majority of children and young people with disabilities were transferred to group homes.

The reality is that the EU-funded *Childhood for All* project resulted in expanding the system of institutionalisation for children with disabilities in Bulgaria. At the end of the project, there were

[69] *Bulgarian National Audit Office (2019) Audit Report N 1000100416 on implementation of the Action Plan for the Vision for Deinstitutionalisation 2009-2015*.

[70] Ibid.

[71] Elena Kremenlieva and Sabina Sabeva (2018) *Deinstitutionalization in Bulgaria – irreversible change of the child care system*. Ppt presentation, slide 7. The presentation is available at: http://esf.bg/presentations/#.

approximately 200 more places in residential settings than under the old system. This figure excludes further expansion of institutionalisation outside the scope of this specific project. Further, some of the old institutions continued operating and accepting babies with disabilities.

Numerous compromises were made throughout the project which undermined the initial positive intentions.

- FUNDING – MONEY ABOVE ALL: At the outset, group homes were designed to contain 12 standard beds and two beds for crisis placements. Funding for the group homes during implementation of the "Childhood for All" project was to be provided based on the number of children and young people living in each home. This funding model introduced a negative incentive to group homes to maximise their capacities to attract maximum funding.

- ASSESSMENTS - EFFICIENCY TRUMPS BEST INTERESTS: Transfer of residents from the large institutions to the group homes was supposed to take place following an assessment process, team decision-making, and coordination and synchronisation of the work of all professionals involved. The initial idea was to transfer children close to their friends and families, and to keep siblings together. However, children were sent to new settings on the basis of lists predetermined by the ASA which overlooked this initial idea because of the influence of municipalities, who sought to have only people with mild impairments accommodated on their territory. This lead the SACP to declare that they cannot guarantee the rights of transferred children and young people.[72]

In 2016, after the official completion of DI of children in Bulgaria, the Bulgarian branch of *Lumos Foundation*[73] carried out research into the effects of the relocation on the development of children and young people to group homes.[74] The research analysed individual cases and evaluated the well-being of individual children and the general characteristics of the group homes. The research did not explore whether the group homes replicated the old institutional culture, and did not address the impact on children and young people of living in a small, closed group, under constant surveillance including by CCTV, nor the effects of the system of control exercised by staff over every aspect of children's lives. Furthermore, the report failed to address the increased use of medication to restrain and control the behaviour of children.

The *Know How Centre for Alternative Care for Children*, which is part of the academic structure of the New Bulgarian University Sofia, published two research reports on DI.[75] The research results include the following: lack of support for families; lack of knowledge about potential support measures; lack of real goals for children and young adults with disabilities who were moved into group homes. Even though these findings are important, group homes themselves are not criticised in these documents and the group home model is accepted as an acceptable 'alternative' to institutions.

For some actors, the DI process for children with disabilities has been successfully completed in Bulgaria. For others, closing the big institutions does not guarantee the human rights of children with disabilities, yet there is no evidence of a clear idea or plan for how to move forward.

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[72] Bulgarian National Audit Office (2019) *Audit Report N 1000100416 on implementation of the Action Plan for the Vision for Deinstitutionalisation 2009-2015*.

[73] See: https://www.wearelumos.org/Bulgaria/.

[74] Lumos Foundation (2016) *Abort the institutionalization, assessment of the results for the children and young people in Bulgaria transferred from the institutions to services in the community.* Available in Bulgarian at: https://lumos.contentfiles.net/media/assets/file/Bulgarian_Outcomes_Report_BUL_WEB_14JUN16.pdf

[75] Know How Centre for Alternative Care for Children (2013) *Research on the process of DI: the case "Bulgaria" – 2013*; and Know How Centre for Alternative Care for Children (2017) *"Deinstitutionalisation - the case Bulgaria" – 2017*.

At this point, there is no discussion about the future for children and young adults transferred to group homes, even though the age limit for remaining in these facilities is set by law at 35 years. There are no apparent plans to reform public housing policy in cities where group homes have been built. It seems clear that the assumption is that 'deinstitutionalised' children and young people will continue living in these smaller institutions even after they turn 35 years old.

> "I suppose that they will change this age to over 35 years like they increased the age a few years ago – it was up to 29 years and then, because these people had nowhere to live, they increased it. Previously, we sent them into large group homes for adults, but now they will close them too." (Staff member in a group home)

From a substantive point of view, the type of care provided in small group homes and the experiences of children are, in essence, the same as in large-scale institutions. The end result is 'better' institutional care, but it is still care that is institutional and which violates independence and inclusion.

6.2 Adults with disabilities

The DI process for adults with disabilities is being managed in a similar way to that for children. It began in 2014 with the development of the policy document *'National Strategy for Long-Term Care' (the 'Long-Term Care Strategy')*, adopted by the Council of Ministers on 7 January 2014.[76] The first Action Plan (the *'Long-Term Care Strategy Action Plan'*)[77] covers a three-year period, from 2018 to 2021. It is coordinated centrally by the ASA and implemented locally by the municipalities. According to information received from the ASA, in November 2018, there were 13 institutions for adults with psycho-social disabilities in Bulgaria and 27 institutions for persons with intellectual disabilities.[78]

A project entitled *Support for Deinstitutionalisation of Social Services for Adults with Disabilities* is under way to close ten institutions for adults with intellectual disabilities and adults with psychosocial disabilities, affecting an estimated 515 people with intellectual disabilities and 363 people with psychosocial disabilities. Admission of new residents to these ten institutions was suspended as of 9 March 2018. Residents of these institutions are to be moved to small group homes and given access to day care services outside of group homes. As at the time of writing this report, total financing allocated under this project has amounted to BGN 41,373,980.19 (approximately EUR 21.1 million). The European Regional Development Fund (ERDF) has provided 85% of the funds, while 15% constitutes contributions from the State budget.[79]

The new social services currently being developed in Bulgaria are considered by the State to be alternatives to institutions. But in fact, they constitute the same form of institutional "care", albeit in a scaled down form.

[76] The Strategy adopted with Decision N 2/07.01.2014 issued by the Council of Ministers and it is available in English at: http://www.strategy.bg/FileHandler.ashx?fileId=9432.

[77] According to the Guidelines for Application, the Long-Term Care Strategy Action Plan was developed by representatives of State authorities, the National Association of Municipalities in Bulgaria and NGOs engaged in the provision of social services (service providers).

[78] Information is on file with the authors of this Report.

[79] Guidelines for applying under the Call for Proposal BBBG16RFOP001-5.002 "Support for deinstitutionalization of the social services for elderly people and people with disabilities". The Guideline was adopted by Order RD-02—287/30.03.2018, which is available in Bulgarian at: http://www.bgregio.eu/media/files/Kandidatstvane/Aktualni%20sxemi/2014-2020/%D0%9F%D0%9E5/180330_Zapoved_Nasoki_5.002.PDF.

From the very beginning, the DI process has been and continues to be implemented with significant financial backing from various EU financial mechanisms which act as a strong incentive for the Government to continue this pattern.

DI for adults in Bulgaria is funded through several EU Operational Programmes under the ERDF. For the period of 2014-2020, funding for the construction of new facilities and provision of services is channelled through the 'Regions in Growth' Operational Programme, while all other activities benefit from funding provided through the 'Human Resources' Operational Programme. Development of social infrastructure connected to the DI of adults is planned to be supported through Axis 5 of the 'Regions in Growth' Programme – 'Regional Social Infrastructure'[80] – with a total budget of 50.8 million EUR for Bulgaria alone.[81]

The 'Regions in Growth' Programme was approved by the European Commission on 15 June 2014.[82] As part of the framework of this Programme and Axis 5, a Call for Proposal for Direct Financial Support under BG16RFP001-5.002 "Support for deinstitutionalization of the social services for elderly people and people with disabilities" was approved. According to the Guidelines for Application for funding for this programme (the 'Guidelines for Application'), approved by Order RD-02—287/30.03.2018,[83] the financial support must be used to build day-care centres and 68 new 'residential centres'. The residential centres are planned to cater for 3,060 people in total. Only 54 of the 265 municipalities in Bulgaria were preselected as potential beneficiaries of this financial support. 26 of these applied for the funding. Their proposals were approved, and the contracts were signed between the national Managing Authority for EU funds (the 'Managing Authority') and successful municipalities.[84] DI of adults is based on the Action Plan, referred to above.[85] The Call for Proposal for Direct Financial Support and related documents use several 'Maps of Services' to determine where new centres are planned to be built and in determining the type of services they will provide.

These maps were not made publicly available. In July 2019, the Center for Independent Living, Sofia, an independent NGO that represents persons with disabilities, asked the Ministry of Labour and Social Policy for information about these 'maps of services'. Even though these maps are already being used, the Ministry responded that the concept of 'maps of services' was only defined within the draft Social Services Act that entered into force only on 1 July 2020. Further, there has been no process of collecting information to identify what services are needed and where. According to the Ministry's letter, this will take place "at some point in the future".

In 2019, the Ministry started another project called 'New Standards for Social Services', in which it contracted a private company to create criteria for the development of the 'maps of services'.[86] The company has published a collection of materials under this contract, entitled "Model for Planning of Minimal Package of Services at the Regional and Municipal Level: Objective Criteria for Development of the Map of Services at the National Level. Map of Needs and Map of Services".[87]

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[80] This Axis targets, among other things, "the transition from institutional to community-based services".

[81] The Program is available in Bulgarian at: http://www.bgregio.eu/programirane-i-otsenka/mrrb.aspx.

[82] See Annex to Model for operational programmes under the Investment for growth and jobs goal to the Commission Implementing Regulation (EU) No 288/2014. Available at: http://bgregio.eu/media/files/Programirane%20i%20ocenca/OPRG%202014-2020_2014BG16RFOP001_1_3.pdf

[83] Available in Bulgarian at http://www.bgregio.eu/media/files/Kandidatstvane/Aktualni%20sxemi/2014-2020/%D0%9F%D0%9E5/180330_Zapoved_Nasoki_5.002.PDF.

[84] Information about the municipalities, their projects and signed contracts is available in Bulgarian at: http://www.bgregio.eu/media/files/Dogovarqne/Sklyucheni%20dogovori%202014-2020/14_03_19_190313_Prilojenie%206.18%20Obiavlenie%20za%20vazlagane%20na%20dogovori%20-%205.002.pdf.

[85] See footnote 82.

[86] Documents with which the company takes part in the competition for this task are available in Bulgarian at: http://profile.mlsp.government.bg/73e9a1c0bfa9b9beefcc8646c70fd1ff.

[87] This document is publicly not available but is on file with the authors of this Report.

Assessing the support needs of persons with disabilities living currently in ten large institutions to be de-institutionalised under the *Support for Deinstitutionalisation of Social Services for Adults with Disabilities* project has not yet started. There was a Call for Proposal that was planned to fund this assessment.[88] The activities under this project should have included: developing a methodology for closure of the institutions and for 'reformation' of all institutions for elderly people; activities to prepare the concerned individuals for relocation; and building the capacity of social support and healthcare systems. According to the plans, the only partners in this process would have been psychiatric hospitals. To our best knowledge, the planned activities were not completed due to the COVID-19 crisis. The aim of the project was to create 68 new 'residential centres'; however, it is not clear on which basis people would be placed in these new centres. As many people are waiting to be admitted to institutions, we can expect completely new admissions to these residential centres. Instead of achieving DI of those people already institutionalised, it is likely that another expansion of the system of institutionalising persons with disabilities will now take place.

EU funding is used for DI in Bulgaria in a chaotic way: formally the Government puts forward that all decisions are taken based on public discussion, but, de facto, the most serious decisions are taken by a small number of institutions and organisations, without the participation of people with disabilities who are affected or any consideration of their real needs.

Examples of some of the planned 68 group homes to be built under the *"Support for Deinstitutionalisation of Social Services for Adults with Disabilities"* project:

Municipality of Sliven: According to a contract between the Municipality and the Managing Authority, the Municipality will create two group homes for provision of social services. These will include a "Care Centre for People with Mental Disorders" and a "Care Centre for People with Mental Disabilities".[89] In total, 30 people will be placed in these new institutions. At the same time, this Region continues to run the biggest institution in Bulgaria for adults with intellectual disabilities – the 'Home for Adults with Intellectual Disabilities' in Kachulka, where 240 people live. This institution is extremely isolated. The situation resulted in concerns being formally raised by the Committee for the Prevention of Torture in its report issued on 4 May 2018.[90] An assessment of the needs of the residents in the Kachulka institution would have been finished already; however, there is no reliable information about the pandemic-related delay of this project. Furthermore, it is not yet clear whether anyone living in the Kachulka institution will be placed into the new smaller institutions. Much more importantly, the new institutions will definitely not fit the needs of anyone, including people from the Kachulka institution.

Municipality of Sofia: A total of nine new centres will be established in this Municipality. Buildings will be constructed in two areas: Knyazhevo, Vitosha District, and Podgumer, Novi Iskar District. At present, there is one large-scale institution in Knyazhevo – the "Home for Adults with Dementia". A new building will be constructed in a space adjacent to this 'Home' and will be used as a 'community-based' social service: a "Day Centre for Support of People with Different Forms of Dementia and Their Families".

[88] See Call for Proposal BG05M9OP001-2.038-0001-C01. The direct beneficiary is the ASA. The call is available at: http://2020.eufunds.bg/bg/4/0/Project/BasicData?contractId=1fgdyAIjZtw%3D&isHistoric=False.

[89] "Information for Issued Orders/ Awarded Grant Under Operational Programme "Regions in Growth" 2014-2020, Priority Axis 5 „Regional Social Infrastructure "Call for Proposal BG16RFOP001-5.002 „Support for deinstitutionalisation of social services for adults and people with disabilities". p. 7.

[90] European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (2018) *Report to the Bulgarian Government on the visit to Bulgaria carried out by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) from 25 September to 6 October 2017*. CPT/Inf (2018) 15. Strasbourg. Available at: https://rm.coe.int/16807c4b74. See for example para 144.

It is clear that this Day Centre will not be "community-based" but rather segregated as it will be built right beside the institution and separated from the surrounding community. In Podgumer, there are currently two institutions: a large-scale "Home for Adults with Intellectual Disabilities" and a group home for 'people with mental disorders.' The latter is in the yard of the former. Under the project, eight group homes will be built in the space adjoining the institution.[91] Each group home will house up to 15 people, so most likely 120 people in total will live there. The concerns regarding the Day Centre service in Sliven are even more stark here. The institution is in an extremely isolated location which is difficult to access, especially in winter. The effect of the project will be to expand the capacity of the existing institution by 120 new places, using EU funding and justifying this as DI.

Municipalities of Srtymyani and of Lakatnik: In Srtymyani the plans are similar to the above examples, while in Lakatnik, the Municipality plans to build the new group homes right beside the existing large institution for women with psychosocial disabilities.

It quickly becomes clear from the documentation and the examples above that the availability of extremely large amounts of funding from the EU provides both an opportunity and an incentive for existing institutions to expand their capacities and the services they provide, without actually releasing any of the residents into genuinely independent living circumstances in the community.

[91] "Information for Issued Orders/ Awarded Grant Under Operational Programme "Regions in Growth" 2014-2020, Priority Axis 5 „Regional Social Infrastructure "Call for Proposal BG16RFOP001-5.002 „Support for deinstitutionalisation of social services for adults and people with disabilities". p. 11.

7. Conclusions

The DI model in Bulgaria focuses on big institutions as the big problem to be solved. Indeed, policymakers and decisionmakers seem to believe that the only real problem with big institutions is their size. Unfortunately, there is lack of real interest on the part of the State in investing EU and State funds into genuine services which promotes independence and inclusion, or ensuring foster families are available for children with disabilities. Similarly, there is a lack of understanding when it comes to closing institutions and the need to provide persons with disabilities with real choices to be able to decide on where, how and with whom they would like to live.

20 years ago, the State wanted to decrease the number of placements in institutions, but statistics show that it has failed to achieve this aim. Nowadays the structure of care for children has changed: from big institutions, children with disabilities have moved to foster care and small institutions; but, strikingly, the overall number of children separated from their families remains at the same level. Statistical measures have been taken which seem to show progress, but upon close examination, overall progress seems minimal and to be grounded in transferring children from big to small institutions.

The attempts to address institutionalisation started 20 years ago and yet some of the same old problems persist: a lack of understanding of what real alternatives to big institutions are; no real improvement in autonomy or inclusion for persons with disabilities; persistent claims that new services are community-based, whereas in fact they continue to segregate and isolate persons with disabilities; and lack of progress on developing universal services that are available and accessible to all. These problems, unsurprisingly, mean that institutional culture persists throughout all service structures designed to serve people with disabilities.

The most important question which remains to be addressed by 'experts' of DI is this: Why does our society continue to separate people with disabilities from our society? The presence of institutional structures can be understood as a symptom, an external sign of something internal, deeply hidden in society. **Placement in institutions is only possible where there is an acceptance that people who are different can be removed. This behaviour is based on a lack of understanding of and lack of respect for the uniqueness of every human being.**

The fears of difference and the belief that difference should be viewed as a problem have deep roots. Prejudice against people with disabilities remains widespread. Doctors still advise parents to abandon their child if they are born with a disability. Parents who decide not to abandon their child with a disability live with the feeling that they are doomed for the rest of their lives. Prejudice and lack of acceptance of differences leads to DI programmes which focus only on the basic physical survival of the child without any hope for them ever flourishing or become full, autonomous citizens with the support they need. Because of this, children with disabilities are rarely provided the chance to prepare for independent life in adulthood.

In reality, the DI process in Bulgaria creates a parallel system for people with disabilities. Whereas people without disabilities generally live in their own homes or rent an apartment, 'deinstitutionalised' persons with disabilities have to live in a group home. Group homes are filled with pre-selected persons with disabilities, with the selection criteria being the type and level of their impairment. Although they have been 'deinstitutionalised', they are still forced into cohabitation with other residents, and have no real possibility to choose where they want to live or who they want to live with. They have no support outside the four walls of the group home. Their 'home' is organised and run by hired personnel and their days are regulated by strict daily routine. Everything in the home is managed in accordance with internal regulations, usually drafted by the personnel.

Furthermore, inappropriate housing, inaccessible physical environment, lack of employment opportunities, and lack of support services, including personal assistance, threaten the inclusion of those people with disabilities who presently live in the community. The system is inadequate, forcing people to receive support only from their friends and family thereby placing them at the risk of being institutionalised at the point when their parents or relatives are no longer able to provide support.

The process of inclusion of persons with disabilities in the community in Bulgaria is like knocking on an illustration of a door on a brick wall and waiting for it to open. It is nothing more than a three-dimensional illusion.

8. Recommendations

To the European Commission:

- Prevent ESI Funds from being allocates to any form of institutionalised care, including group homes, for persons with disabilities.
- Prioritise funding to improve the accessibility of persons with disabilities to general public services including healthcare, housing, employment, transport and education.
- Allocate funds for development of new support systems that are based on direct funding for adults with disabilities and for families of children with disabilities (personal budget system).
- Investigate how EU funds have been spent on the trans-institutionalisation of adults and children with disabilities, drawing on the standards required by the Convention on the Rights of Persons With Disabilities, in particular Article 19 and General Comment No. 5 (2017).

To the Government:

- Designate an independent monitoring mechanism in accordance with the provisions of Articles 33(2)-(3) of the CRPD in order for the independent monitoring mechanism to be able to carry out regular monitoring of all services provided for persons with disabilities.
- Ensure the full and effective participation of persons with disabilities and their representative organisations (i) in the development and implementation of legislation and policies to implement the CRPD, (ii) in other decision-making processes concerning issues relating to persons with disabilities, and (iii) in the independent monitoring mechanism, in accordance with the provisions of Articles 4(3) and 33(3) of the Convention.
- Make sure that statistical data collected about persons with disabilities living in institutional settings and in the community is reliable, transparent and is in line with Article 31 of the CRPD.
- Ensure that all responses to COVID-19 and any future emergencies protect the rights to life, health, liberty, freedom from torture, ill-treatment, exploitation, violence and abuse, the rights to independent living and inclusion in the community, and to inclusive education, among others, for persons with disabilities without any discrimination on the basis of disability.

To the Ministry of Labour and Social Policy/ Agency for Social Assistance:

- Prevent new placements of persons with disabilities in institutional settings (regardless of size and including all forms of group homes) by immediately adopting a no-admissions policy.
- Review and re-think the structure of Bulgarian social policy; assess and evaluate the effectiveness of the current social policy system from a human rights perspective and implement future reforms in line with the CRPD and the CRPD Committee's general comments.
- Ensure that families having children with disabilities are entitled to sufficient income to prevent institutionalisation of their children, and that they are entitled to the same level of services as families having children without disabilities.
- Map out what kind of services are missing for persons with disabilities to live independently in the community, and begin operating new services on the basis of this analysis.

- Halt investing funds in renovation, reconstruction and reformation of existing institutions and in creation of new institutional settings including any types of congregate settings, and any type of group home.
- Provide persons with disabilities with meaningful choices about housing options when they move out from different types of institutions.
- Set up clear timetables, measurable targets, and regular monitoring dates in order to perform an urgent and CRPD-compliant DI process.
- Provide persons with disabilities living in group homes and in other types of institutions with opportunities to learn and exercise skills.
- Provide residents with reasonable accommodations in order to enable them to communicate their will and preferences and the support they need.
- Re-think and amend the current administrative structure related to the execution of social policies and support of different vulnerable groups; adopting a holistic approach of social services to ensure effective coordination between different administrative bodies.

To the Ministry of Health:

- Ensure that the process of closure of the Homes for Medico-Social Care for Children is transparent and civil society has access to these settings and to all documents related to closure plans.
- Ensure that children are never transferred from one institution to another, even if the latter is smaller.
- Ensure that foster families are prepared to care for children with disabilities, including children with profound disabilities.
- Ensure that institutions for babies with disabilities are not replaced by group homes, and that all children can enjoy real family life.

To the Ombudsman:

- Apply provisions of the CRPD and guidance given in general comments of the CRPD Committee when conducting investigations in relation to persons with disabilities, including in relation to their right to live independently and be included in the community.

To the Audit Office of Bulgaria:

- Ensure that investigations reflect on whether implemented projects respected human rights requirements, including provisions of the CRPD and guidance given in general comments of the CRPD Committee.

To the Chief Prosecutor:

- Provide prosecutors with training on how to recognise cases of neglect, violence and violation of the human rights of persons with disabilities, and how to approach and interview persons with disabilities who have been subject to neglect, violence and other violations of human rights.