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# Are Four Centuries of Systemic Segregation Coming to an End?

A socio-historical analysis of custodial care with case studies on  
deinstitutionalisation of children with disabilities in Bulgaria and Serbia.

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## **ABSTRACT**

This study encompasses the phenomenon of institutionalisation of persons with mental disabilities in a holistic manner, from its rise to the fall as the only mainstream form of care for this group. The phenomenon of the period of “great confinement” with regards to persons with mental disorders determined the later development of custodial care systems; hence my thesis examines wrongness of the inveteracy of punitive and control oriented care that was long taken for granted. The perception of mental disorders progressed significantly after the aforementioned period; still today we are able to detect worryingly outdated approaches to mental disability as well as some features of the custodial care that were present a few centuries ago. A significant breakthrough happened with introduction of somewhat vague concept of dignity that allowed theorists and lawmakers to further develop understanding of this concept and incorporate it in international legal instruments. The position of dignity is examined with regards to realization of the rights of persons with mental disabilities and understanding the importance of autonomy as a prerequisite for dignified life. Ultimately, deinstitutionalisation is a tool by which the society loosens the control established upon the persons with mental disorders a long time ago.

The case studies focus on the processes of deinstitutionalisation of children with disabilities in Bulgaria and Serbia. The Bulgaria’s experience gives appreciable insight in this process which Serbia can use to carry out a successful deinstitutionalisation of children with disabilities.

## **Abbreviations**

CoE	Council of Europe
CSO	Civil Society Organization
DI	deinstitutionalisation
ECHR	European Convention on Human Rights
EU	European Union
HRW	Human Rights Watch
MDRI-S	Mental Disability Rights Initiative –Serbia
SGH	Small Group Homes
UN CRC	United Nations Convention on the Rights of the Child
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities

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## **General Introduction**

*Let's face it, disabled people face the most prevalent, world-wide, persistent, resistant to change and endemic form of apartheid, to put it mildly, of any human group throughout the world! V. Finkelstein*

The contemporary development in the protection of the rights of persons with mental disabilities is a confirmation of a substantial progress that has been made in this field. Still, a striking level of similarity between the modern and the earlier societies' approaches to disability is present, showing a huge discrepancy amidst established international standards and the actual practice. This gap gave a space for a significant number of advocates to start working tirelessly in order to close it or at least reduce this gap.

A need of a state to exercise power and control over certain social groups appeared early in the history of statehood. In most of the cases when the state interferes in one's life we will be able to detect a certain level of autonomy left to this person. However, complete deprivation from the right to choose and ubiquitous denial of autonomy with such a meticulous control over person's life is probably only familiar to the institutionalised persons living with mental disability. In this work I will present a correlation between freedom of choice and dignity on the one side and deprivation of control over one's own life on the other side. To do so I will use works of Foucault, Goffman, Rosenberg, Scull and other authors whose contribution to the social science, especially with regards to the states' treatment of persons with mental disabilities and social control is immense.

The purpose of the research behind this paper was to examine a position of persons with mental disabilities in the context of institutionalisation. Starting with the period of the Early modern Europe, when the first large facilities were opened, this thesis gives a comprehensive overview of the phenomenon of mass incarceration of this group. When reading this chapter you will be able to track changes in the perception of disability and persons with disabilities among general public. In many societies they were often, and still are today seen as 'subhuman', lower form of life, and more as an exception than a rule – equal to others. The western states' approaches to the problem of persons with disabilities are presented through

legislation and public policies that were applied during the given period. A road from unregulated field to unethical laws and policies to those with less discriminating quality was long, thorny and conditioned by numerous factors, sometimes by those that you would expect least. However this road was not always and for everyone straight and at times there were ‘u turns’ that remind us that regress is part of our societies’ dynamics as much as progress.

One of the main symbols of institutionalisation of mentally disabled persons are facilities and their architecture. Therefore, I will present some of the most notorious asylums through their architecture that was conditioned by, then and now, present perceptions of mental illness and general treatment of mentally ill persons. This chapter finishes with termination of institutionalisation as an only mainstream option of care provided by the states for persons with disabilities and the beginning of a more humane trend marked with rise of human rights based approach to disability and deinstitutionalisation. Thus, a holistic overview of institutionalisation with all its implications is presented from its beginnings to the present time.

In the second chapter the focus will be on the international and a few national legal standards from the past and nowadays with regards to persons with disabilities and their right to independent living. Starting with a brief overview of the most significant national legal acts and policies in the 17<sup>th</sup>, 18<sup>th</sup> and 19<sup>th</sup> century this chapter gives a legal context to the socio-historical study of institutionalisation that was discussed in the first part. Then, I will proceed to the current international and regional legal standards that provide framework for the process of deinstitutionalisation. I will discuss a role of the concept of dignity in these standards, as an element through which we can understand all the consequences and wrongness of institutionalisation. I will apply a strong philosophical approach to explanation of this concept in the context of international law. Thus, a solid link between philosophy and law will be established, which is necessary in order to correctly understand and apply the given standards. To successfully cover the aforementioned topic, beside the actual legal documents, I will use secondary literature as source to examine position of dignity in the context of institutionalisation. These sources will be works written by philosophers, sociologists and legal theorists such as Kant, Andorno, Lehnert and others. Reports from various non-governmental organisations and their interpretation of the international legal standards are another significant source of information, as well as the interpretations of these legal acts in jurisprudence and by the lawgivers themselves.



Finally, the third chapter will present case studies on deinstitutionalisation of children with disabilities in two Balkan countries. This study was conducted by reviewing recent publications from national and international non-governmental organisation, but also concluding observation of the United Nations Committees, the shadow reports and number of interviews I conducted in Serbia, Hungary, Greece and Belgium, Romania and Bulgaria with state officials and professionals in the field of the rights of disabled persons as well as social workers. My participation to conferences in Hungary, Serbia and Belgium were another important source of information, since the most recent breakthroughs and plans for the future acting were exhibited at these meetings. Namely, Bulgaria was taken as an appropriate subject for this research because of their determination to eradicate large institutions for children with disabilities. As a member of the European Union this country was subjected to close scrutiny of international stakeholders and also a strong support from various agencies, thus leaving behind significant amount of useful information. Bulgaria has also certain similarities with Serbia, especially in the socio-historical, cultural and economic spheres. Hence, I will use the Bulgaria's experience in this process to make a number of recommendations for deinstitutionalisation of children with disabilities in Serbia, by setting a list of actions that should be taken by the State and by the advocates for the rights of persons with disabilities. Children with disabilities are particularly vulnerable group in our society. Risks of institutionalisation are especially high in the case of children, and even short stays in institutions can result in irreparable damages on mind and body of a child. Because of the urgency to shutter institutions for the children and provide them with family or family-like care and accommodation, this group deserves a priority, if prioritization is necessary. I cannot emphasize enough the importance of researches conducted on this topic. They provide stakeholders and governments with the valuable information, continuously searching for more progressive solutions that consider all elements and structures that need to partake, or that will be passively impacted by these changes.

Apart from the main question already contained in the title of the thesis, I will be focused on revealing the reasons that lead to decreasing of autonomy and incarceration of persons with mental disabilities and societal, political and economic mechanisms in which this phenomenon occurred. Understanding the causes of institutionalisation is necessary in order to comprehend the importance and prospects of the opposite process – deinstitutionalisation. Some other question will be raised and answered throughout the thesis such as influence of the 'social model' on the contemporary international legal standards and how these standards

incorporate the concept of dignity with regards to personal autonomy, freedom of choice, independent living and inclusion in the community of the persons with disabilities. The thesis will finish with the answers on the current situations on deinstitutionalisation processes in Bulgaria and Serbia. The main question of the case studies will consider steps that Serbian government and the organisations of civil society are supposed to take in order to have a successful deinstitutionalisation of children with disabilities.

Limitations of this thesis are not inappreciable. Bureaucratic obstacles prevented from conducting interviews with parents and children with disabilities. Access to all institutions for children with disabilities was denied. Official data was almost impossible to obtain in Serbia, in spite of legal obligation to provide the data to which an official access was requested. The accessible data was usually not disaggregated and not up to date. Still, with the help of professionals in this field and a number of interviews and conferences that I was able to attend, those deficiencies were compensated to an extent. Also, the recommendations provided in this thesis have a form of general principles, while detailed roadmap for a process of deinstitutionalisation is almost impossible to provide without a cooperation of various governmental departments and civil society organizations.

## *Phenomenon of institutionalisation*

In this section I will provide a rather brief and concise overview of development of institutions for persons with mental disorders and various social and economic circumstances that determined this process. My intention is to trace a number of perception changes of institutionalisation of mentally ill persons with a focus on the state's regulation of this issue, medical involvement (punitive/curative character) and the effects it had on persons with disabilities. It is fairly hard not to fall into a trap of superficiality when dealing with such a broad and complex theme as the history of mental disability. In order to avoid this I will try to give abridged analysis of the most credible and recent academic works, not forgetting classics such as Foucault's 'Madness and Civilization' in which he gave brilliant theories on the states' exhibition of control and power.

The genesis and evolution of the establishments where mentally ill persons were held was ultimately conditioned by different understandings of mental illness. It shouldn't be forgotten that the development of human rights, especially in the second half of the 20th century, further discredited existence of some types of these institutions. At the same time this argument gave, in a certain way, an excuse for the practices in the earlier periods. This 'excuse' could be set on the fact that there were no international legal provisions that would set standards for care and accommodation, only civil and political rights were gaining the ground, while the social rights came on the scene more than one century later. The institutions that I am going to write about here are so-called 'total institutions'. This name was coined by Erwin Goffman (1961), who also gave one of the best definitions of these institutions: "a place of residence and work where a large number <sup>1</sup> of like-situated individuals, cut from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life".<sup>2</sup> Nonetheless, this highly complex process

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<sup>1</sup> According to the standards nowadays, the number of people in an institution is irrelevant, what is important is existence of 'institutional culture' which is actually described in the given definition.

<sup>2</sup> Goffman's definition does not differentiate prisons from residential institutions for persons with mental or any other type of disability, neither should it. This lack of difference perfectly depicts similarity of living regimes in these two types of establishments. The patients, who are residents of 'total institutions' are virtually prisoners. Recent development of the international legal standards put an emphasis on independent living, freedom of movement and supported decision-making regime instead of substitute decision-making, in order to make a shift from paternalising approach to persons with disabilities, and to empower and emancipate persons with mental disabilities.

could not be successfully explained without an interdisciplinary approach. Therefore, philosophy of mental illness, history of medicine, human rights and social constructionism are disciplines and points of view taken into account during creation of this section.

### ***Institutionalisation in the Early modern Europe***

Foucault (1961) metaphorically attaches the adjective ‘unreason’ to the pre-Classical period when madmen were wandering around European cities free and when they happened to be the protagonists of the best written pieces of that time. Nonetheless, this Foucault’s claim is strongly objected by some writers. Johan Huizinga claimed that insane were “treated with an incredible hardness and mocked” (Huizinga 1954, p.26 in Bennet 2008). Nonetheless, Neaman (1975, p.140 in Bennet 2008) acknowledged an ambivalent treatment of the insane by the Church; namely, clerics often “considered them bestial” while at the same time madmen could be beneficiaries of the special treatment by the Church. Today we can with a lot of confidence say that the treatment of insane in the Middle ages wasn’t a role-model, neither that the insane enjoyed some kind of a heavenly freedom in their non-obstructed insanity. However, what we can say with even more precision is that the Middle Ages were not a period of madmen’s systematic incarceration with punitive character. The Enlightenment era, that ‘Age of reason’, managed to turn the things upside down. Tendency towards segregation of mentally ill appears to be very hard to eradicate even two centuries later.

The widespread trend of building institutions, where the ‘social misfits’ were held, started early as the 17<sup>th</sup> century. One of the most important of this kind was the ‘Hôpital général’. Founded in Paris in 1656, this institution soon got many smaller establishments, such as the infamous ‘Bicetre’ (Hôpital Bicêtre) and ‘Salpetiere’ (La Salpêtrière), under its administrative management. These establishments had very specific administrative status. Everyone who was compelled in these institutions was under its undisputed authority. This practically meant that the institutions had all the powers that, for example, one local government would have: police, jurisdiction, authority to punish, correction *etc* (Foucault 1961, p. 40). Hence, the General Hospital of Paris had a vast autonomy to function without much outer control, which is highly problematic *per se*. Even in today’s world, when the strict standards are set, institutions of confinement (prisons, institutions for persons with psychosocial disabilities *etc*) are often found to be responsible for serious violations of the fundamental rights of its inmates.

Michel Foucault (1961) described the status of the ‘Hôpital General’ as a “semi-judicial structure, which outside of the court, decides, judges and executes” and as a “third order of oppression” alongside the police and the judiciary. Mentally ill persons were compelled without any intent to be medically treated but exclusively to be taken out of sight of the society and controlled. Even though these aims are inhuman, they are still present in every country where institutionalisation is a common practice.

The process of institutionalisation, or as Foucault (1961) wrote the ‘great confinement’, wasn’t limited to the borders of France. In the same period, the so called ‘Zuchthäusern’ were created in German speaking countries. These establishments had many uses, just as in France. They were used as correctional centres, prisons, institutions for insane *etc.* In England, it was an obligation to have at least one institution in every county where poor and homeless would be kept. These establishments were usually attached to prisons, by which they were gradually absorbed (Foucault 1961). Soon, the similar concept would spread across the Europe.

Contemporary sociologists, such as John Howard, who had an opportunity to visit some of these institutions, emphasized an issue of putting all the persons together. Criminals, poor, beggars, insane all could be found in the same buildings and in the same rooms (Foucault 1961, p.45). Even though these establishments were meant to be *sui generis* social institutions, all the data we have today imply that they didn’t have a correctional purpose, neither had they given medical treatment or any other benefit for inmates (especially in France), but they were a tool to keep the outsiders segregated from the society. Foucault argued that this was a new order “that we call confinement”. The reason for the rise of this “third order of oppression” he found in the sensibility of European society. This sensibility, Foucault elaborates further, was well articulated and gave legitimacy for the ‘great confinement’.<sup>3</sup> Perception of insanity and poverty was such that it produced new, radical ways of dealing with poor and insane. Sensibility for these issues led to, at least partially, creation of societies where the moral obligation was a part of legal framework, and where the moral was enforced by ‘authoritarian forms of constraint’ (Foucault 1961).

Ultimately the ‘imperative of labour’ was the core cause for mass incarceration. Therefore idleness was an ultimate trait, and all incapable to work or those without a job were to be

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<sup>3</sup> We may assume that Foucault thought of the sensibility towards deviant behaviour, lack of personal hygiene, physical deformity, obscene language etc.

constrained. The main task of the General Hospital, which at the time contained around 1% of the population of Paris, was to prevent “mendicancy and idleness as the sources of all disorders”<sup>4</sup>. Nonetheless, labour had an essential role in moral correction of the inmates; therefore the moral reform constituted a fundamental ethical justification for incarceration (Foucault 1961, p. 60).

Another factor that caused more people to become homeless and without a protection of their families laid in the change of economical systems, which then influenced changes in social dynamics. Namely, with the rise of mercantilism and capitalism in the pre-Industrial Revolution period caused parts of the agrarian population to move to the cities. This eventually led to weakening of the family ties and to fewer members per family. For insane persons this meant that they could easily be left without care of their family members. Also, in the village, where agriculture was the main activity, people who didn't have very severe disabilities would still be able to contribute to society by working in the field, contrary to the factories where they usually wouldn't be able to work even with a mild mental disability.

Starting as social institutions, and then transforming themselves to commercial organizations, these establishments had ambiguous roles. In different times, especially in different economic circumstances, they were changing their character accordingly. However, this flexibility didn't help them to survive the beginning of the 19<sup>th</sup> century. Their functional value eventually showed to be a failure (Foucault 1961, p.54). Nonetheless, this one and a half century long phenomenon, Foucault claims, was an irreducible socio-economical experiment. It shows the contemporary labour ethic, and an attempt to overcome economical issues in accordance with then existent moral fundamentals in the ‘Age of reason’. The moral standards, conditioned by the Catholic and Protestant work ethics<sup>5</sup>, weren't favourable towards the insane. In the pre-Renaissance period insanity wasn't condemned as such, but only in the Classical period<sup>6</sup> we see condemnation of insanity when the sin of idleness was pegged to it (Foucault 1961, p.58).

Although, the age of ‘the great confinement’ brought almost unimaginable violations of fundamental freedoms of persons that were seen as insane it may have been the practice that in the following decades brought a lot more favourable (but still not good enough, especially

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<sup>4</sup> Referenced in: Foucault, M 1961, *Madness and Civilization: a History of Insanity in the Age of Reason*, abridged edn, Vintage Books, New York

<sup>5</sup> For more on this see: Foucault, M 1961, *Madness and Civilization: a History of Insanity in the Age of Reason*, abridged edn, Vintage Books, New York. p. 55-57

<sup>6</sup> Classical period in the history of Europe is usually marked as a period between 16<sup>th</sup> and 18<sup>th</sup> century

considering today's standards) changes in perception and treatment of mental illness. We get to a conclusion that through establishing a connection between insanity and idleness, and labelling madness as a social threat, the contemporary societies broke up with the idea of madness as a presence of transcendental power that are possessing the madman. In this way the perception of insanity got 'grounded'. By depriving the madness, at least partially, from its metaphysical character, and giving to it a factual and concrete tone, the society, especially the academia, may have got more interested to study and analyse these conditions, thus taking it further from exorcisms and the ancient Humoral tradition's explanations of causes and treatments for these illnesses. Getting madness closer to the sphere of medicine could well have been a credit of the 'great confinement' phenomenon.

Weiner explained the reasons for better care and medical approach to insanity in France by giving examples of French inspectors' writings about asylums and care for insane in the late 18<sup>th</sup> century, just before the Revolution. Namely, the inspectors of King Louis XVI who was involved in the reformation of care for insane, advocated for the better conditions in the asylums by rising awareness and suggesting certain treatments to be eradicated, such as corporal punishment (Weiner 2008). The Enlightenment era shifted charities provision from churches to the state. This was explained by the animosity that *inteligencia* had towards the clerics (Weiner 2008). With the rise of awareness for the welfare of the whole society, the insane were compelled to institutions as much as before but now with an intention to be cured or at least treated for their diseases. Consequently, Weiner (2008 p.270) says that "medical men had developed an interest into their fate (of mentally ill persons) and attempted to transform the madman into medical patient". This transformation from madman to patient is a ground breaking point in the history of insanity and psychiatry.

### ***What was mental illness before psychiatry?***

Lack of psychiatric diagnostics, or more accurately psychiatry as a field of medicine before the 19<sup>th</sup> century, needs to be stressed here. This left the space for creation of vague conditions by which someone was labelled as an insane. An inmate could be described as a person of a "wandering mind", or of a "deranged morals" *etc* (Foucault, 191, p.65). Such labels indicate that selection of those who were chosen to be confined was highly arbitrary, subjective and value-dependent. How much someone's behaviour needs to be strange, unusual or wild, before he or she "deserves" to be called mad? Even in today's psychiatry it is not easy to diagnose someone's disorder precisely, and 'borderline personality disorders' are existent in

the psychiatric nomenclature for a good reason. Borderline personality disorders' diagnostic criteria are: instability of interpersonal relationships, self-image, and affects, and marked impulsivity<sup>7</sup>. This type of mental disorder is of a special importance for those who believe that the social constructionism is crucial for existence of mental disorders and that "there is no order in the world apart from the order that we project onto it" (Church 2004). Of course, the social constructionism, you may assume, is not very favoured among psychiatrist (Church 2004). The question of how clear is the difference between being eccentric and being mad is especially relevant for the period in which moral values were strongly influenced by the Church.<sup>8</sup> Then we can think of those mental disorders which symptoms are so severe that we would immediately assume that the particular sufferer is mentally ill. But we should not forget that there are societies where for the individuals, during their psychotic episodes, are believed to be in higher states of mind. This judgement has greatly varied historically.

"Meanings of mental illness, its manifestations, its consequences, are most certainly deeply affected by the social and cultural context within which it surfaces and is contained" (Scully 1979, p.4).

What insanity really was in this period and how many persons 'qualified' to be insane just for not being obedient or for having different from what the Church prescribed, and not pathological habits, we cannot be sure. Still, by no means should we think of mental illness as a social construct, in the sense if it exists or not.

Jennifer Church (2004) acknowledged that there more levels at which societal constructionism of mental illness occurs; the general level would be the one where society creates some kind of a 'mental order', where the certain mental states are said to be out of this order.<sup>9</sup> Some radical constructionists base their arguments in favour of psychological

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<sup>7</sup> American Psychiatric Association 2013, Diagnostic and Statistical Manual of Mental Disorders: DSM-5, 5th edn, American Psychiatric Publishing, Washington DC.

<sup>8</sup> Here I would like to quote Dr Thomas Szasz, who, in one of his numerous public lectures, said: "No behaviour or misbehaviour is a disease or can be a disease. That's not what diseases are... If child is sick, then there must be some objective science to it, which can be diagnoses by physician and objective tests." Even though, I find Szasz's opinion relevant and well-argued when it comes to the discussion of psychiatric diagnostics in the earlier period of development of psychiatry and in the 'so called' proto-psychiatry period, I stay reserved when the modern psychiatric diagnostics is in question. I also see it dangerous to undermine significance of some milder psychiatric disorders, which if left untreated can have immense consequences for the patient. However, even if 'non-existence' of some mental disorders such as ADHD was brought into question many times, and with a good reason, I would rather keep the focal point of this debate on the issue of stigmatization by diagnose and negative impact on the patients health and social life, and finding a solution to this problem.

<sup>9</sup> For more on this read: Church, J 2004, 'Making Order out of Disorder: On the Social Construction of Madness', in J Radden (ed.), *The Philosophy of Psychiatry: A Companion*, Oxford University Press, New York. p.4-6



diversity at this level of constructionism. An example for this point of view would be the 'Neurodiversity movement'<sup>10</sup>; however, discussions about mere existence of mental illness are not considered to have any scientific grounds and are out of scope of this paper.

Not surprisingly, people were always intrigued by insanity. The first works date from the old era. However this paper concentrates on the period of transition from the middle ages to the Early modern age and later. The reasons why people were, and still are interested in understanding, researching, observing or only thinking about madness were diverse. However, possibly the most significant of all the reasons is fear. A thought of a possibility to become mentally ill must scare every person. Also, less severe mental disorders, which do not affect a sufferer's life significantly, could be a catalyst for a person to become highly interested in this issue. Today, with the progress of diagnostics we know that huge number of people suffers from disorders such as an anxiety or depression. Even though these disorders in their milder forms have very good prognosis of treatment, the symptoms can be very hard for a patient. Not less interesting is the concept of the 'mad genius' that is existent in written sources since Aristotle.<sup>11</sup> Such an intriguing and widespread phenomenon presents fertile ground especially for artistic work with the subject of madness or inspired by an artist's struggles with mental health. In the 16<sup>th</sup> century masterpieces' protagonists such as Cervantes' Don Quixote and Shakespeare's King Lear became very popular, and soon after original versions of these novels, the translations to the other European languages appeared.<sup>12</sup>

### ***From madhouses to deinstitutionalisation; from 17th to 21th century***

I already mentioned two hospitals which were under the administration of the General Hospital of Paris - Bicetre and Salpetriere. These hospitals were exceptionally important not

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<sup>10</sup>For more on 'Neurodiversity' check: Jaarsma, P & Wellin, S 2012, 'Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement', Health Care Analysis, vol 20, no. 1, pp. 20-30.

<sup>11</sup> We can say with certainty that many of the great minds throughout history suffered from different mental disorders. Just to name some of them would hinder the scope of this phenomenon which I would like to emphasize. However, the connection between creativity and mental illness was opposed almost as many times as it has been supported. There are lots of limitations of the numerous studies that have been conducted until now; therefore this question is still open for debate. Still, connection between bipolar disorder and some other mental disorders and creativity is mainly and widely accepted as valid. For further reading on this see: Kyaga, S 2015, Creativity and Mental Illness: The Mad Genius in Question, Palgrave Macmillan, Stockholm. and Kaufman, JC 2014, Creativity and Mental Illness, Cambridge University Press, Cambridge.

<sup>12</sup> Since this paper concentrates on other topic than arts, for more on this subject check, for example: Mora, G 2008, 'Renaissance Conceptions and Treatments of Madness', in JG Edwin R. Wallace IV (ed.), History of Psychiatry and Medical Psychology, Springer. p. 229-234

only for their huge capacities (at the time among the largest hospitals in the world), but also because of the professionals that brought some ground-breaking changes in the management of the insane who were incarcerated within the walls of these institutions. Foucault would claim that Philippe Pinel, a French physician, is father of the modern psychiatry (1961, p.39). Pinel was engaged to the both aforementioned hospitals, where he eventually brought revolutionary practices. Bicetre's administrator, Pussin (before becoming a superintendent, Pussin was an inmate at Bicetre), was the first one who noticed improvement in the mental state of the insane after he ordered to 'loosen the fetters' they were bond with (Wallace, Gach 2008). However, Pinel, allegedly, was the one who ordered to take the chains off the madmen and free them. This was seen as a milestone towards more humane approach to the treatment of insane. The moment of liberation of insane was even portrayed in 1876 by Tony Robert-Fleury, on a painting that he named "Pinel freeing the insane from their chains". This act gained immense popularity and was often glorified as heroic. However, some authors claim that Pussin had more significant impact on the 'liberation' of madmen than Pinel, and even that the story of the Pinel's heroic act is actually a myth.<sup>13</sup> However, the French physician emphasized humanitarian approach to the insane, and their susceptibility to treatment, especially the psychological treatment (Weiner 2008, p. 281). *Traitement moral* was the term which designated that these new treatments were applied to mind and not body (Yanni 2007). Jean-Etienne Esquirol, a Pinel's follower, further developed the 'traitement moral', by transforming madhouses in places for treatment, where doctors and inmates would live together; in Esquirol's private clinic, patients sometimes dined together with his family (Yanni, 2007).

It must have been awfully hard to discontinue non-medicalized, punitive approach to mentally ill persons and start something as revolutionary as the psychological therapy. Still, some authors had challenged this by saying that many before Pinel and Pussin had treated insane with kindness and care; even changes in legislations had happened in some places two hundred years before Pinel's work that had an aim to segregate insane from criminals and poor (Foucault 1961). However, none of the practices that preceded Pinel's work had such a strong impact on the scientists, scholars and other notable person in various fields. Some of his works were labelled as political because of their special sensibility and the period when they were developed (revolutionary Paris). More importantly, Pinel left huge amount of

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<sup>13</sup> To read more on this see: Weiner, DB 2008, 'The Madman in the Light of Reason. Enlightenment Psychiatry: Part II Alienists, Treatises and the Psychological Approach in the Era of Pinel', in ERW IV, J Gach (eds.), History of Psychiatry and Medical Psychology, Springer, New York

writings, thus helping us to better understand not only his work, but also his predecessors' and successors' works. Nonetheless, Pinel had more humane approach to mental illness than many of his successors, which unfortunately is showed in the existence of the same or just slightly more humane treatments in the 19<sup>th</sup> and 20<sup>th</sup> century, than those that Pinel wanted to eradicate.<sup>14</sup>

The term psychiatry entered into use in the beginning of the 19<sup>th</sup> century. Almost simultaneously the beginning of 19<sup>th</sup> century brought two approaches on examination and treatment of mental illness: one was psychological, which focused on behavioural treatment and explored emotions, feelings and thoughts; the other was focused on the nervous system and thus had a physicialist approach (Weiner 2008).

By this time, allegedly, purely custodial approach to treatment of mental illness started to disappear (Weiner 2008). In her work, Weiner provided some examples of the custodial care type and what it meant for the insane. One of the characteristic of the pre-19<sup>th</sup> century period was that for an admission to a madhouse or an asylum, psychiatric diagnosis was not a requirement. In many of these institutions, there were no doctors specialized in mental illnesses or they simply didn't check every inmate (the same is case in some of institutions for children with mental disabilities). When a doctor would provide a person with diagnosis it was usually labelled with an important characteristic: curable or non-curable (Weiner 2008). Those that suffered from non-curable disorders were marked as idiots or natural fools (intellectual disabilities) and senile or demented (psycho-social disabilities). This practically meant, for a contemporary physician, that they cannot benefit from medical care, thus they would never receive it (Weiner 2008). These patients were chained and often held in basements, dungeons and other places that would severely affect any person's physical and mental health.<sup>15</sup> The only medical care they could receive, if they were lucky, was treatment

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<sup>14</sup> At the moment of writing this chapter, the Mental Disability Advocacy Center revealed horrific practices conducted in Tophaz institution for children and adults with mental disabilities. In Tophaz institution, which is located only 30 kilometers from the capital of Hungary, many abusive practices were detected by the MDAC team, such as: seclusion in locked rooms, use of straightjackets, people held in metal cage-beds, malnutrition, untreated open wounds on some residents. The MDAC saw these practices as proofs of ill-treatment and torture. Full report is available online on [http://www.mdac.org/sites/mdac.info/files/straightjackets\\_and\\_seclusion\\_-\\_mdac.pdf](http://www.mdac.org/sites/mdac.info/files/straightjackets_and_seclusion_-_mdac.pdf), accessed on 14 May 2017.

<sup>15</sup> In 1766, the workers who were demolishing Chantimoine Tower in Caen, which was used for confinement of criminals and insane, found a man, Jean Heude, who was incarcerated for 20 years in a cell "which doors were not open so long that the lock had to be knocked of with an iron bar". The man was in horrific state, naked and berserk (Quétel & Morel 1983, p.146 in Weiner 2008).

of physical ailments. Absence of medical treatment<sup>16</sup> for the illness for which a person was compelled to an institution, automatically gives punitive character to the incarceration. Depriving someone from freedom arbitrarily, and compelling him/her in the institution with the worst possible material conditions, and clearly with all-present ill-treatment, cannot by any mean be seen differently than as punishment.

Weiner (2008) claims that dungeons and chains were, supposedly, out of use by the beginning of the 19<sup>th</sup> century. However, we should be careful with this rather optimistic hypothesis at least for two reasons. Firstly, I highly doubt that these means were out of use even if the standards of care improved, or at least they were eradicated only from the institutions that were monitored and where newer treatments were applied. Secondly, and more importantly, I would emphasize that substitution of chains for straightjackets and dungeons for solitary rooms doesn't essentially change the position of the patients. These are practices of seclusion and mechanical restraining, no matter how they are applied. Even though improvement of material conditions is favourable, it doesn't mean that the outcomes of treatments or quality of living in these institutions were better.

Creation of institutions specialised for care or treatment of insane became widespread in the late 18<sup>th</sup> and throughout 19<sup>th</sup> century. It is believed that demographic changes, more precisely – rise of population especially in the urban areas, philanthropic tendencies of higher classes, as well as raising awareness of the illness and societal welfare and care for disadvantaged that were both born during the Enlightenment era. Development of psychiatry, and more generally - medical knowledge was especially creditable for appearance of these specialised institutions. (Grob 2008). Other than that, institutionalisation was seen as a necessary asset in treatment of mental illness. This was an effect of conviction that cause of mental illness, at least in some instance, comes from an inappropriate environment from which patient should be taken out; apart from the patient's isolation from everyday stressors, the doctors could apply many treatments and combine different approaches in the institutions. Since throughout 19<sup>th</sup> century moral treatment was widely accepted, and the accommodation in a specific,

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<sup>16</sup> Interesting statement of Dora Weiner (2008), after observing different methods of treatment to which inmates were subjected when medical care was accessible, was that with the absence of doctors in these institutions, inmates' health actually benefited; implying that 18th century treatments were extremely aggressive and not efficient. To support this statement Weiner gave examples of some of the treatments. Namely, blistering was used to treat mental illness by placing setons under the skin and close to brain, which then caused inflammation and produced large amount of pus. By drainage of this pus, it was believed that the patient's condition will improve (Weiner 2008).

favourable environment was a must for this type of treatment, the institutionalisation was inevitable (Grob 2008).

Already at the beginning of 19th century important ideas of biological causes for mental illnesses appeared. In his works, Benjamin Rushin, claimed that mental illness is a consequence of pathologic processes in the brain. More precisely, Rushin demanded that these are processes of bad blood supply. Even though this theory was overly simplified and incorrect, it brought biological interpretations of the causes of mental illnesses in the focus. More importantly, British and American associations of psychiatrists accepted biological approach to mental illness (Gach 2008). In the second half of 19<sup>th</sup> century huge breakthrough in medical science in general happened when bacteriology and other biological and physical sciences came into medicine (Grob 2008). This was a shift that marked the rise of modern, scientifically based medicine and psychiatry.

Another milestone was an abandonment of strict distinction between curable and non-curable patients. For chronic patients this meant that they will be provided with medical treatment, at least for the relief of their sufferings and improvement of their conditions even if they were not curable. This obvious humanization of care for mentally ill persons happened in the mid 19<sup>th</sup> century. One of the main protagonists of this was Thomas Kirkbride who saw importance in provision of relief and comfort to the most severely disabled persons and also in prevention of further deterioration of patient's already deteriorated mental health (Grob 2008). However, with 20<sup>th</sup> century and the rise of numbers of institutionalised chronic patients, the care for chronic patients worsened.

Another important initiative was promotion of mental hygiene<sup>17</sup> as the best prevention for mental illness (Grob 2009). One of the unfortunate results of the emphasis on the prevention of mental illness was eugenics<sup>18</sup>. Generally, a first association for eugenics is a German policy during the authoritarian rule of National Socialist Worker's Party towards mentally disabled people. Even though the Nazi regime did unimaginable atrocities in the institutions for mentally disabled person, by practically swiping-out this population, it is less known that on the forefront of the eugenics trend was the USA already at the end of 19<sup>th</sup> and beginning

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<sup>17</sup> "The science of maintaining mental health and preventing development of mental illness" (Merriam-Webster 2017), accessible at: <https://www.merriam-webster.com/medical/mental%20hygiene>

<sup>18</sup> Eugenics can be practiced in many ways, however here is discussed about coercive practices imposed by authorities in order to prevent reproduction of the persons who are perceived to have undesirable genes. These undesirable genes are usually existence of disability or different race, ethnicity, nationality, financial and social status etc.

of 20<sup>th</sup> century (Lombardo 2011). In the USA it gained a lot of popularity, and was driven by undoubtedly racist and nationalistic motives.<sup>19</sup> Today, we are often surprised how inhuman some practices from the past were and tend to think that for those there is not place in today's world. However, not many know that exactly eugenics, more precisely forced (without informed consent) sterilizations of female patients in the institutions for mentally disabled people are carried out every day (Nowak 2008, par. 40; 60). These patients are often not even informed to which medical procedure they will be subjected. It is important to say that these practices are common in Serbia and some countries of the European Union. Sometimes, not only mentally disabled person are subjected to sterilization without a consent.<sup>20</sup> About the current problem of non-consensual sterilisation in the institutions for mentally disabled person I will elaborate in one of the following chapters.

The period between two world wars showed to be fatal for moral treatment. Many factors influenced this change, but probably the rise of number of patients and lots of severe somatic ailments shifted a focus of authorities and societies to more acute problems at the time (Grob 2009). However, 1930's and 1940's were marked by innovative practices in psychiatry. Some of the infamous treatments developed in this period were different types of shock therapies such as electroconvulsive<sup>21</sup>, insulin coma therapy<sup>22</sup>, metrazol therapy<sup>23</sup> *etc* (Grob 2009). Probably the most controversial type of treatment in the history of psychiatry is lobotomy<sup>24</sup>. This procedure was developed in 1935 by Egas Moniz who won a Nobel Prize for this discovery (Tierney 2010).

Post-war years were marked by the rise of human rights. United Nations Declaration of Human Rights was adopted and altogether Western society seemed that had got more

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<sup>19</sup> Eugenics in the USA was partly inspired by Darwinism. Social-darwinists even predicted extinction of the black race before the end of 20<sup>th</sup> century because of their intellectual and physical inferiority (Haller 1971 in Brandt 1978).. The same could be applied on persons with disabilities.

<sup>20</sup> Sterilization of Roma women was common in many European countries. Some of these cases ended up before the European Court of Human Rights; to see the case of V.C. against Slovakia visit: <http://hudoc.echr.coe.int/eng?i=001-107364>

<sup>21</sup> Still used today for treatment of severe psychiatric disturbances (FDA 2016). Informed consent is necessary. However CPT found that it was used in Turkey on psychiatric patients, without anaesthesia or muscle relaxants (so-called "unmodified ECT") and even as a form of punishment (Nowak 2008).

<sup>22</sup> At the time the most popular shock therapy. Developed by Manfred Sakel in Vienna (Grob 2009).

<sup>23</sup> Developed by a Hungarian physician, Ladislav von Meduna. Injection of metrazol caused convulsions in patients with schizophrenia.

<sup>24</sup> Probably one of the most infamous treatments ever. Portrayed in many movies, but the most influential one is certainly the "One flew over the cuckoo's nest" (1975). In this film, an antihero played by Jack Nicholson, is subjected to a lobotomy after which he falls in a non-responsive, so-called vegetative state. Eventually his friend and fellow inmate euthanizes him in order to save him from years of unimaginable suffering that would follow.

empathy. This was a period of introduction of new, more acceptable and less stigmatizing terminology, as well (the last one was at the end of 18<sup>th</sup> century). Asylums changed their name to mental hospitals, insane and lunatics became “mentally ill” and “persons of unsound mind”<sup>25</sup> (a British version was still extremely stigmatizing) (Scull 2015).

During mid-twentieth century the numbers of incarcerated psychiatric patients were breaking all records.<sup>26</sup> However, already during 1960s and 1970s, when the rise of the social model of disability started its breakthrough, some emancipatory<sup>27</sup> tendencies saw the light of the day. For example in-patients in England insisted to be engaged in running of the institutions. However, scientists that visited these institutions explained perfectly why this involvement actually does not change anything in the status of the residents. They stated that no matter what kind of activity the patients were involved in, these institutions’ only function was to “maintain disabled people who are socially dead, until their actual death” and that the only difference was if this is going to be done under a “warehousing” or “horticultural” stewardship (Miller & Gwynne 1972 in Finkelstein 2001, p. 6).

One of the first processes of deinstitutionalisation in continental Europe were those in the Netherlands and Nordic countries (Scull 2015). The communist countries didn’t start this process before the fall of communism, and some of them still haven’t. Current processes of deinstitutionalisation will be discussed in the following chapters.

### ***“Architecture of Madness”***

A purpose of the examination of institutional architecture lies in a tight correlation between the spatial organisation of madhouses/asylums and perception about mental illness as well as the practices carried out and regimes of living within their walls (Prior 1984). Similarly to the development in terminology used to describe persons that live with mental disorders, words used to mark buildings where these persons were accommodated changed simultaneously. That is to say, with more knowledge of mental illness as such, with the development of psychiatry and especially with the establishment of the rights of persons with mental disabilities once ‘madhouses’ became asylums, psychiatric hospitals and with the latest

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<sup>25</sup> These were official terms in the USA and the UK.

<sup>26</sup> Namely, in England and Wales there were 150.000 psychiatric inpatients, in the USA around 600.000, and before the “gentle extermination” of 45.000 patients in France, the number was 115.000 (Scull 2015). The decline of psychiatric inpatients in the UK and the USA started already in 1950’s, while the numbers in Western Europe were rising throughout next decades

<sup>27</sup> on page 25

trends - 'family-like homes', 'homes for supported living', 'small group homes' *etc.* Of course, not only the terminology and architecture have evolved, but rather a whole set of socio-economical, medical and legal factors which were intertwined and, in order to be best understood, each of these factors need to be analysed as parts of the whole and not as the entities with separate and independent trajectory of evolution. Lindsay Prior (1984) references to Emile Durkheim and his followers to be meritorious for giving a base for sociological research of space, by claiming that the space, and consequently architecture of the institutions, were "socially produced rather than naturally given".

Scully (1977) claimed that, in contrast to other types of hospitals, "the genuine symbol of madness was a necessity for a special architecture" of these institutions.<sup>28</sup> However, specialised buildings only for accommodation of persons with mental disorders weren't built before the late 18<sup>th</sup> century.

Some of the aforementioned hospitals such as the General Hospital of Paris (started operating in 1656) and Bethlem Royal Hospital (founded in 1247) were not initially used for incarceration of mentally ill persons. Infamous Bethlem (or Bedlam) was built to be a center for collection of goods to support Crusaders quests (Andrews 1997). It is believed that Bethlem started accommodating insane before the end of 14<sup>th</sup> century, while the solid proofs of this practice date from 1403 (Porter 2004). The General Hospital of Paris was initially used to incarcerate poor "of both sexes, of all ages and from all localities, of whatever breeding and birth, in whatever state they may be, able-bodied or invalid, sick or convalescent, curable or incurable".<sup>29</sup> The insane were obviously qualified for incarceration to the General Hospital from its beginnings; however they were just one of the disadvantaged groups that were designated to be confined in this institution. These establishments, and many similar throughout the Europe, weren't specially designed with an aim to improve care or control of persons with mental disorders; therefore architecture of these institutions will not be of my interest in this paper.

Specially designed institutions for confinement started being built in the late 18<sup>th</sup> century. In the previous chapter I wrote about socio-economical changes that created a need for specialised institutions, as well as an importance of institutionalisation for moral treatment,

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<sup>28</sup> Referenced in: Prior, L 1988, 'The Architecture of the Hospital: A Study of Spatial Organisation and Medical Knowledge', *The British Journal of Sociology*, vol 39, no. 1, pp. 86-113.

<sup>29</sup> Édikt du roi portant établissement de l'Hôpital général, Code de l'Hôpital général. Referenced in: Foucault, M 1961, *Madness and Civilization: a History of Insanity in the Age of Reason*, abridged edn, Vintage Books, New York.



which was dominant in the 19<sup>th</sup> century among the psychiatrists. In the following paragraphs I will give examples of popular architectural solutions which were conditioned by the character of confinement (curative or punitive) and the treatments. What was so special about some of these buildings is that their design sometimes was all in favour of maximization of control of the inmates<sup>30</sup>, and sometimes in favour of providing a home-like atmosphere for inmates.

The control that was supposed to be established was not only physical, but also emotional (Prior 1984). Prior (1984) claims that creation of the aforementioned institutions marked the beginning of “an era in which architecture, in general, was used as a weapon in the control and care of the body”.<sup>31</sup> This era started with creation of buildings for various usages but with one aim: the best possible control and surveillance of the persons that live or work in these buildings. Of course, architectural design and urban planning are in service of better surveillance and control indeed; however this is absolutely accepted practice today, and most of the time favourable, especially when an aim is to prevent or to decrease crime occurrence. In spite of its relevancy the topic of securitization and its effects on human rights are out of the scope of this thesis.

This period coincides with the term ‘asylum’ coming into use. Today, this term is used to designate a government’s provision of shelter and safety for a person who has been forced to leave his/her country for their safety or because of war (University of Cambridge 2017). Similarly, in the 19<sup>th</sup> century this term “suggested a refuge from the pressure of civilization” for an insane person (Yanni 2007). In the following chapters some of the most famous and infamous, but very distinct and influential architectural solutions are presented.

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<sup>30</sup> The control that was supposed to be established was not only physical, but also emotional (Prior 1984). Prior (1984) claims that creation of the aforementioned institutions marked the beginning of “an era in which architecture in general, was used as a weapon in the control and care of the body”. This era started with creation of buildings for various usages but with one aim: the best possible control and surveillance of the persons that live or work in these buildings.

<sup>31</sup> From the wording that Lindsay Prior used in the aforementioned sentence, we can conclude that the era, to which she refers, actually finished in some time between the creation of the first institutions of that kind and the moment of writing that sentence. However, Prior could be right about the cessation of the use of architecture as a tool of control, I strongly believe that nowadays, not only inmates, but general population is much more susceptible to the control of both body and mind. A control through architecture is more obvious and therefore fairer, than the control by which we are subdued today. Control through sophisticated technology allows greater insight into person’s activities, while that person is usually absolutely unaware of that control. Today we are much more controlled than 200 years ago; one could even say that a person on freedom today is as much controlled as a person in ‘Panopticon’ once.

### ***Fool's Tower***

The first building in continental Europe intended to accommodate only mentally ill persons was 'Narrenturm' in Vienna.<sup>32</sup> The building was erected during the reign of monarch Emperor Josef II in 1784, next to the humongous Vienna General Hospital. Allegedly, the Emperor went to France in order to visit institutions of the same purpose and pick the best practices before building one in Vienna.<sup>33</sup> The reform in care for the insane which already had begun before building of 'Narrenturm' seems that hadn't had much impact on the Emperor. Popularly known as the 'Fool's Tower', this institution's design and spatial organisation could have easily been the one of a maximum-security prisons, where people convicted for the worst crimes would be confined. Its exterior resembled very much of the Bentham's 'Panopticon'.<sup>34</sup> In the Fool's Tower, the insane were barred and chained to the walls. This practice was totally opposite from what the reformers, such as Pinel and Tuke had in mind (Scull 2015). Obviously, confinement in this institution of 140 beds had exclusively punitive character, since no fruitful treatment could be conducted in such a space and regime. Thus we can say that 'Narrenturm' was an out-dated institution already on the day it came into use.<sup>35</sup>

### ***The York Retreat***

In the same period, on the island of Great Britain another type of asylum was built in the town of York in 1796. This one stood as an antagonist to the Viennese 'Narrenturm'. Founded by a family of Quakers, this building was supposed to be, as its name suggest, a haven for mentally ill persons. William Tuke, similarly to Pinel, didn't allow use of mechanical restraints, and had a kind and humane approach to his patients (Yanni 2007).

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<sup>32</sup> Today, this building is a home of the Vienna Pathological-Anatomical Museum (Pathologisches-Anatomisches Bundesmuseum)

<sup>33</sup> As Dona Weiner (2008) perfectly noticed, the 'Narrenturm' resembled more of Bastille than any of the institutions in France.

<sup>34</sup> Panopticon is an infamous project of Jeremy Bentham, an English philosopher and social theorist. This project, however, never got realized, even if it was praised by many as a space-saving penitentiary which could be served with fewer officers. The main idea, enshrined in its name (Panopticon - all sighted), was that the inmates could be observed by only one watchmen who would be placed in the central tower ("inspection house") around which the cells would be radially organized ('doughnut shape'). The cells would have bars, but the blinds on the central tower would make interior of the inspection house invisible, thus disabling inmates from seeing the guard; "hence the apparent omnipresence of the inspector" would keep them from doing something what is not allowed (Bentham 1787). This practically meant that the whole prison could be observed by one, or could be even left without any watchmen. The author emphasized that the Panopticon is "a new mode of obtaining a power of mind over mind, in a quantity hitherto without example" (Bentham 1787, preface). Moreover, Bentham (1787) claimed that the 'Panopticon' design was applicable not only to prisons but also other establishments, such as asylums, work-houses, manufactories, hospitals and even schools. See Annex 3 for plans of Panopticon and images of the Narrenturm.

<sup>35</sup> The same can be said for the newly built institutions in the 21<sup>st</sup> century across the south-eastern Europe which are supposed to accommodate large numbers of mentally disabled persons. The main difference is that the authorities, by building these institutions today, are violating obligations set under the international law; thus their actions are not only illegitimate but also illegal. More on this in the following chapters.

Event though their practices resembled one of the other a lot, it is believed that they acted independently and without knowledge of the other's work (BBC 2014). Allegedly, one of the reasons for Tuke to build the Retreat was a death of another Quaker in the public York Asylum. Appalled by the conditions and treatment in this asylum, Tuke got inspired to build and manage his own private asylum (BBC 2014). Tuke's philosophy was to treat the patients in a hospitable ambient; they were fed well, had clean clothing and good hygiene, sleep was strongly encouraged, as well as the strict daily regime (Yanni 2007). In, William's grandson, Samuel Tuke's (1813) description of The Retreat asylum he acknowledges that it reminds of a rural farm, with no bars on windows or doors, and that "the garden in front is defended only by a neat common hedge, entirely preventing the aspect of a place of confinement" (p.62).<sup>36</sup> Further, he describes that there are fruits and vegetables around the building, which provides an opportunity for employment and recreation. Also, he acknowledges that the patients have frequent excursions to the town and the surrounding lands, as well as a respectful and kind behaviour of the staff towards the patients. Aggressive treatments were avoided and emphasis was put on comfort. An ultimate aim of the treatment in this asylum was resocialisation of the patient (Yanni 2007). A separation of patients according to sex and gravity of their disorders was prominent. Tuke also provides us with the number of patients accommodated in his asylum; namely, there were 24 male and 38 female patients (p.64)<sup>37</sup>. However, it shouldn't be forgotten that these were paying patients, in contrast to the Parisian pauper madhouses where Pinel worked. Architecture of The Retreat provided domicile environment (Yanni 2007). Differently from Narrenturm's eccentric design, The Retreat was rather humble and conventional, and left an impression of a harmonious institution. Quakers and the Tuke family had immense impact on both architecture and treatment of persons with mental disorders, especially in the Great Britain and the United States. Carla Yanni (2007) affirms that The York Retreat was an important architectural model for American (United States of America) asylums.

### ***Venetian asylums as an example of extreme isolation***

It was a well established practice to build asylums, and later mental hospitals, in the rural areas and away from densely inhabited places. Reasons for this were sometimes humane (importance of environment for recovery); however, in other occasions humane aims were used as an excuse, while the real reason was a wish to take the mentally ill out of sight of the

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<sup>36</sup> See Annex 3 for images of the "Retreat"

<sup>37</sup> Just to compare, La Salpetriere at one point accommodated as much as 10.000 inmates.

rest of population. This caused many undesirable effects, such as absolute exclusion of patients from society and their “social death”, fewer control visits by inspectors or other organizations that led to uninterrupted occurrences of ill-treatment etc.

Which landforms can be more isolating than islands? Some of the most isolated asylums existed in the Venetian lagoon. Namely, the island of Poveglia, San Servolo and San Clemente, all were homes of mental asylums once. These three islands are located in the lagoon, which is on the east closed by 11 km long and in average 300 m wide island called Lido di Venezia. Every year millions of tourists visit Venice without having a slightest idea of the dark past of a few tiny islands, which are so close that can be easily seen and observed from the most popular Venetian spots such as Giudecca, Giardini and Lido.

Island of Poveglia was used as quarantine for centuries. Mostly used as a lazaretto<sup>38</sup> for victims of plague, this island earned infamous reputation very early. In 1922 the buildings on the island were adapted to be used as a mental asylum. For the next 46 years Poveglia was a home for the persons with mental disorders. Today this island is abandoned and unauthorized access is strictly prohibited. Its dark past seems to be still intriguing for many, since in the recent years it was a site for horror-films shootings.<sup>39</sup>

Isle of San Servolo was a mental hospital for 250 years, until it was closed in 1978 (10 years after the closure of the Poveglia asylum) (Fondazione 2017). Percy Shelley and Lord Byron visited San Servolo, while Byron lived in Venice. Later Percy Shelley in his poem “Julian and Madalo: A Conversation” described this fearful experience (Scull 2015). Today, San Servolo is a home of the Psychiatric Hospital Museum of San Servolo. In the museum are exhibited and portrayed means used for restraintment of patients and various devices used for conduction of “shock” therapies. Current work of the Foundation of San Servolo is focused on promotion of research and studies of social marginalization, and psychiatry’s role in the societies.

Island of San Clemente served as a location for madwomen asylum from 1844 until 1992. The interior of the Fool’s Tower in Vienna was used as a pattern for the interior of San Clemente asylum (Winslow 1878). In a description from 1878 (Winslow p.2), as an especially favourable element was stressed the asylum’s location, because it provided “the

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<sup>38</sup> “Institution, such as a hospital, for those with contagious diseases”: <https://www.merriam-webster.com/dictionary/lazaretto>

<sup>39</sup> “The plague doctor” movie was shot at Poveglia: Mangotti, E 2011, Plague Doctor Movie, viewed 8 July 2017, <<https://www.theplaguedoctormovie.com/>>.

almost total absence of all chances for the escape of patients”. Due to its terrifying reputation, this island became a synonym for insanity for the citizens of Venice (Scull 2015). Benito Mussolini incarcerated his first wife, Ida Dalser where she lived until death (Scull 2015); this controversial act was a subject of many theories, however some of the misogynist diagnoses, such as hysteria were not hard to ‘earn’, and this showed to be a convenient way to get rid of someone. Today a five star luxurious residence is located on San Clemente. Scull (2015) notes that the advertisement of the property focuses on its rich history, which is well preserved, and we may assume, pleasant to evoke.<sup>40</sup>

### **Kulina institution**

The first building was constructed in 1936 for railway workers, but in 1953 seventy-two children were replaced from another institution to Kulina when it started functioning as a social care facility (Dom Kulina 2017). In the following years the institution was expanded and accommodated a few hundreds of children and adults with disabilities. Between 2008 and 2013, because of inadequate conditions, the children were finally moved out to small group homes, and today Kulina is a home for 313 adult users living with profound developmental disabilities (HRW 2016).<sup>41</sup>

Kulina institution is infamous for reported ill-treatment, horrible material conditions (MDRI-S 2013) and extreme geographical isolation. Namely, this institution is located in the foot of the mountain Jastrebac in eastern Serbia. Tiny roads lead to the closest urban settlement- a small municipality of Aleksinac which is 27 km away. Niš, an administrative center of eastern Serbia is 37 km away (Dom Kulina 2017). During winter months, these roads are often impassable which seriously compromises provision of food and medication (B.G. 2012). Surrounded by forest this place is one of the extreme examples of physical segregation of persons with mental disabilities.<sup>42</sup>

### **Summary**

The western societies of 17<sup>th</sup> century went through various economical hardships that in combination with more pronounced sensibility towards immorality, which was embodied through persons of deranged minds and other misfits, formed first ideas of perfectly moral

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<sup>40</sup> San Clemente was also used as a monastery and is rich with impressive Renaissance facades and frescoes (Scull 2015). See Annex 3 for images of San Clemente.

<sup>41</sup> In 2015 there was still one child living in this institution (HRW 2016)

<sup>42</sup> See Annex 3 for a satellite view of Kulina’s location.

cities. These ideas were materialized through public policies which prescribed segregation and incarceration as a solution for the problem. This pestiferous part of society was about to be used for work in inhuman conditions of huge facilities that were usually called hospitals, workhouses and poorhouses. With all the catastrophic treatment of mentally ill persons, the period of the great confinement brought mental illness closer to medicine and physicians and contributed to the rise of psychiatry. Therefore, the roots of psychiatry can be tracked back to the aforementioned French hospitals and a notable physician Pinel, who is often seen as the father of psychiatry for developing the moral treatment for mentally ill persons. Further development led to medicalization of mental illness and discoveries of biological causes for it. Soon, specialised facilities for mentally ill persons appeared. At this time some infamous buildings were constructed and their architecture was directly affected by the perception about mentally ill persons and treatments that were carried out inside these facilities. After realizing importance of prevention of mental illness, various eugenic policies appeared in the USA and spread throughout the Western Europe, to finally culminate during WWII. At the time after WWII numbers of psychiatric in-patients were extremely high. Soon, some states which were more progressive in the social protection realized a need to reduce these numbers, and launched the processes of deinstitutionalisation.

In the following section I will present the legal framework in which the aforementioned practices developed, and especially the process of deinstitutionalisation. I will put an emphasis on the concept of dignity in the international law, which gives a strong contrast in the approach to disability and treatment of disabled persons when compared to the period covered in the first section.

## *Theoretical and Legal frameworks for deinstitutionalisation of persons with disabilities*

### **The social and the human rights based approaches to disability**

According to the theory of disability there are at least four possible approaches to the protection of persons with disabilities and these are: charity approach<sup>43</sup>, medical approach<sup>44</sup>, social approach and human rights approach. Here I will briefly discuss only the last two approaches, because they are considered to be the only legitimate and progressive ones nowadays. A reason behind this is that only the social model and the rights based approach emphasize importance of inclusion of persons with disabilities and are able to assure respect for dignity of all disabled persons if followed. Moreover, the United Nations Convention on the Rights of Persons with Disabilities is developed on the main premises about disability that were established long time before by those who invented the ‘social model’.

### **The Social model**

The “social model of disability” was developed in the 1970’s in the United Kingdom by the Union of the Physically Impaired Against Segregation (from hereafter UPIAS). This model represented an answer to the medical approach to disability that was dominant for a very long time. The UPIAS was unsatisfied with medical approach which emphasized the impairment as a reason for a person’s disability and had distinctively individual viewpoint on disability.<sup>45</sup>

Advocates for social model of disability claimed that disability is something that has more to do with social rights, than merely impairment (Finkelstein 2001). These “revolutionaries” encountered a lot of opposition or more precisely indifference towards their ideas.<sup>46</sup> What was so revolutionary about the idea behind the social model was a strong assertion that the non-disabled community is a party that needs to change and not the disabled persons. An idea

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<sup>43</sup> Always present. It was a mainstream approach before 17 century when religious buildings and resources were used to accommodate and help persons with disabilities.

<sup>44</sup> Also called ‘individual approach’. Emphasizes disability as a ‘personal tragedy’ therefore failing to perceive disability as an always present variation in human kind. The main characteristic is a lack of policies for inclusion.

<sup>45</sup> Not less important was the ‘Independent Living Movement’ developed at the University of California, by disabled students who were dissatisfied with student residence that couldn’t accommodate disabled students.

<sup>46</sup> “Anyone suggesting that maybe it was more to do with social rights was regarded as kind of bananas.” (Finkelstein 2001, p. 1)

of adapting the non-disabled world to accommodate disability was so much different from everything before.

Finkelstein (2001) compared the status of persons with disabilities with apartheid regime in South Africa. In his work “Personal journey into disability policy”, Finkelstein quoted Nelson Mandela’s speech where he stated that African people in RSA are disabled because of lack of social and political rights in comparison to white men. Thus, disability of African people was created by the white men-dominant society on the basis of the color of their skin. Similarly, persons with impairments are excluded from the society dominated by non-disabled on the basis of their physical and mental impairments.

One of the main characteristics of the social model is a strong distinction between impairment and disability. The core of this concept and the aforementioned distinction was enshrined in the UPIAS’s “Fundamental Principles of Disability”:

*...In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments...*<sup>47</sup>

However, there is an unbreakable connection between impairment and disability, which no one negates. This connection, in the context of the social model, is in the sense that “impairment is a prerequisite for a being a disabled person, but having an impairment cannot be a cause for a person to become disabled” (Finkelstein 2001). To support this statement, Finkelstein used an example of the 32<sup>nd</sup> president of the USA, Franklin D. Roosevelt. Mr. Roosevelt used a wheelchair because function of his legs was impaired but he was not disabled because all barriers, physical and social, were removed for him. However the society of that period was definitely not more inclusive than today’s (and probably not less inclusive, at least in the rest of the world where the inclusion never started), but the Roosevelt’s status “allowed” him not to be disabled. Still, in all the picture and statues of Roosevelt from that time, artists tried their best to hide his impairments (Finkelstein 2001).

UPIAS decided to root out individual approach to disability according to which a disability is a form of personal tragedy, and put it as a form of social oppression (Finkelstein 2001). Therefore, a road for improvement of the rights of persons with disabilities had to be emancipatory (Finkelstein 2001). Ultimately, UPIAS’s fight was with an aim that persons

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<sup>47</sup> UPIAS 1975, 'Fundamental Principles of Disability', London.



with disabilities reclaim control over their own lives. This was explicitly enshrined in their “fundamental principles”, 33 years before the adoption of the UN CRPD<sup>48</sup>:

*... disabled people should, with the advice and help of others, assume control over their own lives...*

Social movement was often considered to be very radical, especially some of the academics which partook in the movement. This was especially with regards to the arguments that the disabled people should overturn notions of normality. This means that, the social movement should seek to challenge whole understanding of what is normal (Watson 2004). Sutherland (1981, p.18 in Watson 2004, p. 18) put this in the following statement:

*More radical approach is needed: we must demolish the false dividing line between ‘normal’ and ‘disabled’ [meaning impaired] and attack the whole concept of physical normality. We have to recognize that disablement [impairment] is not merely the physical state of a small minority of people. **It is the normal condition of humanity.***<sup>49</sup>

Segregation of persons with disabilities through centuries did not allow general population to be aware of the scope of occurrence of disability. Hence, disability is still, in most of the societies, seen as a personal tragedy and the bigger picture is rarely taken into account. If understanding of disability as a normal diversity in humanity was seen as a too radical idea, today this certainly should not be the case. This idea appeared during 1970s and 1980s and was replicated by the Special Rapporteur for the Rights of Persons with Disabilities in an almost exactly same wording, to argument that disabled persons are unfairly deprived of the support they need in order to have dignified life.<sup>50</sup>

The social movement appeared as a rebellion against the social injustice towards people with disabilities. A financial hardship of disabled was always present, but according to Thompson (1963) a social rebellion requires more than economic difficulties. What is actually necessary for a rebellion is violation of dignity of a group, denial of moral and humiliation of that community, and forsaken recognition (Thompson 1963 in Watson 2004, p. 16).

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<sup>48</sup> Preamble of the UN CRPD paragraph e): *Disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.*

<sup>49</sup> Original emphasis

<sup>50</sup> On Universality chapter

### **The Human Rights based approach to disability**

With the rights based approach (from hereafter HRBA) the persons with disabilities are bearer of the rights.<sup>51</sup> These rights are enshrined through the international legal instruments and they are part of the national legal systems. One of the basic premises of these rights is to ensure participation in the society of disabled persons on an equal basis with other. This approach is assuring respect of these rights by enforcing laws, applying public policies, respecting equal recognition before the law and regulates the private sector. Logically, a main duty bearer is the state, but also the society which is obliged to respect the laws. One of the criticisms of the HRBA is that it is too rigid and puts too much burden on the state. However, this is not true, since one of the main objectives is the public awareness rising about disability and the rights of persons with disabilities. Even though this approach emphasizes law as a crucial element, yet the societal dimension is at least equally important. Hence, another name that implies or clearly shows existence of the social dimension would be more appropriate.

Other criticisms of the HRBA are possibility of cultural imperialism (as for any other international instrument) and problems in operationalization (Katsui 2008). The former criticisms will not be considered in this thesis, while the latter would be examined in the part of the thesis where I will present progress and problems of deinstitutionalisation in Bulgaria and Serbia. In the following chapter I will provide an overview of the legal framework based on the human rights approach to disability that nonetheless was heavily influenced by the social model of disability.

### **Introduction to the legal framework of deinstitutionalisation**

After presenting a phenomenon of institutionalisation from 17<sup>th</sup> to 21<sup>st</sup> century from sociological and philosophical standpoints and through history of medicine, in this chapter I will discuss the legal frameworks in which this phenomenon occurred and still occurs. In the first part, the most influential and sometimes quintessential legal acts from the history, starting with 17<sup>th</sup> century when the first institutions for incarceration of mentally ill appeared, will be briefly presented. Some of these provisions had set fundamentals for protection of persons with disabilities, while others presented lawmakers' and contemporary society's

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<sup>51</sup> Rather than passive receivers of support. This passivity is a characteristic of the outdated medical approach, which is, unfortunately, still dominant in many countries.

animosity towards feeble minded by setting troublesome provisions that had further deepen inequality and disadvantaged this group.

This will be followed with a review of 20<sup>th</sup> century rise of the International Human Rights Law and the most important international and regional (European) legal instruments, such as the United Nations Declaration of Human Rights, Convention on the Rights of Child, European Convention on Human Rights<sup>52</sup>, the European Social Charter and the European Union Charter of Fundamental Rights, with respect to the rights of persons with disabilities, their dignity, personal autonomy and the right to be included in the community. The following part will consider an analysis of the UN CRPD as undoubtedly the most important international instrument for protection of the rights of disabled persons, again focusing on the notion of dignity and the rights set in the Article 19, which is the single most relevant article in the context of deinstitutionalisation.<sup>53</sup>

### **Disability in legal history**

As we already saw in the previous chapter, there was no mass incarceration of persons with mental disorders before the 17<sup>th</sup> century. Michel Foucault (1961) wrote about the Western European<sup>54</sup> cities where the societies, driven by their newly developed sensibility, created moral obligations which eventually became part of the civil law. The aforementioned societies, I already discussed, were not particularly friendly towards homelessness, idleness, mad, people with bad hygiene, deviant behavior, bad language *etc.* However, contemporary societies' sensibility in 17<sup>th</sup> century didn't create a motivation to improve the status of these disadvantaged groups, but rather to segregate them under the excuse of humanitarian and economical reasons. I already discussed why confinement of mentally impaired persons without treatment for their conditions and ubiquitous ill-treatment is nothing else than a punishment for one's impairment.<sup>55</sup> The Royal decree from April of 1656 ordered creation of 'general hospitals' in every French city. These infamous institutions served for confinement of various disadvantaged groups, among which the insane. According to the decree, the poor "of both sexes, of all ages and from all localities, of whatever breeding and birth, in whatever state they may be, able-bodied or invalid, sick or convalescent, curable or incurable" were to

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<sup>52</sup> Officially: "Convention for the Protection of Human Rights and Fundamental Freedoms"

<sup>53</sup> Still, it would be wrong to think that the article 19 is the only relevant article for deinstitutionalisation. Without simultaneous fulfilment of all the rights set in the UN CRPD, the persons with disabilities would not benefit from DI.

<sup>54</sup> Primarily the United Kingdom and France.

<sup>55</sup> Already elaborated in the chapter "From madhouses to deinstitutionalisation; from 17th to 21th century" p. 12

be committed to these new institutions. With this wording, the decree clearly did not have an aim to distinct between disabled and non-disabled, displaying obvious lack of interest for well-being of the insane, seeing it only through the prism of the assets they (didn't) possessed and (in)ability to work.

Still, economic reasons were the crucial element for the creation of the first "laws of poor" In the times of recessions and high unemployment number of confinements would rise sharply (Foucault 1961). Some influential contemporary figures, such as Thomas Dekker a British writer (1622 in Clement 2013, p. 111), expressed their deep concern that the poor will overflood England, and at the same time calling them by the name "pests". Authorities had an answer for this problem in creation of institutions for mass incarceration of everyone who was unemployed or qualified for incarceration for other reasons.<sup>56</sup> Nevertheless, similarly to France, the persons with disabilities were struck by these laws since they constituted non-working, 'pesterous' population.

The famous British "Elizabethan Poor Law"<sup>57</sup> from 1601 did not recognize special needs of mentally impaired persons and put them in the same bracket as other vagabonds (Weiner 2008). Thus, they were left to suffer in the confinement of the large poorhouses. This law was in use for almost 250 years (until 1834), still with numerous amendments. The next legal act in England that considered insane was the Vagrancy Act from 1714, which practically consolidated all previous laws that considered lunatics, poor, beggars, misfits and vagabonds into one act. According to this act officers had an authority to apprehend the aforementioned persons and send them to the workhouses, prisons and other institutions of confinement. The County Asylums Act from 1808 was especially significant, since it recognized a need for creation of specialized institutions for insane. Interestingly, in the text of the Act a need to segregate insane from criminals was explained by highly dangerous and inconvenient practice to keep them together. Hence, the English legislature still at that point hadn't recognized a need for special care and improvement of conditions for mentally ill persons.<sup>58</sup> The next important legislative act, brought in 1834 in England was Poor Law Amendment Act, which practically abolished Old Elizabethan Law. This law established workhouses, which already existed for many decades. Now, to the workhouses were appointed only able-

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<sup>56</sup> In order to keep a focus on the incarceration of insane I will not discuss economical reasons, which I already superficially touched upon in the previous chapters.

<sup>57</sup> Officially: The Act for the Relief of the Poor.

<sup>58</sup> Construction of asylums was allowed "whereas the practice of confining such lunatics and other insane persons as are chargeable to their respective parishes in Gaols, Houses of Correction, Poor Houses and Houses of Industry is highly dangerous and inconvenient." – County Asylums Act 1808.

bodied, thus excluding disabled persons (Bartlett 1993). However it did not explicitly exclude mentally disabled persons without physical disabilities.

A very few legal acts in the history (before 20<sup>th</sup> century) that considered persons with mental disabilities were intended to improve their quality of living. Nonetheless, most of the relations with mentally disabled persons were based on tradition, and the only care for mentally ill persons could come from their families<sup>59</sup>. Scarce attempts by some authorities to regulate the status of mentally impaired were usually futile. Most of these legal acts did not consider them directly but rather as a subgroup of the larger groups that were covered by these laws. Since the persons with mental disabilities have different needs from majority, this inevitably meant either status quo of their rights or even worsening of the conditions they lived in.

### **International Human Rights Law and the persons with disabilities**

Twentieth century brought progressive development of the international law, especially human rights law. Even the first international law instruments were developed in the 19<sup>th</sup> century, still legal provisions concerning persons with disabilities came into scene with the Universal Declaration of Human Rights through the concept of universalism.

### **United Nations Declaration of Human Rights**

This non-binding document was a milestone in development of the international law; thus the international law created before UDHR is mainly referred as 'classical'. UDHR was created with cooperation of professionals and governments from all around the world, which adds on its credibility and importance. A clash between more civil and political rights (individual rights) oriented Western countries and more socially-oriented (collective rights) countries of the Eastern Bloc, had a huge impact on the text of the Declaration by improving it and making it the most comprehensive document that was supposed to protect fundamental rights.

There is a couple of exceptionally important categories introduced with the UDHR. These are universalism and dignity. Both concepts are of utmost importance for the rights of persons with disabilities; hence they will be briefly discussed in the following paragraphs in their relation to disability rights.

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<sup>59</sup> Apart from some religious organization; however this was not a mainstream model and it relied on charity approach.

## On Universality

The UDHR was the first international law document that put universalism as the main characteristic of the fundamental rights it prescribed. The principle of universality is a cornerstone of this declaration. However, many objections were raised against its validity. The process of drafting and adoption of the Declaration was such that was used as one of the main arguments against universality of UDHR since.<sup>60</sup> We can distinct two main senses of universality. These are universality of scope (applicability) and the universality of validity (Ulrich 2011). The universality of applicability means that human rights apply to every human being, irrespectively from any of their characteristics (Ulrich 2011); in other words, human rights prohibit selectivity of application of human rights. Universalism of the fundamental rights is based on a presumption that standards set by them should equally protect all persons without any distinction and should be respected in every corner of the world and in every culture<sup>61</sup>. The character of universality is therefore a base on which United Nations were created and on which they have existed all these years (Baehr 1999).

Persons with disabilities are as diverse group as the human race is diverse. People from indigenous groups, Roma people, rich and poor, those living in remote areas, in Geneva as well as in a village with three houses somewhere in Serbia, black, gay *etc*, can be disabled. Therefore, by recognizing the rights of persons with disabilities we are investing in the concept of universality of human rights (Aguilar 2017).

Even if the cultural relativism is a common reason (excuse) for many governments not to sign or ratify some conventions, it seems that the UN CRPD gained a lot approval all across the world, with the second largest number of ratifications, after the UN CRC.<sup>62</sup> Hence, a need to improve the rights of persons with disabilities is, at least on the paper, recognized everywhere, and not incidentally. At least two reasons exist for the great success of the UN CRPD with the respect to the high number of ratifications. The first would be worldwide recognition of disturbingly bad state of the rights of persons with disabilities. Violations of their rights are so widespread and deeply rooted that many countries realized a need for improvement in this sphere. The other reason, and probably the one which brought more ratifications than the previous one, was an intention of the State parties to look ethical in the

<sup>60</sup> At the time, United Nations had only 56 members, of which just 48 voted in favour while other abstained.

<sup>61</sup> A clash of cultural relativism and universalism of human rights is never ending debate between academics as much as between politicians and governments. For further reading see: Baehr, PR 1999, Human Rights: Universality in practice, Palgrave Mcmillan, London

<sup>62</sup> 173 countries ratified the UNCRPD, 196 countries ratified UNCRC: viewed 4 June 2017, <<http://indicators.ohchr.org/>>

eyes of the global society, or better to say, not to look immoral in case if the ratification never happened. Ultimate hypocrisy of these states is easily detectable, since after the ratifications these states did nothing to improve the state of rights of the persons with disabilities; whatsoever many of them continued harmful practices from the past, which are prohibited by the Convention.<sup>63</sup>

## Notion of Dignity

I chose to write a chapter about dignity since it is the single most important, the most basic and the most violated inherent value of every person; dignity of persons with disabilities is violated in such a scope, that we take for granted treatments (both medical and social) of these persons without considering how it affects their dignity, as if they were never entitled to have it. A reason for this is a general state of ignorance when it comes to the needs of persons with disabilities, particularly those with mental disabilities and especially children.

The notion of dignity dates from the ancient Rome as “*dignitas hominis*”. This term referred to a person with a certain status and rank, therefore dignity was earned (McCrudden 2008 in Saxena & Hanna 2015). In the following centuries, and especially after the WWII the notion of dignity evolved and gained a new, universal meaning and became a distinct right as well as a fundament on which all the other human rights are based.

A meaning of the vague notion of dignity is usually taken for granted. Dignity is often related to pride, or integrity. There are so many possible answers on a question “what is dignity?”; therefore by failing to approach to understanding of its meaning conscientiously and examine it thoroughly one may end up without realizing its full potential and importance for the rights of persons with disabilities, and the human rights in general. We are usually referred to dignity when someone’s violation of the most basic rights is at stake. For example: living conditions of inmates in a certain institution violates their human dignity; or when a politician addresses a female journalist with words: “I like these female journalists who get on their knees easily.”<sup>64</sup> we would say that the journalist’s dignity was violated. The concept of dignity is maybe easier to understand through what is not than what dignity is (Lehners 2016). This debate leaves us without a definite answer, nor will a consensus about the

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<sup>63</sup> For example: chapter The European Union’s infamous funding of segregation

<sup>64</sup> A case of then Serbia’s Minister of Defence, Bratislav Gašić, from December 2015. Gašić was dismissed by the Parliament, which voted 195 in favour and 0 against the dismissal. This scandalous act was seen as a violation of dignity of the journalist, but also all the women and all the journalists. More on this at: <https://rsf.org/en/news/rsf-supports-journalists-refusal-kneel-government>

meaning of dignity ever exist. Still, even the idea of dignity is vague we all have by intuition, a more or less clear picture of what it is and what it is not.

The law of human rights presupposes inherence of dignity in every human being; dignity is therefore an intrinsic value.<sup>65</sup> It does not need to be obtained or deserved, even less bought or earned. For this understanding of human dignity Kant's work is of utmost importance. In the following sentence Kant explains an "immeasurable value of dignity" (Lehners 2016):

*"In the realm of ends everything has either a price or a dignity. Anything with a price can be replaced by something else as its equivalent, whereas anything that is above all price and therefore admits of no equivalent has a dignity."*<sup>66</sup>

The right to dignity or a dignity as an intrinsic value is exceptionally important for the quality of living of persons with disabilities, and persons who are residents of institutions. As Lehners (2016) perfectly noticed and put it very concisely: "If we accept the concept of the inherent dignity of all human being, a patient can never be treated as a case, but always as a person, a unique being."<sup>67</sup>

A question of operationality of dignity rises here. In order to be operational, an abstract notion of dignity needs to be embodied in a concrete notion such as informed consent, physical integrity, confidentiality, non-discrimination, legal capacity *etc* (Andorno 2014).

## Dignity in international law instruments

There is a noticeable trend that dignity should be understood as a base for all other fundamental rights. Therefore, the concept of dignity is frequently being explicitly mentioned

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<sup>65</sup> There are many reflections on the concept of dignity, especially in philosophy. Some of them give distinction of different strands of dignity. For example, dignity can be seen as a rank or status. This standpoint would be on one end of the spectrum of understanding of dignity, while dignity as an intrinsic value would be an absolute opposition to this.

<sup>66</sup> Kant, I 1997, *Groundwork for Metaphysics of Morals*, Cambridge University Press, Cambridge, transl. Mary Gregor.

<sup>67</sup> Similar, but still maybe more operational and more specific definition of dignity with respect to care for ill persons was given by the Royal College of Nursing. This specificity lays in the context of patient-nurse relations. According to this definition treating someone with dignity means treating them "as being of worth, (and) in a way that is respectful of them as valued individuals". Further, the definition explains that persons whose dignity is violated feel humiliated, embarrassed, ashamed, uncomfortable, without confidence, lacking control (emphasis added). However, the definition recognizes existence and need for respect of dignity even when a person is not able to feel or think. Also, it acknowledges that dignified care should continue after death (Royal College of Nursing 2008). A person who is deprived of his personal autonomy cannot lead a dignified life; however, from the previous definition we can derive a conclusion that even when the person is not able to think or feel, and therefore unable to exercise his rights we are obliged to treat him with dignity. With this approach we maintain the idea of inherence of dignity while still claiming that one's dignity is dependent upon existence of his personal autonomy.



in the various international legal instruments. I will mention just a few of them with especial attention to the concept of dignity in the UN CRPD.

Already in the UDHR dignity was placed on a pedestal by putting in on an equal level with the inalienable rights. In the Preamble of UDHR an “inherent dignity” is emphasized as a characteristic of every human being: “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family...” Then again in the article 1: “All human beings are born free and equal in dignity and rights.”

The Charter of Fundamental Rights of European Union in Article 1 states that: “Human dignity is inviolable. It must be respected and protected.”

In the ECHR there is no mention of dignity. However, this term was introduced with the Protocol No. 13 (2002) and absolute abolition of death penalty. Moreover, the Court’s case-law, already in 2002, refers to the respect of human dignity as a “very essence of the Convention” (Goodwin v. UK, par.90).

### **Dignity in the UN CRPD**

Disabled persons are a group whose dignity is violated continually. Apart from being discriminated and marginalized in the society that is made by and for non-disabled, this is also a case in the context of health and social care service from which they should receive support and treatment (Saxena & Hanna 2015). Hence, persons with disabilities as a group, bear a disproportionate burden in our society. Their vulnerability depends on their age, sex, severity of disability, stigmatization of a particular disability, social and economic status of the person, a country and a county where the person lives and many more factors that can amplify their vulnerability. Shakespeare (1994) went a step further, claiming that there is an ever-present hostility of non-disabled towards disabled people. He found psychological origins for this in tendency of non-disabled to deny their vulnerability, fragility and mortality of which disabled persons remind them, but who able-bodied then can oppress, exclude and ignore (Shakespeare & Watson 2002).

Therefore, a need for more specified and universal standards concerning the rights of persons with disabilities was more than prominent. This was achieved with the adoption of the UN CRPD in 2006. This is the first convention that so firmly focuses on the protection of dignity of one disadvantaged group (Saxena & Hanna 2015).

In the preamble of the Convention ‘inherent dignity (and worth)’ is recognized along equality and inalienable rights as for every human being.<sup>68</sup> Thus, the UN CRPD put dignity on the first place and as an essential foundation for everything what is written in the Convention. Then, still in the preamble, the UN CRPD acknowledges that discrimination on the basis of disability is violation of that inherent dignity. Thus, we get to conclusion that dignity, put as a foundation for all the rights in the convention, is inevitably violated when any of these rights are violated.

In the article 1, promotion of “the respect for the inherent dignity” is recognized as one of purposes of the Convention. We see that even though dignity is an inherent, intrinsic value, we cannot enjoy it without having a respect for our dignity from other subjects. Therefore, dignity is highly dependable on the general awareness of its existence. I mentioned earlier that we are usually taking dignity for granted, or better said – we accept its inherence intuitively for every person; however this well may not be the true when dignity of persons with disabilities is at stake, especially those with severe mental disabilities. This is due to lack of awareness about mental disability, what it is and who lives with it; other than that, we tend to observe persons with intellectual disabilities as objects rather than subjects, bearers of rights.<sup>69</sup> Thus, we unconsciously detach this inalienable characteristic from them.

In the following articles of the UN CRPD dignity is explicitly mentioned. In order to understand importance of this concept for the Convention I will briefly examine every one of these articles in the context of correlation between the rights guaranteed by them and dignity:

- Under the Article 3 (a), where the General Principles of the Convention are displayed, “dignity” is put on the first place alongside “individual autonomy”, “freedom to make one’s own choices” and “independence of person”, thus putting a certain equation of importance between these terms. Individual autonomy is essentially a synonym to freedom of choice and independence of person. Furthermore, in many of the attempts to define dignity, individual autonomy appeared as a frequent choice of thinkers; still a clear distinction in favor of dignity was claimed by some authorities and this is a more accepted opinion in the legal practice.<sup>70</sup>

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<sup>68</sup> In the UNCRPD a word “dignity” is mentioned nine times.

<sup>69</sup> “Historically viewed as welfare recipients, persons with disabilities are now recognized under international law as rights holders...” from: Committee on the Rights of Persons with Disabilities 2016, 'General Comment No.4 (2016) on the right to inclusive education', par. 1

<sup>70</sup> Ruth Mucklin claimed that dignity is nothing more than respect for one’s autonomy (Lehners 2016). An opposite opinion was given by the French State Council in the famous case of the “dwarf tossing” in 1991.

- Under the Article 16 (4), where the freedom from exploitation, violence and abuse is presented, “dignity” appears in a context of *reintegration* and recovery in an environment that fosters health, dignity and autonomy. Certainly, dignity of persons with disabilities is undetachable from their integration in society, and any segregation is violation of dignity.
- The Article 24 (1) guarantees the right to education for persons with disabilities. A “sense of dignity” is set in relation to education as an aim that should be achieved with appropriate, inclusive education of persons with disabilities. Even though dignity is intrinsic, a sense of dignity is not and it is a highly susceptible category. Its state and existence are dependable on various social, biological and other factors. These factors can be an education, upbringing, or level of mental development, but also anything that comes from the world and affects us.

Nonetheless, as Lehnert claimed (2016), in a concrete situation the concept of dignity should be always replaced with a specific right that is violated. This way, we can avoid using a philosophical concept in argumentation before the courts since it can lead to endless debates without achieving tangible results. Another problem is a use of legal vocabulary which usually does not allow us to express ourselves to the fullest extent. Therefore, a combination of philosophical and legal approach in examining and explaining a concept such as human dignity is absolutely desirable (Lehnert 2016).

The World Health Organization in their Mental Health Action Plan (2015) recognized a few examples of typical grave violations of the human rights of persons with mental disabilities which absolutely wreck person’s dignity. Some of these are directly connected to institutionalisation:

- Institutionalisation with deprivation of liberty, where they are inevitably secluded from the society and subject to inhumane and degrading treatment;
- Physical, sexual and emotional abuse and neglect, in hospitals and community;

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Namely, a mayor of Morsang-sur-Orge commune prohibited this action to be continued. Soon, a person who was tossed complained on the account that it was his free choice and that he was in danger of unemployment. The French State Council found that dignity overrides one’s individual autonomy and the complainant lost this case. The case ended up before the aforementioned authority and later before the European Commission of Human Rights in Strasbourg which, in 1996, rejected the appeal; Mr Wackenheim (a man that was tossed) appealed under Article 5, Article 8 and Article 14. The UN Human Rights Committee rejected Mr Wackenheim appeal in 2002 (for more on a debate on dignity and personal autonomy in the aforementioned case view: Rosen 2012). Nonetheless, the concept of dignity and its clash with personal autonomy is the most prominent in cases of assisted suicide.

- Full deprivation of legal capacity.<sup>71</sup>

### **Dignity and the children with disabilities in the UN CRC**

Since this research will eventually focus on deinstitutionalisation of children with disabilities in Serbia, I will provide a short overview of the UN CRC and articles that consider the rights of children with disabilities.

A leading principle of the UN CRC with respect to the children with disabilities is set in the article 23 (1) (Committee on the Rights of the Child 2007):

*States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.*

According to the General Comment of the Committee on the Rights of the Child No. 9 (2006) the core principle of this paragraph is inclusion of the children with disabilities in the society. Still, dignity was set as a prerequisite for a decent life, which is unachievable without inclusion of children with disabilities in all spheres of the social life. Thus, the States parties are obliged to take all measures to attain this aim.<sup>72</sup>

Another mention of the “inherent dignity” of the every human being and a child is in article 37 (c), with respect to deprivation of liberty. Firstly, it prescribes a treatment with the respect for a child’s dignity and secondly it obliges State parties not to put children and adults together<sup>73</sup> in the establishments where deprivation of liberty occurs. This is particularly important for residential institutions where children with mental and physical disabilities are often held together with adults.<sup>74</sup> Lack of segregation of children from adults raises already high risks for occurrence of violence and abuse among inmates (MDAC 2017).

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<sup>71</sup> Accessible at: [http://www.who.int/mental\\_health/world-mental-health-day/infosheet\\_wmhd2015.pdf?ua=1](http://www.who.int/mental_health/world-mental-health-day/infosheet_wmhd2015.pdf?ua=1)

<sup>72</sup> However, even the Convention on the Rights of the Child is the single most ratified convention (193 ratifications until now) in the world, 18 years after its adoption, around 80% of the children with disabilities lived with little or no access to services (Committee on the Rights of the Child 2007, par.1).

<sup>73</sup> Unless it is considered that it ‘s in the best interest of a child.

<sup>74</sup> From the MDAC (2017 p.16) report following the visit to Tophaz institution: “Of particular concern to the team was finding children and adults placed on locked wards together – including on the “Children’s Ward” – with minimal supervision. MDAC found a girl sharing the same bedroom with boys and an adult man.”; HRW (2016 ) reported that in some institutions in Serbia children and adults with disabilities shared the same living space.

## UN CRPD Article 19 deconstructed

The Convention set an obligation to the States parties to ensure inclusion and participation in community in a clear manner and without any reservations, recognizing inclusion as an absolute right of all the persons with disabilities. This was demanded also in the article 23 paragraph 5 (states parties are obliged to ensure living in community and within family setting for a disabled child); article 24 (paragraph 1 (c) – an obligation to provide inclusive education with an aim to enable “participation in a free society”); article 26 (an obligation to take “all measures to support participation in the community in relation to habilitation and rehabilitation of persons with disabilities”). Hence, we may conclude that living in the community is most closely linked to all the aforementioned rights, and especially non-discrimination, family rights, freedom of movement, privacy, right to legal capacity and freedom from torture and inhuman or degrading treatment (Commissioner for Human Rights 2012).

The core of the international legal framework with the respect to persons with disabilities is contained in the UN CRPD. In the same way, an essential obligation to ensure independent living and living in community for the persons with disabilities is enshrined under the article 19 of the Convention:

### *Article 19*

*States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their **full inclusion and participation in the community**, including by ensuring that:*

- *Persons with disabilities have the opportunity to **choose their place of residence and where and with whom they live** on an equal basis with others and are **not obliged to live in a particular living arrangement**;*
- *Persons with disabilities have **access to a range of in-home, residential and other community support services, including personal assistance** necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- *Community services and facilities **for the general population** are available on an equal basis to persons with disabilities and are responsive to their need.*<sup>75</sup>

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<sup>75</sup> All emphasis added

The article 19 represents a landmark, and by far the most important provision of the UN CRPD apropos the process of deinstitutionalisation. This is the first explicit inclusion of the right to live independently and participate in the community in one international treaty. Apart from setting an explicit obligation for the states parties to enable participation in society for everyone, it also provides guidance for understanding of what life in community means and how it should be ensured for persons with disabilities (Commissioner for Human Rights 2012).

### Meaning of “independent living”

A phrase “living independently” is probably the most problematic, and usually used to construct contra-arguments for deinstitutionalisation. Some professionals, usually personnel of the residential institutions<sup>76</sup>, will argue that many persons with disabilities are not able to live independently. However, this independence should not by any means be understood as a highly-independent, self-sufficient and self-reliant lifestyle of a person (European Network on Independent Living 2016). It rather finds its base in the social model of disability, which essential idea is that the society is the one who disables, and not the impairment itself; therefore, persons with disabilities are limited by the social and physical environment (Commissioner for Human Rights 2012), so if not supported they cannot be independent. ENIL (2016) pleaded that independent living neither means to live alone. Essentially “independent living” means individual autonomy and *control* over one’s own life, and, very importantly, the State’s support in achieving this. The UN OHCHR (2014) defined independent living in the following sentence:

*Living independently does not mean living alone or in isolation. Rather, it means exercising freedom of choice and control over decisions affecting one’s life with the same level of independence and interdependence within society on an equal basis with others.*

Exactly the aforementioned control was the one that was taken-over from the insane and poor during the period of The Great Confinement, and put into the hands of state. When the state takes a control over a person’s life to the tiniest element of his living, such as of the institutionalised persons, the state deprives him or her of their dignity. Ultimately, independent living is all about giving control over one’s own life back. However, we can

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<sup>76</sup> From an interview with a professional in the social care of persons with mental disabilities.

easily claim that a person can never have total control over his/her own life, and this would be an absolutely correct assumption. There is no state of full independency for a person that lives in the community, nor does more independency necessarily mean more dignity. The answer is in balance between the state control and individual autonomy. The state control should be exercised only in the cases of emergency<sup>77</sup> and in provision of necessary means to ensure inclusion of the persons with disabilities. Therefore, the term ‘institutional culture’ is essentially a culture of control.

Similarly to previously explained notion of dignity, we also tend to take for granted someone’s participation in society. More precisely, we are not considering it at all, while at the same time our whole lives are being inevitably spent in the society. We are born, we grow up, work, retire and die in the society. This participation is so inherent and common that we fail to realize its significance, until we are deprived of it, and still very small number of us ever experiences this deprivation. Exactly this, a life in the community and participation in the society are denied to the institutionalized persons living with disabilities.

### **Inclusion vs. integration**

Wording of the article 19 is put carefully, so “integration” is left out and there is only “inclusion” in community and that with a good reason. Integration means that the disabled persons should fit in the society which is, by a rule, not ready to accept these persons. It is not ready to accommodate disability because of lack of the necessary services, accessibility standards and presence of other social, economical and architectural barriers. While the inclusion “requires removal of all barriers in order to ensure full participation of the persons with disabilities” (European Network on Independent Living 2016).

In the Charter of Fundamental Rights of the European Union under article 26 we find a clumsy formulation on the right of persons with disabilities to participate in the community. Namely, the title of the article only mentions “Integration of persons with disabilities”. Explanation for this outdated formulation we may find in the time of adoption of the Charter (2000) which happened 10 years before EU’s ratification of the UN CRPD.<sup>78</sup>

A similarly formulated provision can be found in the European Social Charter. Under the article 15 “The right of persons with disabilities to independence, social integration and

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<sup>77</sup> Cases of necessary involuntary commitment. The New York State Mental Hygiene Law is believed to have one of the strictest provisions on involuntary admissions. For more on this view The New York State Mental Hygiene Law: accessible at [https://www.omh.ny.gov/omhweb/forensic/manual/html/mhl\\_admissions.htm](https://www.omh.ny.gov/omhweb/forensic/manual/html/mhl_admissions.htm)

<sup>78</sup> And 6 years before adoption of the UN CRPD.

participation in the life of the community” the states parties are obliged to take a number of actions in order to ensure their enjoyment.

### **Paragraph a - Choice**

Individual autonomy is reflected in the right of a disabled person to choose his or her place of residence and with whom and where the person wants to live, and all of that on an equal basis with others. “An equal basis with other” should mean that a disabled person has a possibility to live in private, rented or owned housing and social housing among other types of accommodation in the community. To be able to choose, a person needs to have legal capacity. Enshrined in article 12 of the UN CRPD (Equal recognition before the law), legal capacity consists of two elements: capacity to be a holder of rights and capacity to exercise rights as a legal person (Committee on the Rights of Persons with Disabilities 2014). Therefore, decision-making is a prerequisite for independent living. As long as the persons with disabilities are under full guardianship (substitute decision-making), they are not able to exercise their rights before the law and cannot choose for themselves. Substitute decision-making needs to be replaced with supported decision-making in order to give power of choice to these persons.

Naturally, this provision almost abolishes institutionalisation by setting an individual autonomy and equal opportunities on the pedestal. Therefore, with the respect to mentally disabled persons, the UN CRPD promotes voluntary admissions to the hospitals and treatments, while at the same time pushing for the strict requirements in case of a necessary involuntary commitment of persons who are in need of in-patient psychiatric care.

Even though there are cases when the institutionalized persons do not want to leave an institution, this should not be taken as an argument against deinstitutionalisation. After a long-term incarceration a person can be, and absolutely naturally, scared of life in the community (European Network on Independent Living 2016).<sup>79</sup> Also, a lack of options and pressure from a family can be reasons for a person to state that he wants to live in an institution. Moreover, an institutionalised person may not want to be a burden for their family, or there are long waiting lists for supported living. None of these reasons can be an excuse for institutionalisation, since all of them are a consequence of influence of the society which is not ready to carry out a full inclusion of persons with disabilities.

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<sup>79</sup> I said “naturally” because almost every radical change in one’s own life is followed by at least a minimum amount of anxiety. Another reason, a more specific one, comes from various psychosocial disturbances that can developed from living in a surrounding which functions on the principles of the culture of control.



### **Paragraph b - Support**

The State Parties are left to decide on the type of services which they will provide, in order to ensure inclusion and prevent segregation from the communities; however those services must ensure respect for the individual autonomy and choice of the service users, so that control of their lives is absolutely in their hands (European Network on Independent Living 2016). Another important point is the “residential support”, which should by no mean be mistaken for “residential care”. This way the UN CRPD practically forbids and delegitimizes institutional care (EASPD 2013).

Community-based services are, practically, an essential part of the process of deinstitutionalisation. If persons with disabilities would be placed in the community, but without these services, they wouldn't be able to reclaim control over their lives, and ultimately their dignity would be violated. Therefore, dignity is not reclaimed with simple transition of a person from an institution to a community-based housing, or only with implementation of supported decision-making (even though this is a huge improvement), but only after ensuring that the person has all the rights on an equal basis with others. In order to have these rights, he needs to have access to a wide range of services.

Personal assistance is probably the most important community-based service. It is essential to be accessible to persons with all kinds of disabilities. The persons with intellectual and psycho-social disabilities are especially dependable on personal assistance when individual autonomy and shift from medical to social approach of mental illness are concerned (Office of the High Commissioner for Human Rights 2014).

Participation in the community and self-reliance are also extended to the children with disabilities (art. 7 UN CRPD; art. 23 UN CRC) (Office of the High Commissioner for Human Rights 2014). This is especially important in prevention of children institutionalisation which is supposed to be achieved by developing support for parents that are taking care of their disabled children (European Network on Independent Living 2016).

Mainstreaming of support for the persons with disabilities is an absolute must. This can be done by making social protection policies fully inclusive and making this support provided through universal health coverage, pensions, and other specific services need to be a part of the universal social protection system of a country (Aguilar 2017). Special rapporteur for the rights of persons with disabilities (2017) noticed that in our societies everyone is supported,

and the general public is usually not aware of it anymore. However, this support is designated for non-disabled persons. By acknowledging that the persons with disabilities are normal part of human diversity, we will recognize that disabled persons are unfairly deprived of the support they need in order to have dignified life, which is different from the support for non-disabled. Again, the core argument lays in the argumentation from the social model of disability.

### **Paragraph c - Availability**

This paragraph set an obligation to the State Parties to make accessible and available all mainstream services and the facilities that are used by general public to persons with disabilities. This provision is set broadly to cover all the services that are existent in the community, and also consider schools, public transport, possibility to work in the open job market according to one's aspirations and competencies etc. (Office of the High Commissioner for Human Rights 2014).

This provision is most closely related to Article 9 (Accessibility). The idea of accessibility does not only consider physical barrier-free environment, but also includes human and technical support (EASPD 2016).

### **Significance of the family environment for a child in the UN CRC**

The UN CRC recognizes importance of the family environment for proper physical and mental development of a child. Moreover, in the preamble of this document it is enshrined that for the full and harmonious development of child's personality an atmosphere of happiness, love and understanding is as much important.

This statement is a *sui generis* parallel of the right set in the Article 19 of the UN CRPD. What importance the independent living has for an adult, a family environment has for a child. These two provisions have a meeting point in the right to participate in the community. A child that lives out of the family environment, for which institution is a common alternative, is deprived of possibility to participate in the community (especially if it is also deprived from mainstream schooling). Similarly, when an adult with disability is not independent and lives in an institution he or she is not able to participate in the society because of inevitable segregation and deprivation of his or her individual autonomy.

## Summary

The ‘Elizabethan Poor Law’ and the Royal decree provided the legal frameworks for incarceration of persons with disabilities in France and England in 17th century. These legal acts did not consider only persons with disabilities but wider groups whose main characteristic was inability to work. Hence, the confinement of the persons with disabilities was, in a sense, a collateral damage of the contemporary social and economical trends. The first law that provided a framework for creation of psychiatric asylums was brought in England in the beginning of 19th century under the name ‘County Asylum Act’. Appearance of this law was a result of medicalization of treatment for mental illness, and need for specialized institutions of this type. Other legal acts, that considered persons with disabilities, appeared in the 19th and the beginning of 20th century; however, a breakthrough happened only with adoption of UDHR that provided us with the concepts of universality and dignity. The concept of dignity as an inherent value of every human being is crucial for development and realization of the rights of persons with disabilities. Often taken for granted, this concept provides basis for enjoyment of all fundamental rights and can stand as a distinct right; still in judicial cases, whenever it is possible, dignity should be replaced with the concrete right that is violated, in order to avoid debates over its vague notion and applicability. The core of the legal framework for deinstitutionalisation is settled in the article 19 of the UN CRPD which emphasizes the right to choose and individual autonomy of person with disabilities as fundamentals without which persons with disabilities cannot lead dignified lives. It also set obligation on the State parties to ensure support and services needed for realization of inclusion. The right of children with disabilities to life in the family environment is an analogue to the right to independent living for adults with disabilities; enjoyment of these rights is a prerequisite for inclusion in the society.

In the next chapter I will present a case study on Bulgaria’s and Serbia’s processes of deinstitutionalisation conducted under the analysed legal framework, with the focus on children with disabilities. Finally I will provide a set of general recommendations for the Government of Serbia and the organization of civil society that should lead to successful transition from institutional to community-based care of children with disabilities.

## *Case studies: deinstitutionalisation of children with disabilities in Bulgaria and Serbia*

### **Introduction**

In this section I will provide brief overviews of DI of children in Bulgaria and Serbia. These surveys are important in order to collect positive and negative practices with the respect to the process of transition from institutional living to living in community for persons with disabilities. The DI process with all its complexity has to be observed with detection of certain points of focus in order to successfully cover the most important aspects. Thus, my focus is on the complementarity of the national policies with the UN CRPD, funding of infrastructural and the so-called soft projects in DI process, participation of the organizations of civil society and the progress in DI process expressed in quantitative data, especially with regards to the number of deinstitutionalised children. After examination of the process in Bulgaria, I will present the DI process in the Republic of Serbia and provide recommendations for further changes, based mainly on the Bulgaria's experience. Hence, the purpose of this study is not to provide a comparative analysis of two systems; however comparison is sometimes inevitable, but not a main goal *per se*. The reason behind choosing Serbia for this study is my familiarity with the issues that are existent in the Serbia's social care system, an intention to pursue a professional career in Serbia in the field of human rights, particularly the rights of persons with disabilities.

In these two studies I will put an emphasis on the situation of children with disabilities and the process of deinstitutionalisation of children. The children are particularly vulnerable in the social care system, and consequences of institutionalisation are especially serious in the case of children.<sup>80</sup> However, when presenting the DI process in Bulgaria I will not only focus on the children with disabilities but also the non-disabled children and youth. I will do this because many practices, especially those with political and administrative dimension can be applied in DI of children with disabilities.

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<sup>80</sup> Negative impact of institutions on children

The reason behind taking Bulgaria for this research was based on its certain characteristics which ensured similarity to Serbia's background for DI process. These characteristics are mostly of a socio-economic and historical nature. Namely, Bulgaria was a communist country until late 20<sup>th</sup> century. One of the typical characteristics of the communist heritage, according to some authors, are large residential institutions with established practices of ill-treatment and neglecting of persons with disabilities, as well as the children without parental care.<sup>81</sup> Therefore, in none of these two countries DI process started before the fall of communism (according to some sources in both countries DI process started in 2001). Another, similarity is economical hardship.<sup>82</sup> Bulgaria is a member state of the European Union<sup>83</sup>, while Serbia has a status of the candidate for membership.<sup>84</sup> Both countries ratified the UN CRPD and the UN CRC.<sup>85</sup> Naturally, both states are members of the Council of Europe which issued a recommendation for the states member on actions that need to be taken in order to ensure full inclusion of children with disabilities.<sup>86</sup>

Data presented here are just a part of a more detailed research that I conducted on the topic. Nonetheless, only the practices that are in direct correlation with Article 19 of the UN CRPD and could be implemented in Serbia are presented here. This information is later used to create general recommendations for DI process in Serbia, while at the same time presenting current advance in the process.

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<sup>81</sup> E.g. KPMG 2016, 'EU Funds in Central and Eastern Europe: Progress Report 2007-2015'. Even though institutionalisation of persons with disabilities is usually portrayed as a part of communist ideology, I would challenge this with the following arguments. Institutionalisation is prominent in the countries where extensive social protection of its citizens is emphasized. If we take Scandinavian countries as typical models of welfare states we will notice that institutionalisation is not that common there (save in the case of Denmark). This is because one more element is needed in order to have large institutions for persons with disabilities. This element is predominantly medical approach to disability. Human rights based approach still hasn't been fully implemented in most of the countries in Europe. This will be clear on the example of Belgium. This, one of the most developed countries in the world, has appalling rate of institutionalisation and Wallonia recently announced an investment of 63 million € in the expansion of the capacities for institutional care ([https://www.rtbf.be/info/belgique/detail\\_63-millions-pour-l-accueil-des-personnes-handicapees-en-wallonie?id=9621693](https://www.rtbf.be/info/belgique/detail_63-millions-pour-l-accueil-des-personnes-handicapees-en-wallonie?id=9621693)).

<sup>82</sup> Bulgaria and Serbia are classified as "upper-middle income economies"; GDP of Bulgaria is 143.1 billion and of Serbia is 101.8 billion dollars (2016): The World Bank Group 2017, viewed 18 June 2017, <[https://datahelpdesk.worldbank.org/knowledgebase/articles/906519#High\\_income](https://datahelpdesk.worldbank.org/knowledgebase/articles/906519#High_income)>.

<sup>83</sup> The EU formally acceded to the UN CRPD on 23 December 2010, the first legally binding core international human rights instrument to which the EU is party.

<sup>84</sup> Bulgaria is an EU member state since 2007. Serbia has the status of candidate country since 2012

<sup>85</sup> Serbia 2009; Romania 2011; Bulgaria 2012: Office of The High Commissioner 2017, United Nations Human Rights, viewed 18 June 2017, <<http://indicators.ohchr.org/>>.

<sup>86</sup> Council of Europe 2013, 'Recommendation on ensuring full inclusion of children and young persons with disabilities into society', Committee of Ministers, CM/Rec(2013)2, Strasbourg.

It is important to acknowledge that lack of data on the number of institutionalized persons is a chronic problem for the both countries.<sup>87</sup>

### **Negative impact of institutions on children**

It is not necessary to have abusive treatment in order for institutionalisation to be harmful for wellbeing of a child. Namely, numerous and various studies proved the devastating impact of institutionalisation on a child. Some of the main issues that arise in children during institutionalisation are:

- Deeply negative impact on cognitive, psychological, social and physical development of children. Prolonged stay in an institution can cause psychosocial and other forms of disabilities in children.<sup>88</sup>
- Segregation from community and often lack of personal contact leads to alienation of the child and diminishes possibility for the child to be a functional part of the community, at least without extensive and careful preparation. Still, damage is sometimes irreparable (Carter 2005).
- Children are four times more in the risk of being sexually abused and six times more exposed to physical violence than children included in community (living with families) (SOS Children's Villages 2010 in Luna 2017).

## **Bulgaria**

In the Report of the Commissioner for Human Rights (2015) it was stated that DI process for children living in medical and social care institutions brought many positive results in Bulgaria. However, DI process for adults started recently and is very slow. Sometimes, adults are transferred to smaller institutions, with better physical conditions, but not in accordance with Article 19 of the UN CRPD (Council of Europe 2015).

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<sup>87</sup> According to the article 31 of the UN CRPD collection of statistical data is an obligation for the States Parties.

<sup>88</sup> It is not clear how much time is needed for harmful consequences be developed during child's stay in an institution. However, it was proven that already after 6 months spent in severely deprived institution damage can occur (The Leiden Conference on the Development and Care of Children without permanent parents 2012, p. 177); Also: Carter, R 2005, 'Family Matters: A Study of institutional child-care in Central and Eastern Europe and the former Soviet Union', Everychild, London, p. 23

Significant breakthrough happened with the National Strategy named “Vision for DI of children in Bulgaria”, followed by the Action Plan 2010-2015. The aim is to shut 137 institutions by 2025 and ban residential care for children 0-3 years of age (Council of Europe 2014). Another important point is clearly stated goal to shut the institutions. A provision like this is lacking in many other countries in the Central and Southeastern Europe in their DI processes.

An independent UNICEF (2014) study, which evaluated the first stage of implementation of the National Strategy, found many positive changes, and especially emphasized the political will and commitment towards DI. As a recommendation, The Commissioner for Human Rights (2014) stated that Bulgaria needs to shut all social and medical care institutions, including 24 infant homes, 70 children’s homes and 24 institutions for children with disabilities. A provision from the National Strategy that there shall be no re-use of the institutional buildings for residential care is unique and utterly important.

Another deeply important solution is a provision in the Action Plan according to which “every region has the same level of need for the same types of services for the same number of children and families apart from day-centers, the need for which is calculated per 20,000 inhabitants (Unicef 2014).” In this way, proportionate development should be ensured, and avoided situations, such as in Romania and Poland, where users who live in the cities have access to the services, while persons in the countryside are totally deprived of this possibility.

An inter-ministerial group was created, as well as an expert group for coordination, development, monitoring and assessment of the Action Plan (Council of Europe 2015). Creation of the inter-ministerial group is a positive practice which helps to coordinate work of more ministries and other governmental agencies in the process. Nevertheless, issues in coordination between ministries and CSOs remain (Council of Europe 2015).

For implementation of the Plan, and monthly meetings in order to assess the implementation, are responsible the Interdepartmental Management and Coordination Working Group made up of deputy Ministers.

Technical Units were created for project management on the national level for every of the main activities in the National Strategy.

Regional project management teams plan services and lead implementation of projects on the regional level.

As we can see, Bulgaria utilized massive human resources in order to successfully fulfill the requirements set in the National Strategy. This is opposite from the practices in other countries in the region. Engagement of many groups, teams and units should help, however communication in such a massive system can be challenging; thus, thorough planning and creation of inter-departmental bodies are crucial.

A lack of well-trained and motivated social workers is another issue. Currently one social worker deals with approximately 100 cases (Council of Europe 2015). This could well be a consequence of low salaries for social workers whose job is unusually responsible and emotionally, as well as physically, challenging. Another problem concerning personnel is that the staff is not prepared for the new forms of care. Therefore, high-quality training of the personnel has to follow infrastructural improvements; otherwise the staff that worked in institutions will bring institutional practices in community-based living, which can result in hindering processes of children inclusion.

European Network for Independent Living, in its 'Shadow Report' from 2014, highlighted the problem of replication of the institutional services into community-based ones. Independent living, according to this report, maintains institutional character because the users are not able to choose where and with whom they will live, as well as the number of residents in these living units. The staff is not properly trained to work in the new services, and they usually bring institutional ways of care to the new types of care (Parker & Bulic 2014). Moreover, ENIL criticized building of small group homes for up to 12 children, where the staff acts in the same way as in institutions, and where users are not allowed to go out without a written request to do it and without a caregiver. In its study from 2016, Lumos found that after moving the children to the 'small group homes' use of tranquilisers and neuroleptics increased substantially.<sup>89</sup>

Further, ENIL noticed that the Structural Funds were used to provide employment for the family members of a disabled person who are taking care of this person. This however, has a

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<sup>89</sup> This is a clear sign of replication of the institutional culture from large institutions to the small ones; moreover, not properly educated personnel which don't know how to deal with the new type of care is actually delivering even worse treatment than in the large institutions.



positive impact on the prevention of institutionalisation but doesn't seek ways to facilitate independent living (Parker 2014).

Center for Independent Living (CIL) criticized community-based services in Bulgaria, saying that they were established on the ground of large long-stay institutions (Parker & Bulic 2013). CIL also reported that the residents using community-based services are not, for example, able to do shopping and cooking by themselves, again clearly replicating the old system.

Another problem is possibility of re-institutionalisation of the children. According to the project "Childhood for all"<sup>90</sup> it is planned to build 149 "family-type accommodation centers" and 36 protected homes, which should accommodate up to 12 children and 2 more in case of emergencies, for a transitional period. Still it was reported that these centers became places for permanent living. Hence, instead of being transitional centers, they became small institutions, isolated from the community (Council of Europe 2015).

The state project "Childhood for All" is a good example how DI of children with disabilities could be put in the focus. Children with disabilities are especially vulnerable and usually forgotten in the process of DI. Prejudices and stigmatization often result in lack of political will. Disabled people are seen as someone who should be patronized. Moreover disabled persons are usually perceived as someone who is not able to live independently, without going into all the specificities of different disabilities and not considering their potential for development.

Enil-Eccl (2015) found that existing strategies for social inclusion of persons with disabilities is "highly questionable". Namely, the strategy for supporting the employment is focused on development of special workshops, instead on the inclusion in the open labor market (Enil-Eccl 2015).<sup>91</sup>

At the end of this section it is important to emphasize that DI process in Bulgaria started a decade before adoption of the current National Strategy. Ten years of activity for improvement of the social care resulted in significant progress. During this period many changes had happened; some of these are: creation of the State Agency for Child Protection,

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<sup>90</sup> This project was initiated by the State Agency for Child Protection in 2010. The project focused on DI of children and young people with disabilities, as an especially vulnerable group. An ambitious goal was set – closure of all 24 institutions (Lumos 2014).

<sup>91</sup> As I already wrote in the Second part, it is important to understand the difference between inclusion and integration. The persons with disabilities need to be included and not integrated in the society p. 39

municipal Child Protection Departments and regional Social Services Complexes; then closure of institutions, especially the most notorious ones (Mogilino e.g.); development of more than 75 family-type homes, small residential homes and group homes across the country; strong and vibrant community of the organizations of civil society *etc* (Unicef 2014).

### **Quantitative data**

In 2003 it was found that there were approximately 50 children, under the age of three, per 10.000 in institutional care in Bulgaria (Brown 2004 in Council of Europe 2015). At the same time an average of 11 per 10.000 was found in another 33 countries studied (Council of Europe 2015). Among general children population (0-17) in 2015 Lumos found that 85 per 10.000 were in institutions in 2010. At the same time in England, this number was 10 per 10.000.

The number of children in institutions decreased from 12.609 to 1.502 in one decade, which shows commitment and undoubtable progress in DI of children in Bulgaria. Majority of children homes were shut, however the institutions for children with disabilities were being shut at a slower pace. Initially, these institutions were set as a priority, but with the pass of time, that initiative diminished and the children homes became priority eventually (Council of Europe 2015).

The already mentioned project “Childhood for all” (2010-2015) resulted in significant improvement in the numbers of institutionalised children with disabilities. This programme covered 2.115 children and youth during its course, with an aim to remove all of them from the institutions. According to Lumos (2016), 1.291 were placed in SGHs, 105 reinstitutionalised (placed in another type of institutions), 78 reintegrated with their biological families, 77 put in foster care and 150 of them died during the course of the project.<sup>92</sup>

Lumos (2016) correctly noticed that such a quick change in the system brought some limitations. For example, the format of SGHs was not suitable. All the children living in this type of homes are in danger to experience replication of institutional culture. If we add to the format of these homes the problem with staff which is sometimes not trained to carry out the new type of care, this danger becomes materialized.

When it comes to the cost of alternative care, it was once more proved that institutional care is by far the most expensive. The costs of foster care per child per year was 1.907€ in 2014.

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<sup>92</sup>See Annex 4 for a full chart

According to data provided by the Bulgarian government costs of running of small group homes per child with disability per year was 4.627€, for a non-disabled child this amount is 4.414€ in 2014. In 2014 cost per child per year in institutional care was 7.449€ (Lumos 2015).

### **Participation of civil society**

Participation of the civil society organizations is a crucial asset of DI in Bulgaria. A broad range of interested organizations strengthened their position by creating a coalition named “Childhood 2025” which acts as a non-governmental counterpart to the big decision-making ministries (UNICEF 2014). This Coalition detected progress in the prevention of the children institutionalisation, as well as in the reintegration of the children by putting them in biological families or extended families. The coalition was engaged in developing of the new National Plan on DI for 2016-2020 (Lumos 2016).

The NGOs also commended the development of mechanism for managing and coordination of the process on the national level. However, more recent trends show tendency of exclusion of NGOs from discussions at governmental level (Council of Europe 2015). Another concern gives a fact that NGOs are excluded from applying for EU Structural Funds. Wasted Lives stated (2013) that from 107 million euros of EU funds not one euro was allocated to the NGOs (Council of Europe 2015).

### **Funding**

According to the National Strategy, funding is allocated from two EU operational programmes – Regional Development and Human Resources and Rural Development Programme, as well as from the national budget and donations.

Bulgaria is one of the countries that have to fulfill the *ex ante* conditionalities in order to be eligible for use of ESIFs.

ESF funds (OP HRD) were used for the support of the project “Childhood for all” which lasted from December 2011 to June 2014. There were two main components: “Provision of community-based social services” worth 16.5 million euros and “Planning of measures for Deinstitutionalisation” worth 2.5 million euros. In addition, ERDF allocated 54.5 million euros, while EARDF allocated 8.5 million euros for infrastructural projects (European Expert

Group 2015). Total worth of the EU funds allocated between 2011 and 2014 was 82 million euros.<sup>93</sup>

There are five main projects in the Action plan (2010-2020). Accumulative worth of these projects is 112.43 million euros (UNICEF 2014).

Another problem is that funds saved by shutting of the institutions were not used for improvement of financial sustainability of community-based service (ring-fencing in Moldova .e.g.)<sup>94</sup>, but went to the general state budget (Council of Europe 2015). Using these funds for the support of families and community-based services directly would facilitate the whole process and ease tracking of use of the funds.

Moreover, this model could have a positive impact on the awareness that community-based services are less expensive to run than the institutions. Lower costs of alternative care was proved to be true by the Bulgarian government which, according to Lumos, concluded that institutional care is by far the most expensive, while foster care is considerably cheaper and offers far better outcomes for children. Nonetheless, support for the families in community is by far the best for a child and the least expensive (Lumos 2015).

A study from 2014 showed that Bulgaria is saving 6.8 million € annually after the reforms. Ring-fencing would significantly facilitate further development of alternative care (Lumos 2015).

Lumos reported that in 2007 147.000 € from EU funds were used for renovation of institutions, even if they had been earmarked for DI (Parker & Cojocariu 2016).

A summary of the practices detected as positive or negative during DI process in Bulgaria is provided in the table 3.

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<sup>93</sup> Human Resources Operational Programme is funding so-called soft measures. Regional Development OP and Rural Development Programmes funds are allocated for the development of infrastructure.

<sup>94</sup> Ring-fencing is a way to protect the resources (financial, human and material) in institutions and transfer them to cover the costs of the community-based services that replace institutions. However, deinstitutionalisation should not be a cost-cutting exercise. It should involve the reinvestment of resources in services that result in better outcomes for children (Lumos 2015).

Table 1 Practices in Bulgaria with respect to DI process

Positive	Negative
<ul style="list-style-type: none"> <li>○ National Strategy followed by an Action Plan with an explicitly stated aim to shut all institutions for children by 2025</li> <li>○ Provision in the National Strategy that prohibits re-use of the institutional buildings for residential purposes</li> <li>○ The Action Plan contains a provision for equal development of community-based service throughout the country</li> <li>○ Inter-ministerial group formed for implementation of the Action plan</li> <li>○ For assessment of implementation of the Action Plan a Working Group consisted of deputy Ministers was established</li> <li>○ Creation of a coalition of the civil society organizations that advocate for the right of children to live in the community</li> </ul>	<ul style="list-style-type: none"> <li>○ Institutionalisation of children under 3 years of age is not banned (an aim was set in the National Strategy)</li> <li>○ Low salaries of the care-givers</li> <li>○ Staff not prepared to provide new forms of care</li> <li>○ Replication of the institutional services into community-based ones</li> <li>○ Phenomenon of trans/re-institutionalisation</li> <li>○ No ring-fencing</li> <li>○ NGOs excluded from applying for the Structural Funds</li> <li>○ 147.000 € invested in building, renovation and expansion of big institutions</li> <li>○ Structural Funds were used to provide employment for the family members of a disabled person</li> </ul>

## The European Union's infamous funding of segregation

Numerous reports from various civil society organizations, but also from Intergovernmental organizations stressed the problem of restoration and expansion of old and building of new institutions for persons with disabilities in the countries who committed themselves to deinstitutionalisation. However, at least for some time, the Europe was completely deaf for these alarms.

Mr. Nils Muižnieks, the Commissioner for Human Rights of the Council of Europe, in his speech in 2014 expressed deep concerns about the countries which were “shamefully refurbishing or building new institutions, sometimes with the EU structural funds” ( Nils Muižnieks 2014 in Parker & Cojocariu 2016).

Some studies<sup>95</sup> found that 150 million € of the EU funds were invested in segregation of persons with disabilities between 2007 and 2013, in only six countries among which is Bulgaria. This appalling practices should not be left without an adequate investigation and eventual reparations for the victims of institutionalisation in these countries.

MDAC reported that the European Commission was numerous times informed about the inadequate use of the funds, still they failed to react.<sup>96</sup> Therefore, this was a clear breaching of the international law, since the EU ratified the UN CRPD in 2010.

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<sup>95</sup> Such as: Parker, C & Bulic, I 2013, 'Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living', ENIL-ECCL, Budapest. p. 12

<sup>96</sup> For more on the MDAC initiative see: Mental Disability Advocacy Center 2011, European Commission Funding Disability Segregation and Abuse Breaches International Law, viewed 4 April 2017, <<http://www.mdac.info/en/content/european-commission-funding-disability-segregation-and-abuse-breaches-international-law>>.

## Serbia

It seems that with all socio-economic and political adversities experienced in the last three decades the rights of children with disabilities were not first on the agenda of any of the governments during this period.<sup>97</sup> If the persons with disabilities are the most ubiquitously disadvantaged group, than the children with disabilities is the most persistently disadvantaged sub-group in the world. Various factors are culpable for this situation, however being a child with a disability means to be discriminated for more than just on the basis of the impairment you have. This, so called intersectionality<sup>98</sup>, solidifies a problem of systemic violation of the rights of children with disabilities. Some disastrous practices have been identified in 21<sup>st</sup> century Serbia, especially in the treatment of children. Still, we will see that not everything is so dark in Serbia's protection of disabled children, especially when it comes to foster care which has a long tradition that was established mainly after the WWI and WWII.<sup>99</sup> Nonetheless, a long way of improvement of legislation, policies and rising of public awareness is ahead of Serbia and its citizens.

### Overview

To begin I will take the United Nations Committee on the Rights of Persons with Disabilities concluding observations as the single most credible report on the situation in Serbia to examine current progress in this field. Moreover, I will only select those points that are more directly connected to deinstitutionalisation, especially of children. The Committee adopted the Concluding observations on the initial report of Serbia in April 2016. This document welcomed what appears to be the Government's understanding of the importance to protect the rights of disabled persons (UN CRPD 2016 par.3). However, the Committee (par. 9) recognized a discrepancy between the existing laws and their application, which seems to be epidemical for both states in this case-study. Namely, many laws, particularly those adopted in the recent times, are in accordance with the international standards (especially the EU

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<sup>97</sup> The new Prime Minister of Serbia, Ana Brnabić, explicitly mentioned in her exposé the plan to introduce presently non-existent social support services, to transform social care institutions and develop community-based services that should prevent institutionalisation and enable reintegration in the community: Brnabić, A 2017, 'Program Vlade Republike Srbije kandidata za Predsednika Vlade Ane Brnabić', Narodna Skupština Republike Srbije. p. 61

<sup>98</sup> This term was coined in 1980s by a legal scholar Kimberle Crenshaw and it was related to the multi-layered discrimination that black women face in the society. Nowadays, this term is used to any group in the society that faces more forms of discrimination that overlap, combine and intersect: viewed on 27 June 2017 <https://www.merriam-webster.com/words-at-play/intersectionality-meaning>

<sup>99</sup> However, the foster care is usually "reserved" for children without disabilities.

ones<sup>100</sup>); still the State failed to enforce them, or enforces them partially and not systematically. The Committee stressed this problem with regards to the anti-discrimination legislation. Apart from the inability of the state to systematically apply this legislation, the law itself is not compliant with the UN CRPD. The concept of ‘reasonable accommodation’ is not explicitly included in the national legislature, neither the laws recognize discrimination on the basis of denial of such accommodation (UN CRPD 2016 par.9). This, probably intentional omission of the lawgivers, almost neutralizes possibilities of the persons with disabilities to live, educate and work in the environment that fits their needs, or in other words - to be included in the community.

A public awareness on the rights of persons with disabilities, and the general perception are on a disturbing level. Disabled persons are to a high degree stigmatized, especially those with mental disabilities. Ignorance about disability is a plague of the modern Serbian society. Mental health issues are taboo, thus people fail to subject themselves to the treatments in the early stages of disorder development. While some don’t do this because they are not aware of the problems they have (lack of knowledge), the others are afraid of stigmatization by the society, and even by possible incarceration to an institution<sup>101</sup>. Moreover, prevention of mental illness is not mainstreamed in Serbia, and mental health is not to be found in the curricula during primary and secondary schooling. Socio-economic insecurity is putting a lot of pressure on everyone, especially the youth who are financially the most disadvantaged age group in Serbia.<sup>102</sup> When other factors are added, such as voluminous consumption of alcohol and illicit psychotropic substances<sup>103</sup>, the result is epidemic of mental illness among youth. Without basic knowledge of mental health and with the entire stigma that surrounds it, the youth is usually not able to properly cope with or to prevent these problems. Therefore awareness rising, especially through the mainstream schooling but also with public campaigns is essential (UN CRPD 2016 par. 16).

Equal recognition before the law is another problem, because persons with mental disabilities who are deprived of their legal capacity are not able to marry and vote, and the safeguarding system is seriously malfunctioned. In the previous chapter, I emphasized the importance of

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<sup>100</sup> Serbia is in the process of accession to the EU. One of the crucial chapters in the EU Acquis is 24 which considers also treatment of persons with disabilities.

<sup>101</sup> This is not unusual if we take into consideration how these institutions are perceived in the society.

<sup>102</sup> The Director of the National Office for Employment stated that 31.2% young people are unemployed (Radio Televizija Srbije 2017).

<sup>103</sup> UN Committee on the Rights of Child expressed its concern on this issue in par. 39 of the concluding observations from 2017.



supported decision-making and its advantages over substitute decision-making<sup>104</sup> regime which is still the only one existent in the Serbia's legislation. Until supported decision-making regime is implemented in the national legislative and actually applied, the persons with disabilities will not get their lives back and they will live under control of guardians who are often not interested to consider all their needs (apart from the substitute decision-making regime being inherently problematic since it totally deprives a person from their autonomy and dignity).

### **System of residential care for children with disabilities**

The UN CRPD Committee (par. 37) expressed the highest concerns with regards to deinstitutionalisation of adults and children with disabilities. Serbia's community-based services are basically non-existent (HRW 2016). Numbers of institutionalised persons are high. The resources are still invested in renovation, expansion and building of new large institutions across Serbia.<sup>105</sup> Apart from building one brand new institution and expansion of two old, also three out of five existing large institutions for children and adults with disabilities were refurbished in the last few years. All this happened in spite of the Government's explicit commitment to community-based living expressed in the Plan on Transformation of Residential Social Protection Institutions for Children (Ministarstvo za rad i socijalnu politiku 2011).

The UN Committee on the Rights of Child adopted the concluding observations on Serbia's first and second combined initial reports in February 2017. This Committee recognized extreme vulnerability and inhuman or degrading treatment of children with disabilities, especially those living in institutions, which I will present in the following paragraphs (par. 32). Another issue stressed is institutionalisation of children below the age of 3. Even the national law prohibits this practice<sup>106</sup> the state fails to apply its own laws, which is even more

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<sup>104</sup> *Paragraph a - Choice*

<sup>105</sup> Institution for children and youth "Šabac" – construction finished on 2013; area 2.000 square meters; capacity is 40 users; taken from: <http://csrsabac.org.rs/sr/o-nama-cir/organizaciona-struktura/ustanova-za-decu-i-mlade-sabac-cir>; Institution for children and adults with intellectual disabilities "Stamnica" – construction of additional "home" finished and the building was opened by the Minister for social affairs A. Vulin; cost 66 million RSD (around 550.000 €); capacity 112 users; taken from: <http://stamnicazavod.org.rs/index.php/sr-yu/>; Institution Kulina – construction of a new pavilion; finished in 2014 and opened by the Minister for social affairs A. Vulin; capacity 40 users; cost 39.8 million RSD (around 332.000€); taken from: <http://www.kulina.org.rs/otvoren-paviljon-pink/>

<sup>106</sup> Law on the social protection article 52 par. 2: An institutional accommodation for a child below 3 years of age is not to be provided. Exceptionally, accommodation for the children under the age of 3 can be provided but not longer than 2 months and only in the case when this is especially justified after the Minister for Social Affairs agrees. (personal translation)

asinine than the failure to comply its practices with the Convention it was ratified 16 years ago.<sup>107</sup> Number of children in institutions is still high, while the prevalence of children with disabilities is 80% (UN CRPD 2016). This statistical data clearly shows indifference of the state towards deinstitutionalisation of disabled children. Another issue is that there are five large institutions where children are accommodated and many smaller ones, whose information about capacity is possibly counterfeited (they are likely accommodate more children than it is stated; I will provide arguments for this in the following paragraphs). Living conditions in these institutions are inadequate while segregation, neglect, exclusion from education and play is common; children are subjected to potentially inappropriate medical treatments without consent (UN CRC 2017 par. 39). Support for families in order to prevent institutionalisation, and support to reintegrate in the society for the youth and children who are leaving the institutions are virtually non-existent.

## **Institutions**

There are five large institutions where children with disabilities are in long-term care. In these institutions as of 2013 there were 1.529 users, of which 896 male and 633 female (Republic Statistical Office 2014). In order to get the most recent data I sent requests for access to information of public importance to all the aforementioned institutions and the Ministry for social affairs, asking for numbers of children in the institutions disaggregated according to the age groups, type of disability, sex and ethnic background. Reluctance of Serbia's authorities to give information on their work is widespread. However, in this case would be logic to assume that these institutions were reluctant to respond because this information would not be representative. Still, when it seemed that no-one will fulfill their legal duty, the Department for Social Protection of the Republic of Serbia answered with the following data:<sup>108</sup>

- 1) total number of children with developmental disabilities (below 18) in institutions in Serbia is 564, of which:
  - a) 22 infants (0-2)
  - b) 241 children with multiple disabilities

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<sup>107</sup> Serbia ratified the UN CRC on 12<sup>th</sup> March 2001

<sup>108</sup> See Annex 4 for a whole chart

The biggest institutions in Serbia are:<sup>109</sup>

- Zvecanska - Center for Protection of Infants, Children and Youth: capacity 150
- Sremčica - Institution for Adults and Children with Disabilities: capacity 100<sup>110</sup>
- Stannica - Institution for Children with Disabilities: capacity 250<sup>111</sup>
- Veternik - Institution for Children and Adults with Disabilities: capacity 100<sup>112</sup>
- Subotica - Kolevka Institution for Children with Disabilities: capacity 180

Beside these large institutions there are at least 2 dozens of institutions for “children without parental care and children with disabilities” which individual capacity is below 50 (Vlada Republike Srbije 2012). In the Decree on the Network of Social Care Institutions (2012) we can notice a rather unusual distribution of ‘residential capacity’ and ‘capacity for additional services’. Namely, in the Institution for Children and Youth Bela Crkva, there are 48 places of ‘residential capacity’ and 78 in the ‘capacity for additional services’; the same numbers appear in the Working Unit Voždovac which is under administration of the Institution for Children and Youth, Savski Venac, Beograd. After carefully observing these numbers, and considering that a capacity limit over which an institution is considered to be large is 50, it would be logical to suspect that manipulation with capacities occurred.

All the aforementioned institutions are perfect representatives of the so-called ‘total institutions’. They are administratively centralized; number of staff is very limited, which inevitably leads to deprivation of personal contact; they are almost always located far from the communities<sup>113</sup> and overcrowded, therefore isolation both from the society and families is common (HRW 2016). In three of five mentioned institutions children and adults are in the same wards which is not according to standards and opens possibilities for violence and abuse of the children (HRW 2016).

### **Small group homes**

The ‘small group residences’ (widely used term is ‘small group homes’)<sup>114</sup> were built according to the plan of the Ministry for social affairs developed in cooperation with Unicef

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<sup>109</sup> Vlada Republike Srbije 2012

<sup>110</sup> And 200 adults

<sup>111</sup> And 200 adults

<sup>112</sup> And 400 adults

<sup>113</sup> Except from the Sremčica Institution which is on the outskirts of Belgrade

<sup>114</sup> ‘Small group homes’ is an established name for these institutions in the practice. However, more correct translation for Serbian ‘male domske zajednice’ is ‘small group residences’ or ‘small residential communities’ or even ‘small institutional communities’. This because in Serbian language the word ‘dom’ is usually used to

in 2008. As it usually happens (we will see a similar practice in the following chapter) the children with disabilities were not a group in focus, but rather children without parental care. Only 60 children with disabilities from the Kulina Institution<sup>115</sup> were moved to five SGHs. The main purpose of small group homes is to provide a family-like atmosphere where children should have more freedom and possibility to be included in community. Also, these homes should only provide accommodation temporarily until more appropriate alternatives are found for its residents (biological or foster families). However, children put in these small institutions in Serbia usually remain there permanently or until they reach adulthood (HRW 2016). Thus, we may conclude that these residences replicate institutional culture.

As we already saw, the same happened with the small group homes in Bulgaria. They were intended for a permanent accommodation during transition from institutional to family-like care, but the children would stay there until their adulthood.<sup>116</sup>

Serbia's legal system does not give a definition of an 'institution' for care of children. However, it implies that 'institution' means large residential facility. We already know that this approach is wrong and that an institution can be any facility, independently from the number of its users. In the case of children protection, any type of residential accommodation that fails to closely replicate family-like atmosphere is not in the best interest of the child and therefore is inappropriate.

### III-treatment in the Institutions

Reports of torture, inhuman or degrading treatment and other forms of ill-treatment in Serbia's institutions for children were somewhat common in 21st century. However, this doesn't mean that the situation worsened with the turn of the century, but rather the institutions got under some, but still scarce, scrutiny of professional and attentive public.<sup>117</sup> These reports need to find their path to the general public. We saw how the BBC's documentary "Bulgaria's Abandoned Children" sparked interest in the subject, and resulted with political pressure on the Bulgaria's government to find a way and solve the problem of

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describe some type of residential institution such as: *studenstski dom* (student residence), *popravni dom* (correctional facility/institution) *dom za decu bez roditeljskog staranja* (institution for children without parental care) *etc.* Therefore, this term in Serbian language has a strong connotation of institution, facility or residence; even though when literally translated and when taken out of the given context the meaning is 'home'. I already argued how important it is to understand why certain terms are used to describe institutions for persons with disabilities. Hence, I may say that the term '*male domske zajednice*' (small group residences) actually depicts the situation very well, since it doesn't break-up with terms used for large institutions totally.

<sup>115</sup> See Annex 3 for images of Kulina institution

<sup>116</sup> on page 48

<sup>117</sup> After sending more than a dozen requests for a study visit to these institutions I was left without a single answer from the authorities.

children institutionalisation.<sup>118</sup> Hence, all the reports from Serbia in the future need to be made not for professionals but much more importantly for the general public, ordinary people that often do not even know that these institutions exist. This would be a part of ‘awareness rising’ agenda with an emphasis on urgent action in order to stop all harmful practices.

In 2007 Mental Disability Rights Initiative (MDRI) published a report named “Torment not Treatment”<sup>119</sup>. This report contained some of the most disturbing stories and images from the Serbia’s institutions. The investigators found children in Subotica whose legs were restrained to their beds, and arms wrapped in improvised straightjackets<sup>120</sup>; in Stannica they saw children who were considered immobile and spent years lying in the metal cribs (sorted in rows in order to use the space in the most rational way<sup>121</sup>) never getting out of them, they ate and defecated there; some children were deprived of medical care because their prognosis of life expectancy was not good. These examples, taken out from a pool of others were a clear proof of ill-treatment and possibly torture that was on-going in these institutions.<sup>122</sup> MDRI reported horrible material conditions, filthy rooms and toilets, deprivation of privacy, presence of contagious diseases, lack of medical care and neglect in general.<sup>123</sup> Therefore, we may conclude that Serbia didn’t make almost any progress when compared to the 17<sup>th</sup> century hospitals in Western Europe. I wrote that previously, and I will write again: confinement of ill children, without medical care is exclusively a punitive practice. Hence, Serbia was punishing these children because of their illness or impairment.

In the second report<sup>124</sup>, of what appears to be a beginning of a series of MDRI’s reporting from Serbia’s institutions, we find that material conditions in these facilities slightly improved. Supposedly, interiors were refurbished and decorative details added and repairing

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<sup>118</sup> In my interview with a high-ranked official for protection of human rights in Serbia I got informed how data about the bad situation in institutions for children, “could be misused for political purposes by foreign agencies or from another subjects, in this peculiar moment for Serbia during negotiations with Kosovo”, and that with a clear implication from the source that some information shouldn’t be disclosed. This statement is shocking in many ways, however it perfectly depicts (lack of) importance of the position of Serbian children to the bodies that should protect their fundamental rights (and not to mention to the Government).

<sup>119</sup> Mental Disability Rights Initiative 2007, ‘Torment not Treatment: Serbia’s Segregation and Abuse of Children and Adults with Disabilities’, Washington.

<sup>120</sup> These improvised straightjackets are usually made out of cotton diapers or a piece of clothing.

<sup>121</sup> See Annex 3 for images

<sup>122</sup> European Convention of Human Rights, which is legally binding document for Serbia, in the article 3 prohibits torture, inhumane and degrading treatment.

<sup>123</sup> A careful reader will not resist comparing the described conditions with those from La Salpetriere and Bicetre presented in the First part of this work.

<sup>124</sup> Mental Disability Rights Initiative - Serbia 2013, ‘The Hidden and Forgotten: Segregation and Neglect of Children and Adults with Disabilities in Serbia’, Belgrade.

of some buildings undertaken. There are more than a few problems surrounding these “improvements”:

- Firstly, they were done in spite of commitment of the Government to develop other types of care; therefore the money was invested in segregation instead for the inclusion through development of community-based services.
- Secondly, ratification of the UN CRPD, which strictly prohibits activities like these, was taken in 2009.
- Thirdly and most importantly, what the difference decoration will make for the children who spend years of their lives without medical care and restrained without ever leaving their cribs? Absolutely none.

A special concern was expressed for the children with multiple and profound disabilities, because they got even more discriminated by directing means for material improvements to the wards and institutions where children with milder disabilities were accommodated. Veternik, Kulina and Stamnica were described as institutions with conditions “unworthy of human beings” (Mental Disability Rights Initiative - Serbia 2013, p. 16). Several rooms with bars and padlocks and nothing but urine soaked mattresses on the ground were found. Abuse of medication is ubiquitous and antipsychotics were often given to the children (p. 28). Insufficient number of staff led to abuse of the heavy psychotropic drugs in order to keep the children easy to handle (at the time only one institution had a full time psychiatrist). This practice is called chemical restraintment.

*In Kolevka, a boy with HIV was found in permanent isolation, without adequate stimulation ...this isolation has already taken its toll on his development. What is particularly worrying is that these consequences affecting his development are not perceived as consequences of isolation, but as inherent characteristics of his condition.* (Mental Disability Rights Initiative - Serbia 2013, p. 32)

Immobility and heavy medication have terribly hard impact on the body and psyche of a child (and any other person). Treatments like these will cause disability or lead to death sooner or later.

### **Lack of education in the Institutions**

The third MDRI's report from 2016<sup>125</sup> focused on the education of children with disabilities who are residents of the institutions. Appalling findings of MDRI showed that 56% of the children were "out of the schooling system" while the rest had some kind of education on-going; in one of the institutions observed only 18% of the children were included in the education system (p. 23). In five 'small group homes' (10-13 children) the situation was better, since the education was mandatory. Preparation of children with disabilities through trainings and various workshops is essential when they are moving from institutions to families or other types of community-based living and when they are supposed to start their schooling. Without schooling, inclusion of previously institutionalised children would be impossible; however, segregated schooling (special schools) will not help much in the process of inclusion.

In my interview with a teacher in one of the so-called special schools I got a precious insight in the fraudulent system of Serbian education. Namely, some mainstream schools would take children with disabilities in order to get additional funding from the state and other agencies. These funds are usually used to improve physical conditions in these schools, such as purchasing of furniture or refurbishing. When the financial means are spent children with disabilities gradually become a burden that the school should get rid off. In order to do this, the school's authorities would label the child as incapable for mainstream schooling and put him/her back to the special school.

### **An example of a positive community-based service – 'Family Associate'**

Scarce as Platinum and at least as much worthy are community-based services for families with children with mental disabilities in Serbia. One of this kind was the 'Family Associate' – a programme of professional support for 208 families with multiple issues (parent's health issues, financial hardship, heavy developmental disabilities of the children, one-parent families, inadequate housing *etc*). Developed according to the 'Intensive Family Preservation Services'<sup>126</sup>, this service took a holistic approach to the support; it provided services such as: psychosocial consultancy, legal aid, making appointments and taking care of medical protection, even funding of the living space refurbishment and renovation and many other services according to the specific needs of the families. Education and consultancy, practical

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<sup>125</sup> Mental Disability Rights Initiative - Serbia 2016, 'Exclusion and Segregation of Children with Disabilities in Residential Institutions in the Education System', Belgrade.

<sup>126</sup> National Family Preservation Network 2009, 'IFPS Toolkit. A comprehensive guide for establishing and strengthening Intensive Family Preservation Services'.

support and representation and mediation in the community were under the scope of the FA's responsibilities (Republički zavod za socijalnu zaštitu 2017). The main goals of a family associate was to prevent neglect and violence, to develop parent's capacities for parenthood, to prevent having a child removed from the family, to support child's reintegration in the family after his or her stay in institution. Its intensiveness reflects in frequent visits to the family and development of close ties with the family. Unfortunately, there were many limitations, because the entire programme lasted only two years (2015-2017). After the cessation of the project the families are not able to get this kind of support anymore. Moreover, only the families from four big centers<sup>127</sup> in Serbia had access to the service.

This is a good example of an adequate community-based support programme which is necessary for Serbia's children and their parents. Still, without mainstreaming this programme, making it permanent and equally distributed throughout the territory of Serbia not many will benefit from it, and consequences from the lack of community-based services will continue.

## Summary

Bulgaria's fast progress in children deinstitutionalisation started after a public outcry over the documentary filmed and published by BBC in 2007. "Bulgaria's abandoned children"<sup>128</sup> was a *sui generis* call for help. After gaining a lot of negative publicity, the Bulgaria's government's approach to the problem started to change, and the children came into focus. It seems that political will is terribly hard to get sparked, however international pressure, and pressure from the citizens can give some results. When the voting body becomes interested in a topic, that topic starts to get attention from the officials and the political opposition. Therefore, in order to speed up process of DI the general public needs to be informed and educated about the issue, thus putting closer to the political focus. With a lot of international help, mainly through foreign expertise and funding some impressive results were achieved, especially in the infrastructural improvement. However, the infrastructural improvements are only a prerequisite for a successful DI. A problem with replication of institutional culture to the SGHs is a strong signal that highly trained social and medical personnel that can deliver high quality care is an essence of SGHs. Otherwise, trans-institutionalisation will become reality and all the previous efforts will appear futile. The DI process would not be even this much successful if the CSOs were not that active and included in the process by the

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<sup>127</sup> Belgrade, Novi Sad, Niš and Kragujevac.

<sup>128</sup> Accessible at: <https://www.youtube.com/watch?v=UQZ-ERQczj8>



Government. Still, there is a lot more space for participation of NGOs, from which everyone will profit eventually.

Serbia's DI seems unorganized, and when one step forward is taken, two steps back follow. However, the number of institutionalized children with disabilities is not huge. This can only be a motivation to solve the problem of institutions in the time shorter than it is needed for countries with more concerning numbers of children in institutions. Similarly to Bulgaria, DI of children with disabilities is slower than non-disabled. This practice is alarming and discriminatory. Therefore Serbia needs to put DI of children with disabilities in focus and immediately stop with the discriminatory approach.

In the following chapter I will provide a list of recommendations addressed to the authorities and CSOs based on the experience of Bulgaria and other countries that I didn't present in this paper.

### **Recommendations to the Serbian Government and the organizations of civil society**

It is hard to say how much time Serbia will need to fulfil its core obligations under the UN CRPD and the UN CRC. We saw that a lot depends on political will, which seems to be non-existent, or at least not used in the correct way. Still in the rest of this chapter I will provide some general recommendations that are mandatory in order to establish functional system that could conduct deinstitutionalisation in a reasonable time frame.

*All policies and programmes should be set on the basis of the best interests of the child<sup>129</sup> and it should be duly taken into account in every service provided for the children with disabilities and any other action affecting them.* (United Nations 2006 par. 29)

Before any other action a thorough assessment of the current situation is necessary. Presently the data are scarce, decentralized, not disaggregated and not enough precise to develop an efficient strategy and action plan for DI.

The following recommendations are:

- 1) Adoption of a national strategy for deinstitutionalisation of children with disabilities<sup>130</sup>:

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<sup>129</sup> Article 3 UN CRC

<sup>130</sup> Or a separate project focused only on the DI of the children with disabilities under an umbrella of the National Strategy for DI of all children.

- a) The strategy should cover a time span of at least 10 years, with explicitly stated intention to shut all institutions for children by the end of this period, and prohibition of re-use of those institutions for institutional care.<sup>131</sup>
- b) This should be done by a Working Group which needs to be consisted, among others, of the representatives of civil society organizations (CSO).
- c) Creation of an interdepartmental Coordination working group for implementation of the DI. Representatives of the CSOs should be included in this body.
- d) Creation of Technical units for project management on the national level for every of the main activities in the National Strategy.<sup>132</sup> Representatives of the CSOs should be included in these units.
- e) Local project management teams plan services and lead implementation of projects on the local level.<sup>133</sup> Representatives of the CSOs should be included in these teams.
- f) The strategy should introduce the ‘ring-fencing’ of funds.<sup>134</sup> All funds saved by shutting the institutions should be directly used to develop community-based services and support systems.
- g) Awareness rising through the mainstream education by introducing classes that should inform pupils and students on the nature of disability and challenges of persons with disabilities. This should also be done through campaigns, and especially via mainstream and electronic media, so it is available to general public.

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<sup>131</sup> This solution is introduced in the Bulgaria’s National Strategy. It is seen as a good practice to prevent possible re-use of the institutions in cases of lack of sustainability of community-based services and support systems.

<sup>132</sup> Such as in Bulgaria.

<sup>133</sup> The local project management teams, technical units and the coordination body were all developed for the DI process in Bulgaria.

<sup>134</sup> Showed to be of a great importance for the DI process in Moldova (Lumos 2014).

- 2) By investing in the large institutions it is clear that these will be used for many years to come; hence, funding of renovation, expansion and creation of new institutions must be ceased immediately. All the funds for these purposes need to be redirected to development of community-based care and services (ring-fenced funds). This includes:
- a) Infrastructural investments (in small group homes that should not have more than 6 residents, and day-care centers); duration of stays in the SGHs needs to be strictly limited.
  - b) Investments in development of professional staff that will be able to provide care which will not replicate care and living regime present in the institutions;<sup>135</sup>
  - c) Development of community-based day-care centers and ‘mother and baby units’ for parents and children with disabilities. These centers must be allocated equally throughout the country (like in Bulgaria, for every 20.000 residents)<sup>136</sup>. The municipalities that are not able to fund creation and functioning of these centers need to receive funds from the budget of the Republic or from another municipality, private donors or any other source. The National Strategy should contain a provision to set-up at least one day-care center in every administrative unit by the end of the period covered by the strategy.
  - d) Other services and support such as: psychosocial support, health care (which should be integral with the mainstream healthcare system), adequate and sustainable financial support for biological and foster care families (one of the main reasons for putting child in an institution is poverty) and other forms of support.
- 3) Participation of civil society organizations needs to be ensured and supported by the Government. CSOs need to be included in development and planning in all stages of deinstitutionalisation:

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<sup>135</sup> Especially paying attention to avoid overmedication of children with tranquilizers, which was already seen in Bulgaria’s SGHs. Instead, put an emphasis on preparation for transition and psychological support before coming to SGH and during stay.

<sup>136</sup> on page 48

- a) CSOs should participate in all the bodies I mentioned previously, thus creating counterbalance to the political bodies. Through these bodies CSOs should be able to monitor: use of funds, quality of community-based services, monitoring of payments of social benefits *etc.*
- b) CSOs should be allowed to monitor all institutions that accommodate children with disabilities. This authorization should be as broad as possible and unconditional.<sup>137</sup>
- c) CSOs need to create a coalition which will be able to counteract possible negative political decisions and act prior to adoption of such decision.<sup>138</sup>
- d) Work on the awareness rising of general public through the mainstream and electronic media should be one of the priorities.

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<sup>137</sup> Transparency in institutional care and process of DI must be a priority. Institutions and other forms of care must be under constant public scrutiny.

<sup>138</sup> The 'Coalition 2025' is Bulgaria's network of CSOs whose acting was seen as immensely important in DI process. A group of leading Belgium NGOs agreed on creation of a similar coalition at a conference to which I take participation as an independent researcher, held on 23<sup>rd</sup> of July.

## Conclusion

Institutionalisation of persons with disabilities appeared as a consequence of various systemic political and economic malfunctions, as well as changes in societal perception of public moral standards. However, those times have passed and the institutions have not only been preserved but their position strengthened in the countries throughout the Europe in the following centuries. Changes in the form and purpose were noticeable; still these institutions were always used to establish control over persons with disabilities and especially those with mental issues. This control sustained until present time and exists in every place where the care for persons with disabilities is carried-out in the settings which function under the principles of institutional culture.

The continuous societal progress and development in legal theory, but even more importantly profound adversities gave a quintessential legal concept that can change the way we see ourselves and others. Despite inherence being the main characteristic of dignity, it is still a socially constructed concept that entered the legal systems with the first international human rights instruments. Without presumed inherence the concept of dignity would not have the significance in the sense we recognize today. By gaining an operational value through the instruments such as UN CRPD and UN CRC the concept of dignity became usable despite its vagueness. Thus, the concept of dignity allows us to analyse the social phenomena in the history with the perspective that was not known before. Today, we are in the position to say that deprivation from individual autonomy of persons with disabilities in the sense of denial of possibility to choose a place to live, surrounding and lifestyle is a repugnant exhibition of social control delivered by the authorities. Therefore, deinstitutionalisation is ultimately a process of loosening control towards those who are perceived not to have capacity to enjoy their autonomy. However, in the core of societal omission to understand the proportions of injustice that is continuously being committed lies the existent perception about incapacity of persons with disabilities (especially mental) to live independently. Hence, the control exercised on the institutionalised persons is control imposed by us, the general public, through the bureaucratic systems.

We were able to observe this through the examples of two countries studied in this thesis. These states have many cultural, economic and political similarities. Still, they have different

approaches to deinstitutionalisation, mainly as a consequence of financial resources that come from the international subjects. We have seen that it is fairly easy to fall into a trap of trans-institutionalisation in the case of Bulgaria's system when other services are not developed enough, in spite of the impressive infrastructural improvements. Serbia's current system of social care is rather detrimental; still, its impressive professional resources and the vibrant civil society will be able to make a difference if they are given enough political space to do so.

The answer to the main question of this thesis is undoubtedly – yes, the time of segregation and exercise of tight control on the persons with disabilities is over; still it is not coming to all parts of the world at the same time for various reasons. Therefore, the future researches should be carried-out with an aim to discover efficient models for DI processes in different cultural, economic and political environments. Deinstitutionalisation is a lot more than an administrative process, it is a movement that gained a lot of support through decades and continues to attract attention of professionals, academics and governments. However, as any other struggle to reclaim fundamental rights, it is going to be a permanent endeavour in which all of us have a duty to participate; as Desmond Tutu, a well-known apartheid opponent, said:

*If you are neutral in situations of injustice, you have chosen the side of the oppressor.*

Except that in the case of rejection, segregation and failure to recognize the potentials of the persons with disabilities we, the majority, are those oppressors.

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## Annex 1

### Definitions

- Persons with disabilities:

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.<sup>1</sup>

- Mental disorders:

Generally characterized by a combination of abnormal thoughts, perceptions, emotions, behaviour and relationships with others. Mental disorders include: depression, bipolar affective disorder, schizophrenia and other psychoses, dementia, intellectual disabilities and developmental disorders including autism.<sup>23</sup>

- An Institution:

Any residential care where (the size is not relevant):

- residents are isolated from the broader community and/or compelled to live together;
- residents do not have sufficient control over their lives and over decisions which affect them;
- the requirements of the organisation itself tend to take precedence over the residents individual needs.<sup>4</sup>

- Deinstitutionalisation:

The full process of planning transformation, downsizing and/or closure of residential institutions, while establishing a diversity of other community-based services regulated by rights-based and outcomes-oriented standards.<sup>5</sup>

- Community-based care/services:

The spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure,

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<sup>1</sup> United Nations 2006, 'Convention on the Rights of Persons with Disabilities'. art. 1 (2)

<sup>2</sup> World Health Organization 2017, Mental Disorders, viewed 8 July 2017, <<http://www.who.int/mediacentre/factsheets/fs396/en/>>.

<sup>3</sup> Therefore 'mental disability' is an umbrella term for all long-term intellectual and psychosocial impairments which in interaction with various barriers may hinder person's full and effective participation in society on an equal basis with others

<sup>4</sup> 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. p. 25

<sup>5</sup> Unicef 2010, At Home or in a Home? Formal Care and Adoption of in Eastern Europe and Central Asia. p. 52

which should be accessible to everyone regardless of the nature of their impairment or the required level of support.<sup>6</sup>

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<sup>6</sup> Ibid. p. 27



## **Annex 2**

### **Note on terminology**

Even though the word ‘madness’ was once used by physicians<sup>1</sup> today this is not a medical term. However, the ‘madness’ is a “common sense category” and is widely used nowadays as much as in the past (Scull 2011, p.2). In this thesis a few politically incorrect and offensive words for describing mentally ill persons will be used. The purpose of their use is to evoke the perception of mental illness in the period concerned. Therefore, I used these terms as they were used in their historical context. When progressing chronologically through this thesis, the use of the aforementioned words will be less frequent and eventually ceased.

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<sup>1</sup> We could even say that the ‘madness’ wasn’t a medical term even before the 19<sup>th</sup> century and the rise of psychiatry. The term came into use from the ‘everyday’ language and stayed in the use by the physicians until psychiatry gained ground and established its terminology, when the first terms that describe mental disorders actually became ‘medical’.

### Annex 3

Image 1 "Panopticon", Source: N/A

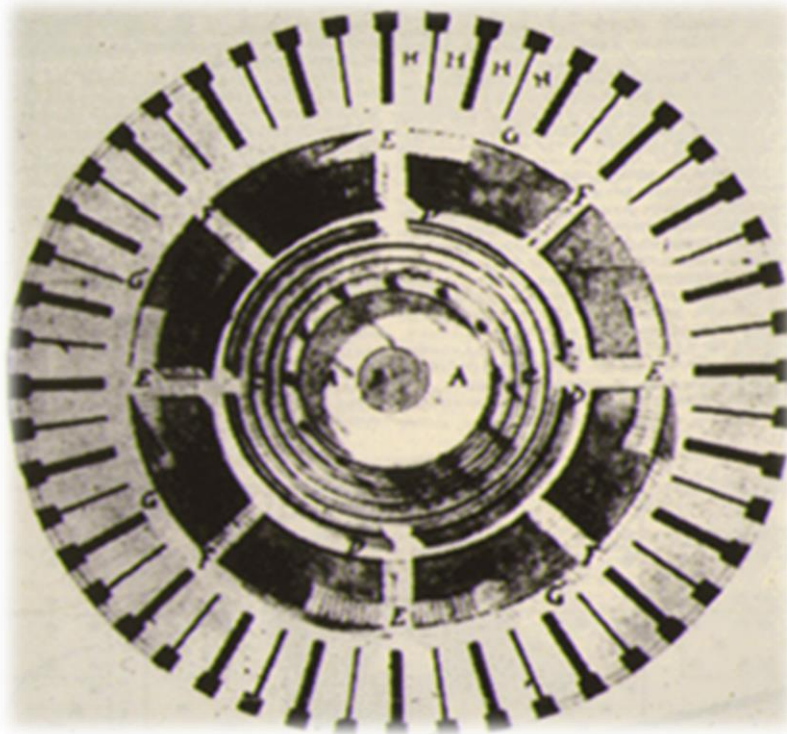


Image 2 "Panopticon", Source N/A

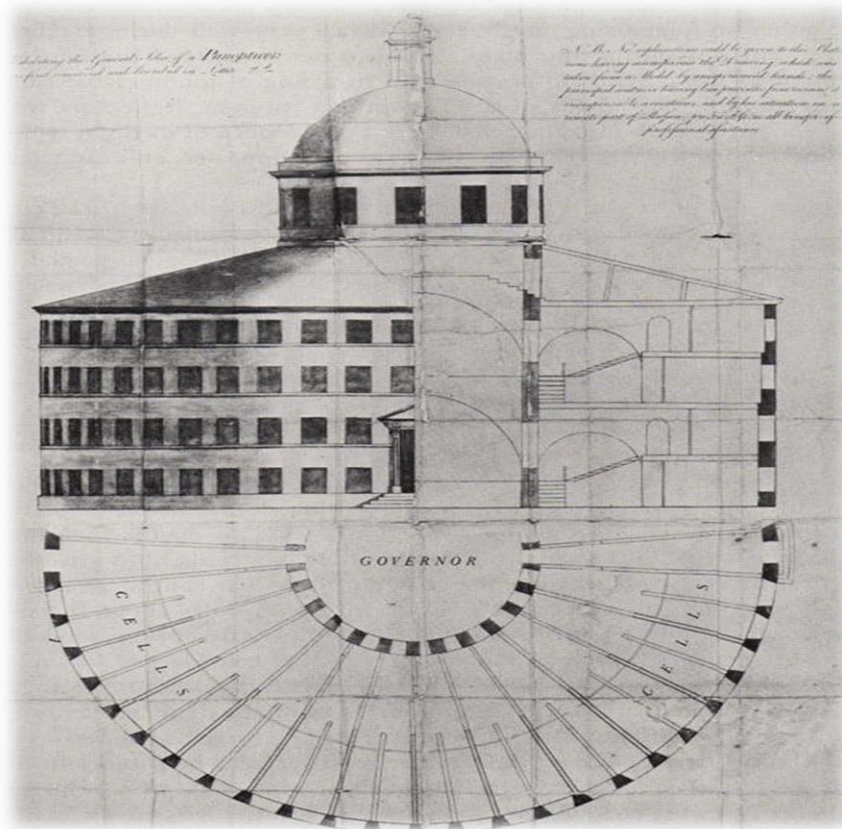


Image 3 "Panopticon" inmate's view from a cell, Source N/A

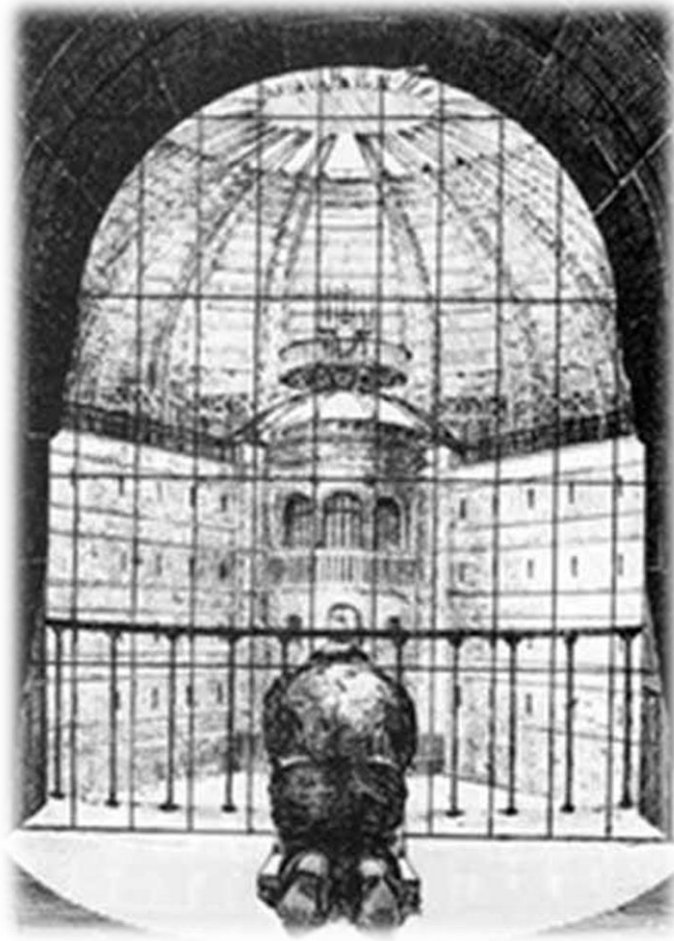


Image 4 "Narrenturm" /Fool's Tower Vienna, Source N/A



Image 5 "Narrenturm" corridor, Source N/A





Image 6 "Narrenturm" model, Source N/A

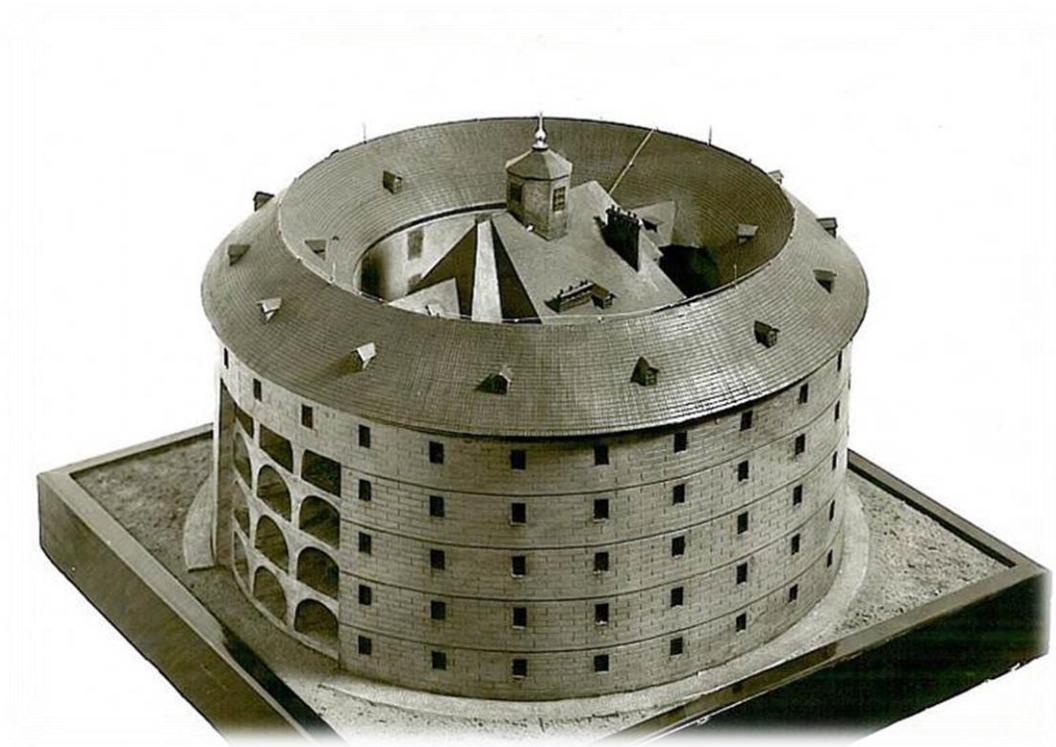


Image 7 The York Retreat, Source N/A

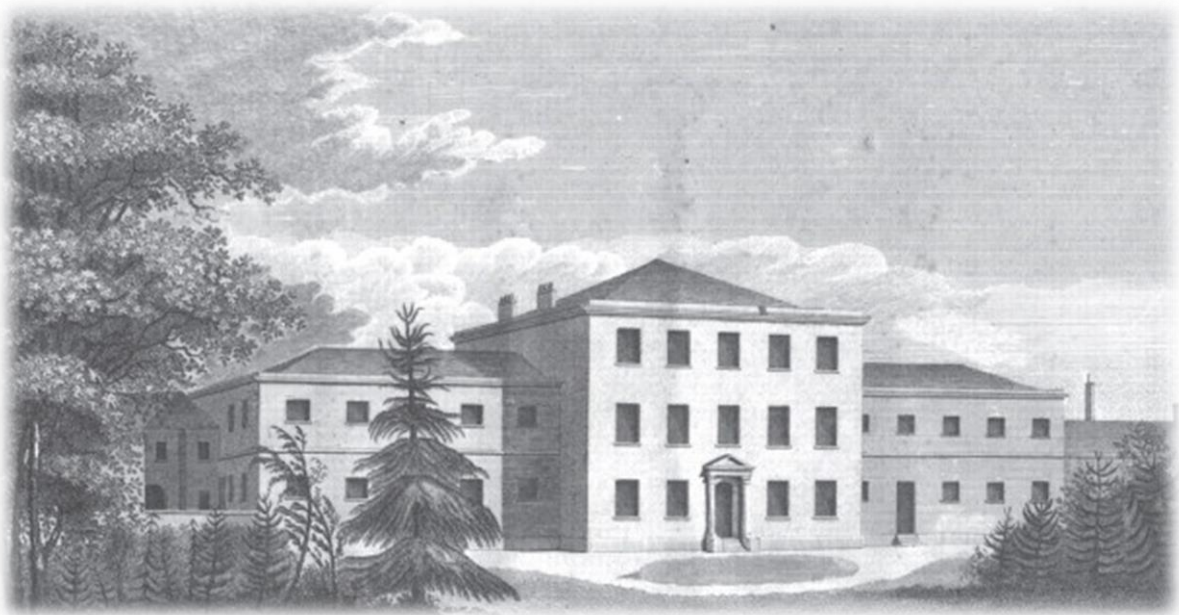


Image 8 Island of San Clemente and a luxurious hotel, Source N/A



Image 9 Satellite view of Kulina Institution's location, Source "Google maps"





Image 10 Adult dormitory in Kulina institution, Source MDRI-S 2013



Image 11 Isolation room in Veternik institution, Source MDRI-S 2013





Image 12 Restraining equipment in Veternik, Source MDRI-S 2013



Image 13 Bathroom in Stamnica institution for children and adults with disabilities, Source MDRI-S 2013

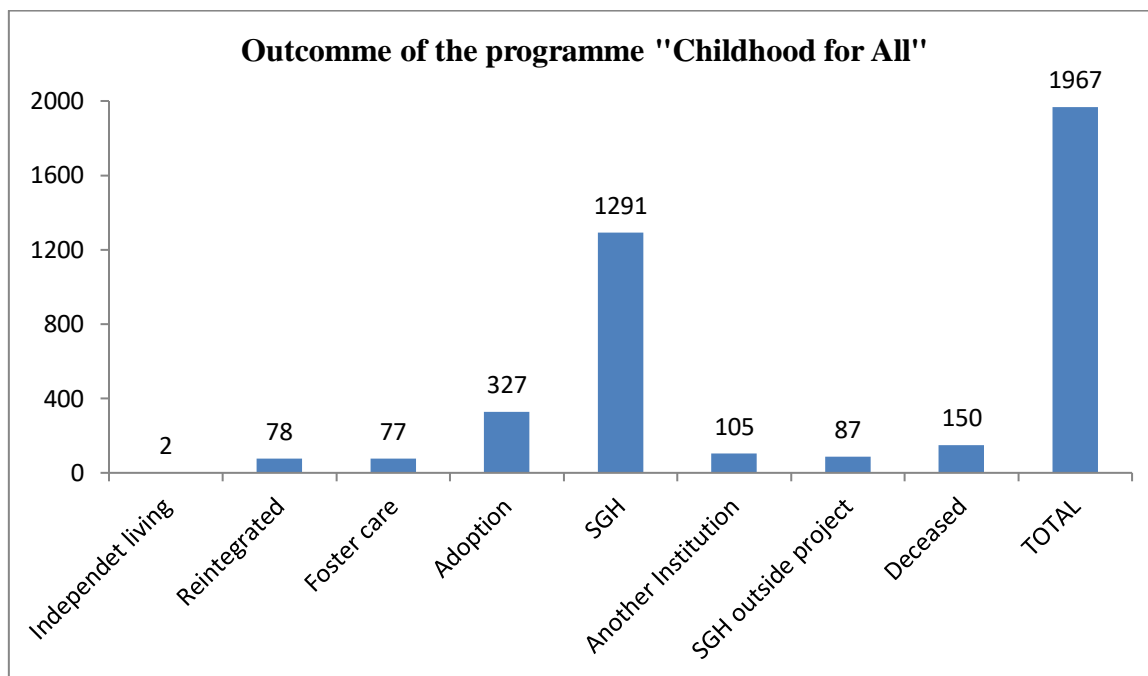


Image 14 Children dormitory in Kolevka institution, Source MDRI-S 2013



## Annex 4

Outcome of the programme "Childhood for All", Bulgaria Source: Lumos 2014, p. 15



Number of children with developmental disabilities residents of social care institutions in Serbia, 31 December 2016.  
Source: National office for Social protection, 2017

