Advancing the right of persons with disabilities to live independently and being included in the community - taking advantage of EU leverage

By: Rados Keravica

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Thesis Supervisor: Janos Fiala-Butora, S.J.D.

Central European University

1051 Budapest, Nador utca 9.

Hungary

Contents

Executive Summary

This thesis research looks into the scope and the content of the right of persons with disabilities to live independently and to be included in the community as well as its state of the implementation at the level of chosen national jurisdictions – Croatia and Serbia and the European Union as the regional integration organization which has confirmed the Convention on the Rights of Persons with Disabilities. The right to live independently and to be included in the community enshrined in Article 19 of CRPD has profound effect on the realization of all other rights set out in the CRPD and includes both civil and political and economic, social and cultural rights and engages both positive and negative obligations of the States Parties. These obligations are contained in the three core elements of Article 19: choice of the place of residence, access to disability-specific community-based services and access to services for general population. Still, there are more than 1.2 million of Europeans with disabilities being placed in the residential care settings limiting their choice and control over their own lives. People with intellectual and psychosocial disabilities are at the heightened exposure to this malpractice due to presumed mental incapacity to make autonomous life decisions.

The CRPD was the first international human rights treaty concluded by the European Union and it has the status of "mixed agreement" in EU law as it is ratified both by the EU and its Member States which are sharing the competences between each other for CRPD implementation.

Chapter 1 explores the scope and the content of the right to live independently and to be included in the community to develop the understanding of its hybrid nature and unique concepts it brought into international human rights law. Chapter 2 maps the current challenges in Europe in regards the implementation of Article 19 seeking to make clear the distinctions between institutional and

community-based care and to map the steps needed to create CRPD-compliant response in terms of the transition from institutional to community-based care. It also proposes the set of indicators to monitor the progressive realization of Article 19.

Chapter 3 is dedicated to the position of the CRPD in EU law denoting the legal effects of CRPD in EU law and mapping the obligations which the EU has under Article 19 both in relation to its Member States and the countries in accession to EU membership.

Chapter 4 looks into the implementation of Article 19 in the national jurisdictions of Croatia and Serbia which are sharing the legacy of institutional care for persons with disabilities and are experiencing the similar challenges in the transition from institutional to community-based care. Both countries are sharing the experience of EU integrations – Croatia joining the EU membership in 2014 and Serbia having the status of the candidate country. The effects and the potential of EU's policy of conditionality to advance the right to live independently are explored on the basis of these two national jurisdictions with the set of recommendations set out in the conclusion resulting from this research.

Introduction

The UN Convention on the rights of persons with disabilities (CRPD)[1] adopted in 2006 by the UN General Assembly represents the embodiment of long-desired recognition of disability rights as legitimate part of international human rights law and human rights discourse. It resulted from years of advocacy efforts by persons with disabilities and their representative organizations from all around the world who took an active part in drafting and negotiating the final wording of the CRPD. A widely spread mantra among disability movement is that the CRPD does not introduce any new rights but merely clarifies the rights enshrined in the International Bill of Rights and sets out the measures and steps that the State Parties should undertake to guarantee the human rights to persons with disabilities on an equal basis with others[2]. However, this claim is at least arguable if not completely false as the CRPD did introduce some rights which had never before been mentioned in any other binding regional or international human rights treaties[3]. One of the rights mentioned for the first time in the CRPD is the right to live independently and be included in the community (Article 19 of the CRPD[4]). Undoubtedly, the right to live independently and to be included in the community is of crucial importance for exercising other rights set out in the CRPD such as the right to education, to employment, the right to privacy and family life, the right to physical and mental integrity, due to the potential of residential institutions to segregate and isolate people from local communities. This interrelation and interdependence of article 19 with other rights and the detrimental effects of institutionalization on their enjoyment are clearly visible from

[1] UN General Assembly, 'Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly', A/RES/61/106 (2007)
[2] Marianne Schulze, 'Understanding the UN Convention On The Rights Of Persons With Disabilities. A Handbook on the human rights of persons with disabilities', (Handicap International 2010) p.7, para. 1.
[3] Frederic Megret, 'The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?' (Human Rights Quarterly, Vol. 30 2008)
[4] Article 19, UNCRPD

the example of access to education of children with disabilities residing in institutions in Serbia. According to available data, two thirds of the children who are living in institutions and are of primary school age are not enrolled in any education program[5]. It is not difficult to assume that, consequently, their chances of participating in employment in the future are significantly reduced.

This being said, Article 19 depicts very well the spirit of the CRPD and the intended "paradigm shift"[6] related to societal attitudes towards disability. The social model of disability brought up into the sphere of international human rights law by the CRPD thrives on the concept of disability as a social construct and distinguishes between impairment and disability. This is clearly reflected in the definition of disability put forward in Article 1 of the CRPD which says that "*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*."[7] Article 19 addresses social exclusion, isolation and segregation resulting from those barriers and insists on personal agency, choice and control over one's life while it puts obligations on the State Parties to ensure that persons with disabilities "are not obliged to live in a particular living arrangement"[8], and that community-based services are available for persons with disabilities as facilitators of independent living and social inclusion, including those specially designed for persons with disabilities and those for the general population[9].

[5] Lea Simokovic et al. 'Practicing universality of rights: Analysis of the implementation of UNCRPD in view of persons with intellectual disabilities in Bosnia and Herzegovina, Kosovo and Serbia', (People in Need 2012)
[6] Peter Mittler, 'The UN Convention On The Rights Of Persons With Disabilities: Implementing A Paradigm Shift' (Journal Of Policy & Practice In Intellectual Disabilities 12.2, 2015)
[7] Article 1, para. 2, UNCRPD
[8] Article 19, para. 1 (a), UNCRPD
[9] *Ibid,* para. 1 (b) (c)

Even though the CRPD enjoys the status of the most ratified UN human rights treaty after the Convention on the Rights of the Child, with 171 ratifications and 160 signatories[10] as of 21 March 2017, we are still witnessing the ongoing practices of segregation and isolation of persons with disabilities across the world contrary to the obligations set out in Article 19. Persons with intellectual and psychosocial disabilities are especially susceptible to various malpractices and forms of isolation and segregation from the community as they are often being perceived as incapacitated to make decisions on their own and to be full and active members of society[11].

This thesis explores the ongoing challenges in the implementation of Article 19 at national and EU levels with special consideration of the role of the EU and its funds to spark and complement the effective implementation of the CRPD in its Member States and accession countries while focusing on two national jurisdictions: Croatia and Serbia and the EU itself as a third jurisdiction. Croatia and Serbia are the countries with the history of institutionalized care models for people with intellectual and psychosocial disabilities and have a particularly complex task before them to abandon the heritage of residential institutions for people with disabilities as a form of segregation and to undertake concrete steps towards community-based alternatives as stipulated in Article 19. This exercise has proven to be quite challenging for many countries and requires integral policy response to put in place in order to realize the requirements of Article 19.

Dismantling residential care institutions, including both social care and psychiatric care institutions, is not only a matter of housing and transformation of these institutions. It rather requires concerted and coordinated efforts of policy reforms in a number of different policy areas,

[10] Source: UN Division for Social Policy and Development https://www.un.org/development/desa/disabilities/
[11] Camilla Parker, 'Forgotten Europeans Forgotten Rights: The Human Rights of Persons Placed in Institutions' (Office of the United Nations High Commissioner for Human Rights, Regional Office for Europe 2010).

including but not limited to education, health-care, social services, anti-discrimination and legal capacity.

Having in mind the level of exclusion of the residents of the institutions from education opportunities or employment, their exposure to deprivation of legal capacity and the level of stigma and discrimination by society it is clear that these safeguarding policies have to work in conjunction to enable the full social inclusion of people with disabilities in their respective communities and to render the right to live independently and be included in the community practical and effective.

The deinstitutionalization (DI) process is not free from financial and political costs for decision-makers[12] which may face strong opposition from professionals and service providers employed in these residential care institutions. It certainly requires decisiveness of policymakers to introduce the adequate set of measures conducive to independent living and ensure proper funding for the transition towards community-based care. Therefore, this thesis will look into the scope of the right entailed by Article 19 and its implementation in chosen jurisdictions seeking to answer the following research question: **What kind of obligations has the confirmation of the CRPD created for the European Union with regards to the implementation of Article 19 with special consideration to the utilization of EU funding mechanisms to support the deinstitutionalization process in the chosen EU Member States and accession countries?**

Further on, it will explore the underlying factors of the DI process with an aim to determine the reasons of its varying results in chosen countries for comparative analysis. Finally, the European Union as a supranational organization with the set of human rights policies and funding

[12] Jim Mansell and others, 'Deinstitutionalisation and Community Living– Outcomes and Costs: Report of a European Study' (Tizard Centre, University of Kent 2007).

mechanisms is undoubtedly an influential factor on political agendas in its member states and accession countries. Its influence is reaching beyond the areas of its exclusive or shared competences conferred to it by the Member States and it extends to influence in the areas of significance for DI process which fall out of its competence through its various mechanisms including the financial ones like the EU Structural funds or the Instrument for Pre-accession Assistance (IPA). Therefore its role cannot be disregarded when analyzing how the policy agendas are being set in the countries, what sources of funding are used to support the implementation of these policies and how high on the list of priorities of decision-makers in the countries the DI process will be positioned.

Methodology

This study will rely on desk research aiming at reviewing primary and secondary sources relevant for the field of deinstitutionalization of persons with intellectual and psychosocial disabilities in two national jurisdictions (Croatia and Serbia) and the jurisdiction of the European Union. The jurisdictions are chosen on the basis of their common historical legacy vis-à-vis the practice of institutionalization of persons with intellectual and psychosocial disabilities and their different status in the process of EU integrations.

Croatia and Serbia share the same legacy of residential institutions for people with intellectual and psychosocial disabilities as well as underlying factors and barriers for deinstitutionalization such as the system of deprivation of legal capacity dating back from the time of the Socialistic Federative Republic of Yugoslavia. However, after Yugoslavia has fallen apart through a turbulent period which included a civil war, the newly independent States have experienced a different pace and progress in the process of EU integrations. Croatia has acceded EU membership in 2014 while Serbia has the status of candidate country and has recently started the process of EU membership negotiations. The review will include the policy frameworks in both countries relevant for deinstitutionalization, the role that the EU played or is playing to advance the DI processes through its policy of conditionality and EU funding used in those countries to support deinstitutionalization in the current budget period (2014-2020) through the European Structural Funds (Croatia) and the Instrument for Pre-Accession Assistance (Serbia).

The sources used in the analysis of the role of the European Structural Funds include States' Partnership Agreement with the EU on the usage of the ESI Funds, the national Operational Programme for the usage of ESI Funds including the thematic priorities focusing on the priorities

relevant for deinstitutionalization as well as the available evaluation reports for implemented projects in the field of social inclusion and/or deinstitutionalization of persons with disabilities funded through ESFs. As it regards Serbia, the IPA Framework Agreement will be reviewed focusing on the parts relevant for DI, as well as EU Progress Reports on Serbia, Screening reports on accession negotiations Chapters 19 and 23, as well as any available evaluation report for projects in the field of deinstitutionalization and community-based service development funded by the EU.

Further to these sources, the reports of intergovernmental agencies and human rights bodies and mechanisms on the interpretation and scope of Article 19 as well as their findings on the implementation of Article 19 in the three chosen jurisdictions as CRPD State Parties, as well as the work of individual researchers and scholars on EU law and the CRPD and the deinstitutionalization of people with intellectual and psychosocial disabilities will be analysed. The analysis will also include any relevant decisions of the European Court of Justice in the field of the CRPD ramifications for EU law with the focus on Article 19. The analysis will also rely on sources available in the databases of the Academic Network of European Disability Experts (ANED) and its DOTCOM tool, which include policy reviews at the EU level and at the level of the Member States and acceding countries pertaining to all CRPD provisions.

1 The scope of the right to live independently and be included in the community

Despite the common understanding that the CRPD has not created any new rights for persons with disabilities but elaborated how the existing set of rights refers to persons with disabilities, it is true that some concepts and articles from the CRPD considered as rights have not been mentioned before in this form in any other human rights treaty. Frederic Megret argues that the contribution of the CRPD to existing human rights is visible in "affirmation", "reformulation", "extension" and "innovation" of human rights and that this "group-specific" treaty is doing much more than simply clarifying how the human rights from the International Bill of Rights are relating to persons with disabilities[13]. According to this author the "affirmation" refers to the enjoyment of existing human rights for persons with disabilities as well as for all others, "reformulation" stands for modifications of human rights to make them applicable for persons with disabilities, "extension" depicts prolongation of the existing list of rights with the "new category of rights"[14] while "innovation" captures the unique experiences of persons with disabilities by introducing some disability specific rights[15].

On the basis of these arguments, the right to live independently and be included in the community can be deemed as an innovative one since concepts such as independent living, personal assistance or community-based services are mentioned in it for the first time in international human rights law[16]. Thus, Article 19 entails the right which denotes some specific experiences of people with disabilities, namely the experiences of isolation and segregation and deprivation of the possibility

[13] Mégret (n 3), p.6
[14] *Ibid* p.6, para. 3
[15] *Ibid*
[16] Schulze (n 2), p. 113 - 114

to make autonomous life choices, which was not the case with the majority of the population and consequently not deemed as "problematic" and worth of coverage by human rights provisions.

As argued in the lines above, the right covered by Article 19 is a hybrid right containing both civil and political rights, and economic and social rights, as well as the negative and positive obligations of States Parties. When approaching the analysis of the scope of article 19 it is necessary to start from its wording:

"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:

(a) 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;

(b) 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;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."[17]

Breaking down article 19 in parts and starting with the analysis of the first paragraph it is clear that it contains both negative and positive obligations for the State Parties. A negative obligation in the

[17] Article 19, UNCRPD

introductory paragraph is reflected in the wording "**recognize** the equal right of all persons with disabilities to live in the community"[18] and it refers to refraining from the interference with the liberty of persons with disabilities solely on the basis of disability, as for example the involuntary placement of persons with disabilities in residential institutions. The same paragraph continues with outlining the positive state obligations prescribing them to "take effective and appropriate measures" so to guarantee the "full inclusion and participation in the community"[19] of persons with disabilities. The mix of negative and positive state obligations becomes already evident from the introductory paragraph of Article 19 indicating on the one hand the need to "respect" the right (to refrain from the wrongdoing) and on another hand, the need to "fulfill" the right (to take positive steps and measures) so to enable the community living for persons with disabilities.

Independent living as a concept originated from the social movement of people with disabilities in the USA in the 1970s which started as the fight of students with disabilities to access higher education, accessibility, and support services[20]. Independent living as a concept and philosophy does not mean to live in isolation from others but to foster the same kind of interdependence with community members and to exercise autonomy in making choices and decisions in the largest possible degree, being provided with the adequate support if needed[21]. To understand the normative content of Article 19 it is also useful to look at the definition offered by CRPD Committee in its recently published General Comment 5:

[18] *Ibid*
[19] *Ibid.*
[20] Kathy Martinez, 'The Road to Independent Living in the USA: an historical perspective and contemporary challenges', (Disability World, A bimonthly web-zine of international disability news and views. Issue no. 20. 2003)
[21] Schulze (n 2), p. 113

"*Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives."*[22]

The core principle contained in the article is the "personal autonomy and self-determination" which shifts the view of persons with disabilities as the ones possessing full personal agency to make life decisions and choices with adequate support if needed. On the basis of the same principles such support is to be managed and controlled by persons with disabilities themselves and serves to render the right to live independently in the community truly effective.

The analysis of the normative content of paragraphs (a), (b) and (c) of Article 19 will further reveal the above mentioned hybrid nature of this right and types of the States Parties' obligations stemming from it.

1.1 The element of choice

In section (a) of Article 19, it is emphasized that persons with disabilities should not be "obliged to live in a particular living arrangement". It is noticeable that the explicit mention of "institutions" is omitted so as to encompass all possible forms of involuntary living arrangements occurring across the world and resulting in isolation and segregation such as, for example, shackling of people with psychosocial disabilities. In this way, the different cultural approaches are taken into consideration, thus reflecting the universality of the right applicable to all countries and their culture, the level of socio-economic development and features of historical treatment and views

[22] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community'.para.16 (a)

on disability. Living arrangements can also vary according to prevailing social norms. In some communities, the prevailing social norm might be a communal life in all stages of life with more generations of family living together while in some societies people might be leaning more towards individualistic lifestyles. Regardless of the social norms and living arrangements characteristic of a particular community, the message of section (a) of Article 19 is that people with disabilities should be able to choose how and with whom they want to live, without being forced to accept an imposed living arrangement. The phrase "living arrangement" is not reduced to the form of housing but encompasses also the matter "how" the person lives in terms of the lifestyle and daily routine and possibility to exercise basic daily choices related to if, when and how to do particular activities[23]. The main feature of section (a) is the emphasis on 'choice' as the first key element of Article 19. The accent on the choice that people with disabilities should be able to exercise, positions people with disabilities as decision-makers with full capacity to make their life choices regardless of the type and severity of their disability. Here, the inextricable connection between article 19 and article 12 is clearly visible. The barrier to exercise choices and make decisions is often embedded in laws allowing the deprivation of legal capacity on the basis of disability, which prevents people to exercise the control over their own lives and creates the precondition for involuntary placement into residential institutions, contrary to the previously discussed section (a) of Article 19. People with intellectual and psychosocial disabilities are especially vulnerable to the practice of legal capacity deprivation due to deeply entrenched societal presumptions on their lack of capacities and abilities to form and express their will and preferences. Explicit prohibition of

[23] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 24

involuntary placements in residential institutions solely on the basis of disability is elaborated in the Guidelines on CRPD Article 14 – Liberty and security of a person[24].

The inability of persons with disabilities to choose is not only conditioned by legal barriers such as legal capacity deprivation and guardianship systems but also a genuine lack of alternatives in the community and lack of range of community-based support services and inaccessibility of community services and facilities for the general population[25]. Lacking the inclusive environment in the community limits the choices of persons with disabilities if the support services are tied to the residential institutions and persons with disabilities are only left with the informal types of support such as the support from their family members.

Paragraph (a) draws inspiration from civil and political rights, in the first place the right to liberty as placement in the institutions constitutes a deprivation of liberty. The prohibition of involuntary placement of people with disabilities into residential institutions as a form of deprivation of people with disabilities to exercise choice vis-à-vis living arrangements has an immediate effect and falls under negative obligations or obligation to respect, that is not to interfere with the right. The obligation to respect also includes the need to repeal all laws that allow for the placements of people with disabilities in the institutions and laws which allow for legal capacity deprivation. The investments in the institutions beyond what is needed to ensure safety and health of the residents, admission of new residents or opening new ones is also considered as interference and a breach of the duty to respect[26]. Similarly, the obligation to protect refers to preventing private actors to

[24] Committee on the Rights of Persons with Disabilities, 'Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities'.
[25] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 25
[26] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). paras. 47 - 49

segregate and limit the choices of or discriminate against persons with disabilities (e.g. privately-run institution-like service providers).

1.2 The element of disability-related support

Section (b) of Article 19 elaborates the preconditions to ensure that people with disabilities can effectively exercise their right to live independently and be included in the community. These preconditions refer to a "range of in-home, residential and other community support services, including personal assistance"[27]. The notions of 'community support' services or 'personal assistance' have never been mentioned before in international human rights law. They are to be understood as means for overcoming the barriers in society and achieving full, effective inclusion of persons with disabilities in communities. At the same time, such services should foster personal autonomy, dignity, equality, and participation of persons with disabilities. It is of essential importance for decision-makers in States Parties to acquire an understanding of what are 'community-based support services' for persons with disabilities and their features, as ensuring availability, accessibility, and affordability of such services is part of the positive obligations of the States Parties under the CRPD. What matters as the key indicator to recognize the service as community-based one is not the physical location of the service, removing the segregated forms of housing from the outskirts to central locations of the settlements, but the contribution of such support service to an independent living of a person and social inclusion enabling and fostering the interaction between the person and different actors in the community[28].

[27] Article 19 (b), UNCRPD

[28] Lilia Angelova-Mladenova, 'The Right to Live Independently and Being Included in the Community. Addressing Barriers for Independent Living Accross the Globe' (European Network on Independent Living 2017). p.13, para. 1

The manner and extent to which such services are provided to people with disabilities reflect the approach of the State to disability and care for persons with disabilities. The CRPD brings up the paradigm shift from the medical model to the social model of disability. The key differences between the two models or views of disability are clearly seen in the contention between institutional care for people with disabilities and community-based care.

The medical model of disability is based on a perception of persons with disabilities as abnormal ones whose impairments, be they physical, sensory or intellectual, have to be cured or fixed so that to achieve the 'normality', the disabled person should undergo a prescribed medical treatment. If 'fixing' or 'curing' the impairment is not possible then the person is regarded as a misfit and becomes an object of charity, less valued then other members of society without such impairment. The history of institutionalization of persons with disabilities and their segregation and social exclusion reflects the medical model of disability as it is based on a perception of people with disabilities as incapacitated and in need of care, whose best interest is to be decided by someone else, often a medical staff or in the best case a family member or relative.

On the contrary, the social model of disability is the 'heart and soul' of the CRPD which substantially changes the perception of disability as an individual problem turning it into the problem of the whole society and the barriers that it creates which prevent persons with disabilities from fully participating in it. The emphasis is no longer on the need to 'fix' the impairment but on eliminating the attitudinal and environmental barriers in society and guaranteeing human rights for people with disabilities. Persons with disabilities are to be the ones to articulate their needs and advocate for their best interests as they are in the best position to recognize them. The shift from institutional to community-based care, imposed by Article 19, is to be understood in this context

as founded on the respect of the principles and values of autonomy, personal agency, choice and control.

Community-based services and personal assistance, as part of the States' positive obligations, have to be available, accessible, affordable and accountable[29]. This so-called 4A principle will be discussed later on in Chapter 4.

Marriane Schulze defines personal assistance through its function and purpose saying that it "provides support for tasks and activities, which the person would do by herself or himself if she or he did not have an impairment. The assistance is provided for all tasks and activities necessary to lead an independent life."[30] Another definition is offered by European Network on Independent living which describes personal assistance as "individualized support for disabled people, which enables them to overcome environmental barriers and to live independently"[31] and goes further in outlining the requirements for personal assistance which enable the maximum level of choice and control for the person. It involves the requirements that disabled person should be able to "choose their own assistant, and to decide how, where and what support is provided to them", that the number of hours is provided on the basis of individual needs, that it is provided for all impairments and age groups and that if needed the support is provided on how to manage the assistance[32].

Community-based services include a wide array of support services for people with disabilities necessary for an active involvement in community life, "preventing isolation and segregation from the community"[33] and incorporate the following examples: housing services, family support,

[29] Diana Chiriacescu, 'Shifting the Paradigm in Social Service Provision – Making Quality Services Accessible for People with Disabilities in South East Europe', (Handicap International Regional Office for South East Europe 2008). p.29, paras.3-6
[30] Schulze (n 2), p.114, para.2
[31] Angelova-Mladenova (n 28). p.13, para 2.
[32] *Ibid.*
[33] Article 19 (b), UNCRPD

education services, rehabilitation services, training and development of personal capacities and independent living skills, peer support, self-advocacy and others. Community-based services are not explicitly defined in the CRPD and the listed examples are not exhaustive. They are subject to innovations as technology is advancing and new ways to foster the inclusion of people with disabilities are designed. However, their key feature is found in their purpose – to promote the independent living and inclusion of persons with disabilities in their community and foster the principles mentioned above: autonomy, choice, and control. The CRPD Committee's General Comment 5 explains this purpose of community-based services explicitly and indicates that "any institutional form of support services, which segregates and limits personal autonomy, is not permitted by article 19 (b)"[34]. Although the article does not mention in its text residential institutions, the General comment is explicit in denoting the institutions as a form of segregation and makes clear the responsibility of the States Parties to undertake steps toward deinstitutionalization.

The process of transition from institutional to community-based care is part of the right to live independently and be included in the community and creates for the States Parties positive obligation (obligation to fulfill) to provide *"appropriate legislative, administrative, budgetary, judicial, programmatic, promotional and other measures"*[35] which are supposed to enable adequate range of disability-specific support services. Such obligations undoubtedly incur costs and States are supposed to develop the strategies and action plan (immediate effect) for progressive realization according to its maximum available resources.

[34] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para.30

[35] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 54.

1.3 The element of availability of community services for the general population

The third element of Article 19 can be read from its last paragraph which refers to "availability of community services and facilities for the general population" to persons with disabilities as well[36]. Unlike paragraph (b) which refers to disability-specific services and types of support, paragraph (c) imposes the positive obligation on the States Parties to render all services available in the community intended for the general population, accessible for persons with disabilities. Such services which are intended for the general population are often referred in the literature as "mainstream" services including but not limited to "housing, public libraries, hospitals, schools, transport, shops, markets, museums, the Internet, social media and similar facilities and services"[37]. They should be designed and developed respecting the principle of "universal design"[38] meaning that such a design would ensure accessibility and allow for the universal use of the services regardless of one's age, type of the impairment, gender or any other characteristic. Mainstream services should also be affordable and adaptable to the needs of persons with disabilities and acceptable for them taking into account age, gender, and cultural appropriateness[39].

It is particularly interesting to see the approach CRPD Committee used in regards of the housing. It recognizes availability, accessibility, and affordability of housing as "crucial for deinstitutionalization, including housing for families"[40] and it sets out the positive obligation to

[36] Article 19 (c), UNCRPD
[37] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para 32.
[38] *Ibid.* para 38 (d)
[39] *Ibid.* para. 35
[40] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 59

provide for publicly subsidized housing programs for those persons with disabilities in need[41]. However, it is true also that the accessible and affordable should not only be available to former residents of the institutions but to all people with disabilities facing similar barriers who were kept out of the institutions thanks to the informal support they received (e.g. support by their family members) or who are perhaps homeless. Such consideration has to be taken into account as it extends the coverage of needed housing programs and raises the cost of inclusion in the community[42].

It gets clear from this section of the article that the process of deinstitutionalization does not take only the transformation or closure of residential institutions but that it takes parallel effort and steps to create an inclusive environment in the community so the people can lead prosperous lives in the communities. Creating the enabling and inclusive environment means the availability of sufficient disability-specific community-based services and accessibility of public services intended for the whole population and also the creation of inclusive culture in terms of acceptance of persons with disabilities by the community through awareness raising. Decomposing the deinstitutionalization process in these elements it gets evident that deinstitutionalization relies on the realization of both civil and political and economic, social and cultural rights and is thus, the subject of progressive realization.

[41] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 93

[42] Janos Fiala-Butora, *The Right to Independent Living and Its Limits* (2017), unpublished.p.12

2 Current challenges in the implementation of Article 19 of the CRPD

Identifying and recognizing the ongoing challenges in the implementation of the right to live independently and being included in the community and the key barriers that prevent persons with disabilities of full participation in the life of the communities is a crucial step towards designing the effective response to the practices of segregation, isolation and social exclusion. The effective public policies which would render this right a reality for persons with disabilities across the globe require the analysis of the challenges and the barriers impeding the effective implementation of Article 19. The local context and the reality have to be taken into account when deciding on the measures to be undertaken towards full implementation.

The global report on the right to live independently and being included in the community published by the European Network on Independent Living[43] outlines the key barriers to the full realization of the right grouping them into several categories of the barriers as following:

- "Misunderstanding and misuse of key terms;
- Negative attitudes and stigma;
- Lack of support to the families;
- Prevalence of institutional services;
- Barriers related to the community support services;
- Barriers in mainstream services and facilities;
- Barriers to other CRPD rights that impact on the independent living."[44]

[43] Angelova-Mladenova (n 28).
[44] Angelova-Mladenova (n 28). p.11

Common understanding of the key concepts such as independent living, community-based services or the institutional care among decision-makers, Disabled People's Organizations (DPOs), advocates and persons with disabilities and their families is necessary so to avoid measures and actions which are not compliant with the normative content and the scope of the right to live independently and being included in the community. The lack of understanding might lead to the use of already limited resources for the programs and services which actually perpetuate segregation and isolation of persons with disabilities under the guise of independent living schemes and services.

The concepts such as independent living, deinstitutionalization, personal assistance or community-based services each demand clarification and interpretation which would ensure that the CRPD requirements are translated into reality through national policies in places. This chapter does not intend to define these concepts as they were explained in the previous chapter, but to indicate to some common misunderstandings, myths and misbeliefs around them which are causing undesirable outcomes for persons with disabilities.

The **misunderstanding of independent living** is sometimes reflected in beliefs of not only decision-makers but persons with disabilities and their families themselves believing that to live independently means to live alone and to move out of the family or that the independent living means independence from any kind of support including the state's support[45]. However, the truth is that independent living embraces the "same level of independence and interdependence within society on an equal basis with others"[46] with the emphasis on the choice and control which should be in the hands of a person with disabilities at the largest extent possible with enough support to

[45] Angelova-Mladenova (n 28).p.12 para. 3

[46] 'Thematic Study on the Right of Persons with Disabilities to Live Independently and Be Included in the Community' (Office of the United Nations High Commissioner for Human Rights 2014) A/HRC/28/37. para.13

make this right effective. Similarly, the **deinstitutionalization** could be wrongly understood as the mere closure of the residential institutions including psychiatric hospitals and social care institutions without providing sufficient alternatives in the community[47]. Also, the misunderstanding might stem from the attempts to define institutions by size **which may lead to mere multiplication of smaller institutions**, group homes, day-care centres or other forms of segregation fostering an institutional culture where people with disabilities are still deprived of choice and control over their lives. Community-based services can also be misunderstood in that way that the key feature of community-based is wrongly seen as physical location of the service rather than organization of the support services in that way which supports inclusion in the community, including the stronger ties and interactions with community members, using of other mainstream community services and again the choice and control of persons with disability over the service and the way how it is provided.

Lack of understanding of these key components of Article 19 prevents to design and put in place CRPD compliant public policies. Here lie the power and significance of the interpretation of the normative content and scope of Article 19 by CRPD Committee through recent General Comment 5.

Negative attitudes and stigma attached to a disability may render more difficult inclusion of persons with disabilities in the community life, especially those with intellectual and psychosocial disabilities which are often more susceptible to stigma[48]. This is largely reflected to labelling of the people with disabilities by other community members as weak or incapable of making their

[47] See for example https://beta.theglobeandmail.com/news/world/more-than-100-dead-in-neglect-of-psychiatric-patients-in-south-africa/article34031501/?ref=http://www.theglobeandmail.com& Accessed on 25th November 2017

[48] Angelova-Mladenova (n 28).p.18, para.4

own decisions or even the auto-stigma of persons with disabilities due to the lack of confidence or as a consequence of living in the isolation for the long-time, fearing of the unknown - the life outside, especially if having the experience of being labelled, bullied or rejected by other community members[49].

Families of persons with disabilities are often the great source of support to both children and adults with disabilities. Sometimes they are best positioned to provide support as they are the closest to a person and know well the needs or the way of communication of a person, being able to interpret the will and preferences of a person especially when it comes to people with speech impairments of with the high support needs. Family support is regarded as informal support which can play a vital role in the prevention of institutionalization[50]. However, the **availability of informal circles of support, including the one provided by family members does not mean that it should be considered as a substitute to formal types of support** provided or funded by the state. Families of persons with disabilities, especially there where the family members are caregivers are under risk of unemployment and poverty, due to the enhanced living cost of disability and the fact that the caregivers are often forced to leave their jobs[51]. Deinstitutionalization policies should direct provision of the support not only to the people currently placed in the institutions but also to those being currently out thanks to the efforts of their families. [52]

Another barrier for independent living in the community is **the legacy and the prevalence of institutionalization of persons with disabilities**. Most of the European countries were

[49] Jim Mansell and others (n 12). p.56, para. 3
[50] Janos Fiala-Butora *The Right to Independent Living and Its Limits* (n 42).p.12, para.3
[51] Angelova-Mladenova (n 28).p.22, para.2
[52] Janos Fiala-Butora *The Right to Independent Living and Its Limits* (n 42).p.12, para.3

characterized by the institutional care for persons with disabilities for decades, some even from the beginning of 19th century[53]. There are both social and economic reasons for it. Social ones include negative perceptions of disability and capacities of persons with disabilities, inabilities of families to take care of their disabled members, stigma, and embarrassment of disability while economic reasons could be found in the economy of scale and the efficiency of service provision at one location for a large number of people[54]. While the Western European countries have started moving from the residential care towards community-based care after Second World War with varying successes under the influence of disability movements and positioning of disability as a civil rights issue[55], countries of Central and Eastern Europe were and are still lagging behind. This legacy is largely due to ideology factors under communism, medical approach to disability and its perception as abnormality under the strong influence of defectology in the communist era[56]. Such legacy with the high prevalence of residential care makes visible the organizational barriers to independent living in terms of opposition towards deinstitutionalization among the certain groups of stakeholders such as management staff members of residential institutions who are often keen to maintain residential care. Further on, the existence of the institutions in the state's welfare system means that there are already entrenched financing mechanisms of residential care that need to be transformed so to enable the funding of alternatives in the community[57].

Here comes the issue of development and provision of the "alternatives in the community" referring to the range of disability-related support services which should enable the inclusion in the communities for persons with disabilities. The types of such services were discussed in the

[53] Jim Mansell and others (n 12).p.1, para.2
[54] Jim Mansell and others (n 12).p.43, para.1
[55] Jim Mansell and others (n 12).p.1, paras 2 and 3
[56] David Tobis, *Moving from Residential Insitutions to Community-Based Social Services in Central and Eastern Europe and the Former Soviet Union* (World Bank 2000).p.9,para.1
[57] Tobis (n 56).p.12-13

previous chapter but important to say is that the imperative for "available, affordable and accessible" community-based services **creates challenges in relation to sufficient availability and coverage of those in need, funding system and sustainability of services, quality of services conducive of independent living and access to services in terms of eligibility criteria put forward to determine who qualifies as service user**[58]. All these challenges will be addressed in the cases of Croatia and Serbia as chosen national jurisdictions in the Chapter 4.

2.1 The transition from institutionalized care towards community-based care in Europe

The countries with the prevalence of institutional care for persons with disabilities are expected to embark on the process of transition towards community-based care and to design the strategy how to complete this transition. Even though, the implementation of Article 19 is subject to progressive realization as part of the corpus of economic and social rights, the States Parties still have the *"immediate obligation to enter into strategic planning with adequate timeframes and resourcing in close and respectful consultation with representative organizations of persons with disabilities to replace any institutionalized settings with independent living support services."*[59]

The assessment of the current situation is needed for every country in order to plan carefully the steps that need to be taken to ensure and guarantee the right to live independently in the community for persons with disabilities. While it is no question that institutional placements represent the form of segregation and isolation of persons with disabilities and thus violation of Article 19, the

[58] Angelova-Mladenova (n 28).p.31 - 40
[59] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22).para. 42

prevalence of the institutions, number of residents, their age, gender and type of the impairment, geographical location, existence of family members and relatives, deprivation of legal capacity, accessibility of services for general population can differ significantly in every local context. Therefore, States are given the margin of appreciation to decide how the "programmatic implementation will look like".[60] A research has shown that the community-based care is usually guaranteeing better outcomes for persons with disabilities in terms of better quality of life and that the community-based care is more cost-effective[61]. However, important to note is that there is a high risk of multiplication of smaller institutions, calling it community-based care, while in fact the same institutional culture is kept in such services and segregation of persons with disabilities is continued due to lack of understanding what genuine independent living services look like. That is why this section will break down the phases in the process of transition and critically reflect on them so to identify the milestones against which the progress could be monitored. This part of the chapter will also offer a brief overview of the current situation in Europe and the context in which the transition from institutional to community-based care is or should be happening.

A landmark study funded by the European Commission in 2007 has offered the first data on the extent and type of institutional care in 25 European countries with the goal to map the current situation and the potential costs of the transition from institutional to community-based care[62].

This study was the first one to offer cross-country comparisons in Europe on the prevalence of institutional care and the number of residents of the institutions but it should be noted that the study itself is identifying the challenges faced in data collection phase caused by inconsistent and

[60] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22).para.42
[61] Tobis (n 56).
[62] Jim Mansell and others (n 12).

unified national systems of data collection and differing definitions of institutions. Therefore, the data from 2007 which has already been biased is still used when estimating the number of people with disabilities placed in the institutions in EU countries. This estimate is 1.2 million of people with disabilities[63] while there is no data available for Council of Europe area. The study has identified a high prevalence of the institutions with more than 30 residents in 21 out of 25 countries[64], while in 16 out of 25 countries that had provided the data institutions were accommodating more than 100 residents, mostly state-funded[65]. Worth noting is that the residential services counting less than 30 places were typically provided by non-governmental organizations which may indicate the robustness of state-run system of institutional care and existing financing mechanisms in favor of large-scale institutions which needs to be shifted toward community-based services. It may also indicate the better understanding of the concept of community living by NGOs and user-led services which are often the initiators of positive changes, meaning that the service provision sector has to be pluralistic in terms of same conditions for state-run, NGO and private-run services. Ass for the types of the impairments of residents of the institutions it is indicative that the most represented group is people with intellectual disabilities (265 000), followed by people with mixed impairments (162 000) and people with psychosocial disabilities (124 000)[66]. That corresponds with the assumptions that people with intellectual and psychosocial disabilities are under the heightened risk of institutionalization, segregation, and isolation due to the perception of lacking decision-making capacities caused by mental incapacity and due to the widespread practice of legal capacity deprivation in Europe which is enabling involuntary

[63] Jim Mansell and others (n 12).p.25, para.2
[64] Jim Mansell and others (n 12).p.21
[65] Jim Mansell and others (n 12).p.22
[66] Jim Mansell and others (n 12).p.29, para.2

placements in the residential institutions[67]. It is important to note here when discussing the statistics and the data related to institutionalization practice in order to map the scale of the problem, that the consistent, comparable and disaggregated data by age, gender and type of the impairment is not available and is not being collected in the systematic way across countries and regions which makes planning of the steps in the transition to community-based care more difficult.

Development of available, accessible and affordable alternatives in the community which respect the independent living principles[68] before the residential institutions are closed down is the key component of deinstitutionalization process. That is why it is crucial to know the scale of the problem and to know well the target group and their needs and to include them in every phase of the process of transition to the community. As it is to happen progressively, it means that the investments of the resources in support services for persons with disabilities will have to be heightened as the funding of parallel systems of care will be required for certain period of time[69].

If wanting to make sure that the investments are spent for the right purpose and that they guarantee in the end the better outcomes in terms of better quality of life for persons with disabilities and their families it necessary to have a vision and a sense of what steps does the transition from institutional to community-based care take. For such purposes, the European Commission, more specifically it's Directorate General for Employment, Social Affair and Equal Opportunities had initiated forming of a group of experts with the task to devise the guidance and the recommendations for the States on how to implement the transition from institutional to

[67] Fundamental Rights Agency of European Union (ed), *Legal Capacity of Persons with Intellectual Disabilities and Persons with Mental Health Problems* (Off for Official Publ of the Europ Union 2013).
[68] Debbie Jolly, 'Independent Living Manual' (European Network on Independent Living 2015) p.12, para.5
[69] Jim Mansell and others (n 12).p.10, para.1

community-based care resulting in the detailed Guidelines[70]. The Guidelines are referring to 10 steps or the elements of the process of transition that the states should follow in order to complete the transition successfully. According to the mentioned source, those include:

- "Making the case for developing community-based alternatives to institutions;
- Assessment of the situation;
- Developing a strategy and an action plan;
- Establishing the legal framework for community-based services;
- Developing a range of services in the community;
- Allocating financial, material and human resources;
- Developing individual plans;
- Supporting the individual and communities during transition;
- Defining, monitoring and evaluating the quality of services;
- Developing the workforce."[71]

The progress of national jurisdictions chosen for this analysis in the process of deinstitutionalization will be assessed against these steps reflecting upon the most relevant integral elements of each of the steps for this thesis. The ensuing comparative analysis will also rely on the selection of human rights indicators for the implementation of Article 19 as the lack of consistently used indicators and comparable data stemming from differing definitions of institutions or community-based services is rendering cross-country comparisons difficult This aims to set the

[70] Ines Bulić, 'Common European Guidelines on the Transition from Institutional to Community-Based Care' (European Expert Group on the Transition from Institutional to Community-based Care 2012).
[71] Bulić (n 70).p.11 - 14

ground to determine the key challenges and gaps in the implementation which needs to be addressed if the investments in the transition process are to be truly effective.

2.1.1 The definition challenges: the features of institutionalized care vs. the features of community-based services

In order to conduct proper assessment of the situation vis-à-vis Article 19 and to determine the extent to which people with disabilities are segregated and isolated from their respective communities and afterwards to develop the comprehensive strategy for the process of deinstitutionalization, it is necessary to reach the understanding of what "institutions" are and what is the subject of the transformation so to avoid that one form of segregation is replaced with another.

The landmark study mentioned above had used the definition of the residential institution in relation to the size of the institution. Bearing in mind that in the focus of the study was a transition of large-scale institution it defined it as "an establishment in which more than 30 people lived, of whom at least 80% were mentally or physically disabled" and "the congregation of people with disabilities together and isolation from the wider community"[72]. It further described large residential institutions as characterized by "depersonalization, social distance, block treatment and rigidity of routine"[73]. It is exactly those features combined with the lack of privacy, lack of personalized support, power hierarchies between residents and staff members that are making the

[72] Jim Mansell and others (n 12).p.6, para.1
[73] *Ibid.*

institutional culture which has the detrimental effects on the development of potentials of residents. The size of the institutions should not be the key determinant in the attempt to define and map residential institutions for people with disabilities, although it is true that the risk of abuse and neglect and the lack of appropriate support services is much higher in the large-scale institutions, it is rather the institutional culture referred above that should be used to denote institutions[74]. The segregation of residents from the community which is not based on their free choice, the absence of autonomy in decision-making over one's life choices and the failure to respond to individual needs are among the key features of institutional culture[75]. That means that the support services are tied to the buildings and the range of offered services is predefined and not flexible so that persons with disabilities have no meaningful choice of the support they are getting reflecting the approach "one size fits all".

OHCHR in its report on the rights of residents of the institutions defines the institutional care as the "provision of care in "traditional" long-stay institutions, i.e., premises in which residents have little, if any, control over their lives and day-to-day decisions", emphasizing the lack of possibility to accommodate individuals' needs and preferences in terms of basic daily activities[76]. The key "take-away" from these definitions is that the institutional care cannot be merely defined by size but the present institutional culture which could pertain as well to much smaller residential services in terms of a number of users. It is the absence of choice and control over one's life that renders such services non-compliant with Article 19 standards and opens the door for the abuse of other

[74] Directorate-General for Employment, Social Affairs and Equal Opportunities, 'Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-Based Care' (European Commission 2009).p.8, para.1
[75] Directorate-General for Employment, Social Affairs and Equal Opportunities (n 74).p.8, para.5
[76] Parker (n 11).p.5, para.4

human rights including physical and sexual abuses, inhuman and degrading treatments, lack of privacy as it was found in multiple studies and reports[77].

If the institutional culture is not exclusively related to large-scale social care institutions, which type of the services are deemed as segregated forms of living arrangements? The studies has attempted to map all the possible forms of institutions including the following: group homes for small number of residents (up to 10), residential homes (10-30 residents) with 24-hour support staff, campuses with clusters of group homes, residential schools for disabled children and adults, social care residential institutions (more than 30 residents), hospitals for more than 30 residents (including psychiatric hospitals)[78].

While it is made sufficiently clear what constitutes violations of Article 19 and why institutional care is non-compliant with the CPRD thanks to the growing body of evidence and reports on the rights of the residents and negative impacts on their lives, it is less clear what would on the opposite, constitute a CRPD compliant response and how the community-based support services should look like. The imperative for personalized flexible services stems from the heterogeneity of the population of persons with disabilities, which differs not only by the impairment but the multiple aspects of personal identity and different goals, wishes and preferences of each person. As residential institutions are providing "block treatment" services, same service in which all users have to fit, the separation of housing and support service provision in terms of availability of support services in the family home of the user, for example, would be a stepping stone towards community-based response. If the provision of needed support service is not conditioned with the place of living people and their families would have a genuine choice to choose the preferred living

[77] Parker (n 11).
[78] Jim Mansell and others (n 12).p.21 - 22

arrangement on the assumption that the services for the general population are made accessible and affordable for people with disabilities. One of the key distinctions between the two models of care is that the person in institutional model of care is forced to fit into the existing services while in the community-based models of care persons with disabilities should be included in all phases of service development, from planning and designing of service to its delivery and evaluation. Such involvement of users is referred as "co-production"[79] fairly recent term meaning that services should be developed not only "for" persons with disabilities but "with" persons with disabilities.

2.1.2 The suggested indicators for tracking the progress in the implementation of Article 19

Human rights indicators are important to track the progressive realization of human rights and to know what kind of data the states should collect through their statistical systems. They are almost indispensable in the process of human rights monitoring when assessing the current state of implementation of human rights helping to develop evidence-based policies They help to hold the governments accountable and transparent about the actions it has taken or failed to take and it gives more or less clear overview of the needed steps and measures to be undertaken towards full implementation. Office of High Commissioner for Human Rights has offered following definition of an indicator:

"a human rights indicator is specific information on the state or condition of an object, event, activity or outcome that can be related to human rights norms and standards; that addresses and

[79] See the Fact Sheet of European Network on Independent Living on co-production: http://www.enil.eu/wp-content/uploads/2014/05/FAQ_Co-production.pdf

reflects human rights principles and concerns; and that can be used to assess and monitor the promotion and implementation of human rights"[80].

The use of indicators could be of special use in the context of progressive realization of economic, social and cultural rights when decision-makers are in the position to decide on different policy approaches and public budget expenditures. In the context of scarce resources and limited public budget human rights indicators could help to provide insight in which measures to invest the funds so to advance the compliance with human rights. That is why this section aims to reflect on the **possible specific indicators for the realization of the right to live independently and be included in the community especially to be used with regards of planning the investment of funds in the transition from institutional to community-based care and the evaluation of usage of funds and the outcomes it achieved**. Such consistent use of comprehensive indicators which include both quantitative and qualitative ones would contribute to the prevention of using the funds for the wrong purposes which are not guaranteeing better outcomes and quality of life for end beneficiaries – persons with disabilities and their families. Indicators help to translate human rights norms into policy measures and render the human rights more "tangible and operational"[81].

The obligation to respect, protect and fulfill contain the "obligations of conduct and obligations of results for duty-bearers", where the obligations of conduct refer to specifically designed actions calculated to realize certain rights and obligations of results relates to the state of implementation itself, to achieve specific targets which can be measured[82]. In the context of Article 19, an example

[80] 'Human Rights Indicators: A Guide to Measurement and Implementation' (UN Office of High Commissioner for Human Rights 2012) HR/PUB/12/5. p.16, para.1
[81] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80). p.2, para.3
[82] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80).p.13, para.1

for the obligation of conduct would be "to ensure that public or private funds are not spent on maintaining, renovating, establishing, building existing and new institutions in any form of institutionalization"[83] as part of the obligation to respect. On the other hand, the example of the obligation of results in this context would relate to the specific target such as the reduction of the rate of institutionalization[84]. The types of the indicators are stemming from these types of the obligations of the States Parties and include structural, process and outcome indicators as suggested by UN Office of High Commissioner for Human Rights[85]. The indicators can also be quantitative and qualitative ones where former refer to the type of indicators whose data can be expressed in a numerical way with figures and collected through the statistical system and latter to the indicators which include narrative descriptions of the data[86].

This section aims to explore the indicators that could be used to assess the efficiency and CRPD compliance of financial investments in the process of deinstitutionalization including through international assistance. The indicators could be of great use to donor agencies in order to plan and prioritizes the investments and evaluate their use and outcomes. The relevance becomes visible and tangible if having in mind the events of misuse of EU funds through the European Structural Funds resulting in the continuation of isolation and segregation of persons with disabilities[87] which is in the focus of this research. The consistent use of human right indicators would help to guide the use of any funds for the purpose of implementation of Article 19. However, the data for good and reliable indicators is not always easy to obtain, especially having in mind that the qualitative

[83] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 51

[84] Rate of institutionalization is calculated as number of residents per 100.000 population. See: Jim Mansell and others (n 12).p.32

[85] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80).

[86] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80).p.16, para.4

[87] Camilla Parker, 'Wasted Time, Wasted Money, Wasted Lives, a Wasted Opportunity?' (European Coalition for Community Living 2010).

indicators play prominent role in the assessment of the right to live independently and being included in the community and the evaluation of outcomes related to quality of life of persons with disabilities as such data is hard to obtain through statistics.

How to select the good and reliable indicators which should be populated with the data which would show us what is the extent to which people with disabilities can enjoy independent living in the community? The first task would be to answer what is measured with the indicator. Reflecting upon the obligations of the States Parties which include both obligations of conduct and obligations of results, it implies that apart from the outcomes, the process of implementation is to be measured as well. Still, even when determining what is being measured, the question remains which and how many indicators to choose to measure certain subject. The starting point in this analysis will be the existing work of the international human rights bodies and institutions on indicators of Article 19 realization with an aim to suggest the ones to be used when assessing the investments plans in the process of deinstitutionalization. The indicators should stem from the attributes of the right which is the subject of analysis. Thus, the initial exercise is to decompose the analyzed right to the key attributes which can be derived from the interpretation of the normative content of the right and in this case it is the CRPD Committee's General Comment on Article 19 which is of particular use. Further on the attributes of the right are the basis for deriving the "clusters of indicators" for identified attributes[88]. The indicators should cover both the outcome, that is the state of the realization of the right and the "underlying processes" which are causing the certain outcomes and can be brought into direct correlation with the implementation outcome[89]. The approach in the categorization and selection of the indicators rests on the

[88] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80).p.31
[89] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80).p.34, para.2

identification of structural, process and outcome indicators[90], where the structural indicators reveal the commitment of States to guaranteeing the human rights seen through status of ratification of human rights treaties and existing national legislative framework and institutional mechanisms in place, process indicators reflect policy measures and steps undertaken to fulfill those commitments and outcome indicators tell about the actual state of the realization of the right.

As for the indicators on Article 19, the focus will be on attributes of the right related to the transition from institutional to community-based care.

CRPD Committee has developed a range of indicators for all articles of the CRPD for the purpose of new simplified reporting procedure for States Parties[91]. It is to be used for periodic reports of States Parties on the implementation of CRP. Among the indicators proposed by the Committee for Article 19 all three types of indicators, structural, process and outcome indicators can be found. Its purpose is to guide States Parties' periodic reporting on CRPD implementation making it more clear which data to collect and include in the periodic reports. Taking look at the Committee's proposal of the indicators for reporting, it gets clear that they are broadly formulated. For example, structural indicators suggested in the Guidelines refer to "legislative measures adopted for the recognition of the right… to choose their place of residence and with whom they want to live and to have access to social support and security…"[92] or "deinstitutionalization strategies and plans with baselines, indicators, targets, benchmarks, timeframes and sufficient budget allocations adopted and implemented…"[93]. Process indicators outlined by the Committee include among the

[90] 'Human Rights Indicators: A Guide to Measurement and Implementation' (n 80).p.34, para 3
[91] Committee on the Rights of Persons with Disabilities, 'Guidelines on Periodic Reporting to the Committee on the Rights of Persons with Disabilities, Including under the Simplified Reporting Procedures*' (United Nations 2016) CRPD/C/3.
[92] *Ibid*. para.103
[93] *Ibid.* para. 110

rest the "measures adopted to ensure that all persons with disabilities maintain their autonomy and self-determination in choosing their place of residence and where and with whom they live, are not obliged to live in a particular living arrangement"[94] or "measures adopted to ensure that persons with disabilities regardless of place of residence have access to a range of in-home, residential and other community support services, including personal assistance, which is controlled and managed by them"[95]and "measures adopted to ensure that mainstream community-based services and facilities provided to the general population, including housing, are accessible, affordable, and available…"[96]. Here it gets obvious that the Committee has been following the structure of Article 19 and its 3 elements: choice of the living arrangement, access to disability-specific services and access to services for the general population. Although it is understandable why the indicators are formulated so broadly referring to "measures taken", as the States Parties are given a margin of appreciation to decide on how they will implement the right, especially the positive obligations stemming from it, the impression is that they are not sufficient in number and not clear enough and concrete. This is especially problematic in the context where decision-makers are lacking the understanding what kind of measures are truly CRPD compliant enabling the people with disabilities choice and control. If the recent General Comment on Article 19 helps to mitigate this problem, it is still evident that the list of proposed indicators by the Committee is lacking a quantitative indicators, especially concerning the budgetary allocations, number of residential institutions, number of residents, coverage of users by community-based services and personal assistance, just to name few for example. The list is also lacking more outcome indicators as currently only one is included: "…*Extent to which persons with disabilities, regardless of place of*

[94] *Ibid.* para. 104
[95] *Ibid.* para. 105
[96] *Ibid.* para. 108

residence, perceive that they have sufficient ability to choose by themselves and thereby, have control over important choices regarding their daily life"[97] and that one is difficult to populate with data as it is qualitative and judgement-based one. The outcome indicator such as this one should be disaggregated by age, gender, type and severity of the impairment as certain groups of people with disabilities including people with severe intellectual disabilities can be left behind as the results of the policy measures which fail to address the needs of the people with high support needs.

Therefore, in addition to few structural and process indicators referred above which were formulated by CRPD Committee, the additional indicators proposed by other stakeholders will be taken into account.

The European Union Agency for Fundamental Rights has proposed a set of indicators for Article 19[98] to assess the level of its implementation in the EU Member States relying on the structure-process-outcome approach proposed by OHCHR. This set of indicators is more elaborated and clear and detailed. It decomposed the Right to live independently and being included in the community in the attributes drafting a range of indicators for each attribute. It starts with the indicators related to cross-cutting issues and a principle of participation of persons with disabilities which are having an impact on Article 19 implementation. Those include CRPD accession, the existence of relevant action plans and strategies, DPOs involvement, non-discrimination and reasonable accommodations, quality standards, training and retraining, awareness of support services, monitoring and complaints and redress[99].

[97] *Ibid.* para. 112
[98] European Union Agency for Fundamental Rights, 'Human Rights Indicators on Article 19 of the CRPD'.
[99] European Union Agency for Fundamental Rights (n 98).p.5 - 11

Here the emphasis will be given on the indicators related to the attributes related more directly to a transition from institutional to community-based care. The three elements of Article 19 are further broken down into the attributes.

The element of choice of the living arrangements has indicators related to living arrangements, institutions and involvement in deciding where to live[100]. Indicators that bear particular relevance for the assessment of the success of the process of deinstitutionalization[101] can be the following:

- Existence of any legal provisions that recognize the right to choose the place of residence and existence of any legal restrictions of this right including the ones linked to the age or impairment (structural indicator);
- Allocated budget for providing the living arrangements in the community as compared to the budget allocated for residential care (process indicator);
- Proportion of persons with disabilities living in private households and social housing disaggregated by age, gender, impairment type and the level of support needs as compared to a proportion of people without disabilities (outcome indicator);
- Legal provisions allowing for involuntary admissions to the institutions on the basis of impairment (structural indicator);
- Number of people involuntarily placed in the institutions (outcome indicator);
- Commitment of the State to shut down long-stay residential institutions, stop new admissions to long-stay residential institutions and not to build new long-stay residential

[100] European Union Agency for Fundamental Rights (n 98). p.12-13

[101] The indicators rely on the proposed set of indicators by EU Fundamental Rights Agency and Council of Europoe's Commissioner for human rights and include the selection of adapter indicators to better fit the purpose of this research.

institutions reflected in the national strategy for deinstitutionalization with clear and concrete targets and benchmarks and the timeline (structural indicator);

- Allocated budget to support persons with disabilities to move out of the institution to a living arrangement of their choosing (process indicator);
- Number of people living in the long-stay residential institutions and number of places available disaggregated by age, gender, type and severity of the impairment (outcome indicator);
- The existence of legal obligation to consult with persons with disabilities in decisions on choice of the living arrangement including the provision of support in decision-making (structural indicator).[102]

The element of disability-specific services outlines the indicators related to access to support services, their transferability, eligibility for usage of services, users' control over the services, adaptations of places of residence and informal types of support services[103].

Possible indicators to be used in order to assess if the measures taken to establish the community alternatives are truly conducive to independent living and community inclusion can be the following:

- The existence of legal provisions setting out the right to access the range of community support services for independent living including the personal assistance with the specification of scope of the services (structural indicator);

[102] European Union Agency for Fundamental Rights (n 98).p.12 - 13
[103] European Union Agency for Fundamental Rights (n 98).p.14-21

- The extent to which community-based services are enabling the use of other services in the community intended for general population "rather than having them brought into the living setting and provided in a collective manner"[104];
- Allocated budget for community support services conducive to independent living (process indicator);
- Number of users of particular community support services disaggregated by age, gender, type and severity of the impairment (outcome indicator);
- Existence of legal provisions setting out the right to receive personal budgets (structural indicator);
- Budget allocated for personal budgets (process indicator);
- Number of recipients of personal budgets (outcome indicator);
- Legal provisions which define eligibility criteria for community support services and personal budgets (structural indicator);
- Legal provisions which enable individuals with disabilities or families of children with disabilities to express will and preferences and choose the type of support service provided, extent of support provided, provider of support service and changes in the support (structural indicator);
- Procedures for provisions of support services which include self-assessment (process indicator);
- Legal recognition of informal types of community support services (structural indicator);
- Budget allocated for informal types of community support services (process indicator).[105]

[104] Thomas Hammarberg, 'The Right of People with Disabilities to Live Independently and Be Included in the Community' (Council of Europe Commissioner for Human Rights 2012).p.46, point 2
[105] European Union Agency for Fundamental Rights (n 98).p.14 - 21

Outlined set of indicators above can be helpful to assess the institutional framework for the transition from institutional to community-based care but also to assess the steps and the pace of the countries towards development the alternatives in the community. It is of special importance to consider the use of indicators related to procedures of service provision and the involvement of persons with disabilities in all phases of service provision in order to assess the extent to which persons with disabilities have choice and control over the support they get. The Commissioner for Human Rights of Council of Europe has proposed a set of indicators for independent living and following ones can be helpful to distinguish between community-based services conducive to independent living and the ones which are just replicating institutional culture:

- The extent to which individuals are provided with the opportunity to "recruit and manage staff providing personal assistance, determine the activities for which support is needed, determine how the budget for services and supports will be used, choose types of equipment and adaptations to best meet their needs"[106];
- Type of inputs that users can provide in the process of service provision[107];
- Percentage of service providers led by persons with disabilities[108];
- The average number of individuals residing "together in settings presented as community-based ones for which support is provided"[109];
- The proportion of community-based settings located "on the grounds of an institution, within a neighbourhood, on the outskirts of town, in a remote part of the countryside"[110].

[106] Hammarberg (n 104).p.48, point 13
[107] Hammarberg (n 104).p.48, point 14
[108] Hammarberg (n 104).p.48, point 15
[109] Hammarberg (n 104).p.52, point 25
[110] Hammarberg (n 104).p.52, point 26

If the data is collected using this set of indicators it would help to avoid replication of institutional culture under the guise of community living and to make clear distinctions between community-based services and forms of the support which tend to segregate and isolate persons with disabilities as it will be seen in the following analysis.

Finally, there is a set of indicators pertaining to the element of services for general population but they will not be explored further here as the goal of this analysis is to find suitable indicators which would inform the efficiency of the investments made to develop the alternatives in the community in terms of disability-specific community-based services in the process of deinstitutionalization and to prevent that the funds are used for the forms of care which continue to isolate and segregate people with disabilities.

3 The European Union as a party to the UN Convention on the Rights of Persons with Disabilities

The European Union played a prominent role in the process of negotiations of the text of United Nations Convention on the Rights of Persons with Disabilities which had taken place from 2001 – 2006. It was for the first time that the EU was taking part in the process of negotiations of one international human rights treaty. The European Commission was authorized actor to take part in the negotiations on behalf of the European Community representing the stance of the EU and coordinating to the largest extent possible the joint position of EU Member States on the subjects of negotiations. It found a legal basis to do so in the ex-Article 13 of EC (today's Article 19 of Treaty on the functioning of European Union) which allows taking "appropriate actions to combat discrimination based on…disability…"[111] and in Article 95 of TEC (today's Article 114 of TFEU)[112] on internal market implying that the EU's obligations reach into other areas apart from non-discrimination. However, the EU had been considerably changing its positions in CRPD negotiations and the perceptions of the need for it and the way how it should look like. In the very beginning since Mexico has proposed a disability-specific human rights treaty, the stance of the EU was that instead of elaboration of group-specific treaties, the implementation of the existing International Bill of Rights should be strengthened which should be enough to protect and guarantee the rights of persons with disabilities[113]. When it became evident that there is a political will in the international community to draft a disability-specific and legally binding human rights treaty, and when the Ad Hoc Committee was formed to draft the text of the CRPD, the EU has

[111] The Treaty on the Functioning of the European Union, Official Journal of the European Union, C 326/47 (2012). Article 19 (ex Article 13 TEC), para.1
[112] *Ibid.* Article 114 (ex Article 95 TEC)
[113] Gráinne de Búrca, 'Experimentalism and the Limits of Uploading: The EU and the UN Disability Convention', *Extending Experimentalist Governance?* (Oxford University Press 2015) p.7, para. 2

decided to take part in the work of Ad Hoc Committee and to influence the outcome seeing a chance to become a party for the human rights treaty for the first time. At the beginning of the Committee's work, the EU was pushing for a treaty whose main purpose would be to ensure non-discrimination in relation to enjoyment of already existing sets of rights by persons with disabilities, advocating for usage of its own model of protection of discrimination from EU anti-discrimination law in this new international treaty[114]. That view was not pursued and instead, the new treaty used hybrid approach having both the equality dimension and number of substantive rights of persons with disabilities clarifying the measures which States Parties should undertake so to guarantee the equal enjoyment of human rights for persons with disabilities. That meant that the legal effects of the CRPD extend way beyond the non-discrimination and that the EU as the regional integration organization was supposed to consider the implications for its own legal system if acceding the CRPD. The intention of the EU to accede the CRPD was already clear since its involvement in the process of negotiations. As a result of the EU's involvement in the process of negotiations specific provision was made in the CRPD in Articles 43[115] and 44[116] with the specific reference to "regional integration organizations" aiming directly at the EU and its accession.

The possibility of the EU as regional integration organization to accede international treaties had existed and was already used respecting the principle of conferral of competences. However, the accession to the CRPD was the first accession of the EU to one international human rights treaty.

[114] Búrca (n 113).p.8, para.1
[115] Article 43, UNCRPD
[116] Article 44, UNCRPD

The European Union has signed the CRPD in 2007 and concluded it in 2010 whilst it entered into force in January 2011[117]. The CRPD has the status of "mixed agreement" in EU law, meaning that the CRPD is ratified or confirmed both by the EU Member States[118] and the EU itself. Such status implies that due consideration should be given to careful delineation of the competences of the EU and its Member States as the CRPD creates obligations for the EU to the extent of transferred competences by its Member States in the areas covered by the CRPD[119]. It requires a detailed analysis of each the CRPD provision and their scopes so to identify which competencies of EU and its Member States are engaged. As the CRPD incorporates number of substantive rights, each single right and respective provision has to be considered in order to infer if the EU has an exclusive competence in certain area, the Member States have competence, the EU is sharing the competence with its Member States or EU actions are only supporting and supplementing the actions of the Member States[120]. The areas in which the EU has exclusive competence[121] are quite limited and less relevant for the right to live independently and being included in the community. The shared competences are defined in Article 4 of TFEU and among the rest include the social policy and economic, social and territorial cohesion[122] which seemingly bear more relevance for the right to live independently. In the case of shared competences, "the Member States remain free to act collectively, individually or jointly with the Union to fulfill the obligations under international agreements"[123]. That is why here the line between what is the responsibility of the

[117] Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities (2010/48/EC), 0J L 303/16 (2010).
[118] Up to date, all EU Member States have signed and ratified the CRPD except Republic of Ireland which has signed it but still has not ratified it.
[119] Article 44, UNCRPD. para.1
[120] Lisa Waddington, 'European Union and the United Nations Convention on the Rights of Persons with Disabilities: A Story of Exclusive and Shared Competences, The [Article]' [2011] Maastricht Journal of European and Comparative Law 431. p.9, para. 3
[121] TFEU (n 103), Article 3, para.1
[122] TFEU (n 103), Article 4, para.2
[123] Waddington (n 120).p.9, para.4

EU and what is the responsibility of Member States in relation to obligations from CRPD Article 19 is more blurred and this will be the subject of further analysis. Generally, if the EU has not acted in the field of shared competences, the responsibility to implement CRPD provisions in that particular area rests with the EU Member States[124]. Prior to conclusion of the CRPD, the EU had to adopt the Code of Conduct which regulated the representation of the European Community in the meetings and bodies created by the CRPD and more importantly for this discussion, dealt with the arrangements on CRPD implementation and monitoring between the EU and its Member States and coordination of common positions[125]. The document clarified that on the matters of shared competences the EU and its Member States will strive to "elaborate common positions"[126] and it listed what those areas are[127]. Interesting to note is that at that time there was no mention of economic and social cohesion policy or social policy which are now part of the shared competences as defined in Article 4 (2) which as will be argued here have an impact for independent living of people with disabilities.

Article 44 on Regional integration organization envisages that: "Such organizations shall declare, in their instruments of formal confirmation or accession, the extent of their competence with respect to matters governed by the present Convention"[128]. Thus, the Council's decision to conclude the CRPD was accompanied with the Declaration of Competence[129] listing the sources of EU law which contained a reference to disability with a view to identifying clearly the EU's

[124] Waddington (n 120).p.19, para.1
[125] Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities, Official Journal of the European Union. 2010/C 340/08 (2010)
[126] *Ibid*. Article 5, para.1
[127] *Ibid*. Article 5 (b)
[128] *Ibid.*
[129] Council Decision 2010/48/EC, 0J L 303/16 (2010), Annex II

competences for CRPD implementation[130]. It should be borne in mind that it refers to the competences transferred to the EU by its Member States through the former founding treaty in the moment of conclusion. At that moment the EU had conducted internal, subjective review of the legislative acts that it perceived as having an impact on the implementation of CRPD provisions. It enumerated 48 legal acts out which 9 acts pertaining to the field of independent living and social inclusion and work and employment[131]. None of the acts listed concerns the transition from institutional to community-based care as evidently the EU at that time did not consider the regulations of its funding mechanisms as having an impact on the independent living of persons with disabilities. Independent review of EU's legislation, made shortly before the Declaration of Competencies found 102 legal sources in EU law as having the implications for the rights of people with disabilities[132] which might have been an indicator of lack of understanding of CRPD breadth by the European Commission. This independent review is conducted annually on a regular basis from 2008 by Academic Network of European Disability Experts and the most recent review has found more than 200 relevant legal sources in EU law[133]. It also includes the regulations of EU's financing instruments[134] with the specific reference to those of special significance for a transition from institutional to community-based care[135]. Not only that the Declaration of Competences omits the relevant acts it fails to elucidate how the competences are engaged and in relation to which obligations of the CRPD making it seem of little use for detailed delineation of competences between the EU and its Member States.

[130] *Ibid.* Appendix – Community acts which refer to matters governed by the Convention
[131] Council Decision 2010/48/EC, 0J L 303/16 (2010), Appendix, p.2
[132] Academic Network of European Disability Experts. 'Annotated review of European legislation which makes a reference to disability', (2009)
[133] Janina Arsenjeva, 'Annotated Review of European Union Law and Policy with Reference to Disability' (Academic Network of European Disability Experts 2017). p.108, para.1
[134] *Ibid*. p.96 - 99
[135] *Ibid.* p.100 – 101, documents 10.02 and 10.03

3.1 The effects of the CRPD in EU law

The matter of delineation of competences and elucidation of how the CRPD engages those competences and which obligations it creates for the EU especially under Article 19 is the important one as the CRPD has become an integral part of EU law. The EU as supranational political organization has become a prominent human rights actor both internally and externally with the legal, political and financial influence both in relation to its Member States and third countries.

The legal effect of the CRPD comes from Article 216 (2) of TFEU which states that the "agreements concluded by the Union are binding upon the institutions of the Union and on its Member States"[136]. I the case of *Z. v. A Government department and The Board of management of a community school*[137] the European Court of Justice examined the issue if the CRPD can have a direct effect on EU law. The direct effect of the international treaty would allow the private party to submit the claim to the national court on the incompatibility of the EU legal act or the act of a Member State if implementing EU law with the provisions of that treaty, in this case, the CRPD. The ECJ had confirmed that the "validity of an act of the European Union may be affected by the fact that it is incompatible with rules of international law"[138]. However, the assessment of the incompatibility with the provisions of an international treaty can take place if the provision and the obligations emanating from it are "unconditional and sufficiently precise"[139] so that they do

[136] TFEU (n 103), Article 216, para.2
[137] *Z v A Government department and The Board of management of a community school,* [2014] Court of Justice of the European Union C- 363/12.
[138] *Ibid.* para.84
[139] *Ibid.* para. 85

not require "adoption of any subsequent measures"[140]. The Court in its judgment has seen the CRPD as "programmatic" treaty which requires the transposition to the legal order of the Contracting Party by means of introduction of subsequent measures. Therefore, according to Court's interpretation, **the CRPD does not include the obligations which are "unconditional and sufficiently precise" that could produce a direct effect**. It concluded that with no direct effect the validity of EU's legal act cannot be challenged on the basis of non-compliance with the CRPD but the act has to be "interpreted in a manner that is consistent with that Convention"[141]. Thus, the **CRPD prevails over EU secondary law only in so far as the secondary law has to be interpreted in line with it**[142]. This **finding of the ECJ is, the least to say, arguable** as the CRPD as a hybrid human rights treaty contain both civil and political and economic, social and cultural rights and different types of obligations including both positive and negative ones and those having an immediate effect. CRPD provisions should be dissected in terms of exploring the concrete provision and its multiple obligations. This is of special relevance in the context of the right to live independently and being included in the community and recent General Comment which elaborates different obligations of States Parties and it will be further explored in the next section of this research.

The confirmation of the CRPD by the EU has led in some areas to a visible shift of perception of disability and a stronger disability policy of the EU as well as the mainstreaming of disability into EU legislation. The impact of CRPD confirmation to a paradigm shift in EU law is visible for example in the judgments of the European Court of Justice related to the protection of discrimination in employment if the Court's stance is compared in the cases before and after CRPD

[140] *Ibid.* para.86
[141] *Ibid.* para.91(2)
[142] *Ibid*. para. 72

confirmation. In the judgment on Chacon Navas case,[143] the ECJ has used quite a narrow definition of disability excluding the long-term illness from disability and consequently the protection of discrimination on the basis of disability. After CRPD confirmation it seems that the ECJ has made the shift towards a social model of disability widening the definition. In the case Ring and Wenge vs. Pro Display A/S[144] which came after the EU has confirmed the CRPD, the European Court of Justice in its judgement made a specific reference to the definition of disability as a social construct from the CRPD[145] recognizing that the people having a long-term illness can benefit of protection of discrimination on the basis of disability if the illness interacts with societal barriers hindering their participation in professional life[146]. The willingness of the ECJ to interpret the existing secondary EU legislation in the manner consistent with the CRPD is encouraging and promising for challenging the secondary legal acts by individuals as it provides for the indirect path for using the CRPD and its norms if it cannot be used directly.

The commitment of the EU for implementation of the CRPD is also visible in its elaboration and adoption of the European Disability Strategy 2010 - 2020[147] and its response to requirements of CRPD Article 33 related to designated focal point for CRPD implementation[148] and independent monitoring mechanisms[149].

[143] *Chacón Navas v Eurest Colectividades* [2006] Court of Justice of the European Union C-13/05.
[144] *Ring and Wenge vs Pro Display A/S/* [2013] Court of Justice of the European Union C-335/11.
[145] *Ibid.* para.37
[146] *Ibid*. para. 41
[147] COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010) 636 final, European Commision, (15 November 2010).
[148] Article 33, CRPD.para.1
[149] *Ibid*.para.2

The introduction of the focal point is the novelty in the human rights treaty and serves to ensure coordinated effort within the governments for CRPD implementation and to mainstream disability issues across different government domains. Designated focal point in the EU is the European Commission[150] and its High-Level Group on Disability[151].

In the next section, the relationship between EU law and the right to live independently and being included in the community will be explored so to identify the actions which the EU is doing or could do in order to advance and enforce this right within its existing framework for CRPD implementation.

3.2. EU law and the right to live independently and being included in the community

Until Amsterdam Treaty no EU founding treaty contained a specific reference to disability[152]. The first explicit mention of disability was made in the Amsterdam Treaty in the provision on discrimination which included the ground of disability which now can be found in Article 19 of TFEU[153]. It is exactly on this basis and according to the competences conferred to the EU by its Member States that the EU has played the most visible role in the disability rights protection in the field of anti-discrimination. Its landmark Framework Employment Equality Directive 2000/78 on the prohibition of discrimination in the field of employment including on the basis of disability denoted very progressive approach to disability discrimination in terms of recognition of denial of

[150] Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities, Official Journal of the European Union. 2010/C 340/08 (2010). Article 11 (a)
[151] See more at: http://ec.europa.eu/transparency/regexpert/index.cfm?do=groupDetail.groupDetail&groupID=1259
[152] Waddington Lisa. 'From Rome to Nice in a Wheelchair, The Development of a European Disability Policy'. (Europa Law Publishing, 2006)
[153] TFEU (n 103), Article 19

reasonable accommodation as a form of discrimination[154]. Although EU's anti-discrimination law is limited to the field of employment, the EU had been advocating for incorporation of its own model of antidiscrimination in the CRPD across all field beyond employment, during the negotiations of the CRPD and was successful in this effort as the CRPD incorporated the definition of discrimination inclusive of denial of reasonable accommodation as a discrimination form. For the time being, the EU has exercised its shared competence to combat discrimination only in the field of employment which bears relevance for the inclusion of people with disabilities in community life. With the introduction of the Lisbon Treaty, new references to disability have been made. Article 10 of TFEU makes a mainstreaming reference to the aim of combating discrimination "in defining and implementing its policies and activities"[155] opening the door for the EU to exercise the competence in this area beyond employment. The Lisbon Treaty has also changed the status of the EU Charter of Fundamental Rights[156] affording it the "same legal value as the Treaties"[157]. The Charter addresses disability rights in two articles: Article 21 on non-discrimination[158] and Article 26 on the integration of persons with disabilities[159]. Article 26 bears special relevance for the independent and community living of people with disabilities as it proclaims the following:

[154] Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation, Official Journal of the European Union, L 303 , 02/12/2000 (27 November 2000). Article 5
[155] TFEU (n 103), Article 10
[156] Charter of Fundamental Rights of the European Union, Official Journal of the European Union, 2000/C 364/01 (2000).
[157] The Treaty on European Union, Official Journal of the European Union, C 115/13 (2008).
[158] Charter of Fundamental Rights of the European Union (n 156), Article 21
[159] *Ibid.,* Article 26

"The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community."[160]

The scope of the Charter covers the actions of the EU institutions and bodies and those of EU Member States when they are implementing EU law[161]. This implies that the legal effects of the Charter and its correlation with the CRPD should be explored in order to identify the actions of the EU and its Member States which are having an impact on the right to live independently and being included in the community and to determine whether those amount to the implementation of EU law.

The ECJ approached the examination of the direct effect of Article 26 of the Charter in the case *Wolfgang Glatzel v. Freistaat Bayern*[162] but it did not deal with the normative content of the article. However, such exercise could be potentially useful as it should read into Article 26 at least some of the obligations from Article 19 of the CRPD. What the Court did in the aforementioned case is that it confirmed the impact of Article 26 on the secondary EU legislation in terms of its interpretation in accordance **with the principles contained in Article 26**[163]. It also made clear that the responsibility of the EU to "recognize and respect"[164] does not mean that the EU has the obligation to introduce any measures in relation to this right. This vision implies that only negative duties emanate from the wording of Article 26 and more problematically it sees Article 26 as a principle rather than a right[165] which does not allow an individual to claim it and serves merely for

[160] *Ibid.*
[161] *Ibid.,* Article 51, para.1
[162] *Wolfgang Glatzel v Freistaat Bayern* [2014] Court of Justice of the European Union C- 356/12.
[163] *Ibid*. para.74
[164] Charter of Fundamental Rights of the European Union (n 156), Article 16
[165] Israel Butler, 'COMMUNITY, NOT CONFINEMENT The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to Live in the Community' (Open Society Foundations 2015), p.32, para.3

the interpretation of other EU's legal acts. The Court thus concluded that Article 26 does not bear direct effect that would enable individual to use it and that in order to make it fully effective "it must be given more specific expression in the European Union or national law"[166]. If the Court in the future approaches the examination of the content of Article 26 of the Charter changing its perception towards the right and even if it considers that Article 26 contains only negative obligations, it could bring it into direct link with the CRPD and the negative obligations from CRPD Article 19, including the prohibition of investments in the institutional care[167].

The power of Charter and its Article 26 is perhaps more visible and less uncertain in its usage for legality assessment and interpretation of EU legal acts and the acts of Member States when they are implementing EU law but here comes the issue of bringing the particular legal act under the scope of Article 26 in terms of determining if the general purpose of the legal act pursues the principle contained in Article 26. This issue will be elaborated more in the section 3.2.2 on enforcement mechanisms.

3.2.1 The role of EU financing instruments

The EU is sharing the competences with its Member States on the matters related to the right to live independently and being included in the community. The main way how the EU is contributing to the transition from institutional to community-based care, which is the subject of this analysis, is through its financing instruments which are supposed to help countries to bridge to cost-related barriers in this field. The potential of Structural Funds lays in the financing programs which aim

[166] *Wolfgang Glatzel v. Freistaat Bayern* , C-356/12, para. 78

[167] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para.49

to develop community-based services, to train staff working in those services or to provide technical support for systemic reforms in the country necessary to make independent living a reality[168]. Those financing instruments in relation to EU Member States are commonly referred as European Structural Funds (ESI Funds) which consist of five funding programs: the European Regional Development Fund (ERDF), the European Social Fund (ESF), the Cohesion Fund, the European Agricultural Fund for Rural Development (EAFRD) and the European Maritime and Fisheries Fund (EMFF)[169]. The key problem in the relation of usage of these funds which adversely affects the right of persons with disabilities to live independently in the community is the allocation of these funds for national projects which actually perpetuate segregation and isolation from the communities.

The problem was identified through the monitoring efforts of civil society including Disabled People's Organizations which have published numerous reports on the subject of inappropriate spending of Structural Funds. These findings indicate that in the budgeting period 2007 – 2013 six EU Member States, notably Bulgaria, Hungary, Romania, Slovakia, Lithuania, and Latvia, have used around 150 million EUR as the investments in the residential care facilities[170]. The same report identifies the key factors which had enabled inappropriate usage of Structural Funds emphasizing the "lack of governments' vision for the transition to community living; focus on poor physical conditions, resulting in the renovation of institutions; lack of co-ordination of different EU funds and other systemic barriers to community living"[171].

[168] Camilla Parker and Ines Bulić, 'Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living' (European Network on Independent Living – European Coalition for Community Living 2013).p.4, para.2
[169] Arsenjeva (n 133).p.97, para.2
[170] Parker and Bulić (n 168).p.11 - 12
[171] Parker and Bulić (n 168).p.7, para.3

These funding programs, in the current budgeting period are regulated by the General Regulation which outlines the purposes of the EU Structural Funds to strengthen the economic, territorial and social cohesion across the EU towards smart, sustainable and inclusive growth and to reduce the regional disparities and inequalities under the EU Cohesion Policy as well as the shared management system in place between the European Commission and Member States. It is commonly referred as Common Provision Regulation (CPR)[172] and includes a number of references to disability. Its Article 7 includes non-discrimination provision in the context of preparation and implementation of the programs makes a mention of accessibility that should be taken into account in planning and implementation of funded programs[173]. Accessibility is further elaborated among the horizontal principles requesting that "all products, goods, services and infrastructures" resulting from ESF are accessible[174]. CPR also sets out 11 thematic objectives which serve as a basis for specific priorities of each of the funds. Thematic objective 9 "promoting social inclusion, combating poverty and any discrimination"[175] is especially relevant for the transition from institutional to community-based care. The key novelty introduced with the CPR for current budgeting period 2014 – 2020 which had not been there before in the regulations for previous budgeting period 2007 - 2013[176] are "ex-ante conditionalities"[177] that Member States have to fulfill before using the ESF. These ex-ante conditionalities as "pre-defined and critical factors"[178] for the achievement of the objectives are important for the reason they represent the safeguards which are supposed to ensure that the ESI Funds is used in accordance with EU law

[172] REGULATION (EU) No 1303/2013 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL, Offical Journal of the European Union, L 347/320 (17th December 2013)
[173] *Ibid.* Article 7 (2)
[174] *Ibid.* Annex I, section 5.4
[175] *Ibid.* Article 9 (1)
[176] COUNCIL REGULATION (EC) No 1083/2006, Official Journal of the European Union L 210/25, (11 July 2006)
[177] REGULATION (EU) No 1303/2013 (n 164), Annex XI
[178] *Ibid.* Article 2 (33)

and the EU's policy objectives. The first group of ex-ante conditionalities is set up against the thematic objectives and investment priorities of each of the five funds and they also include the set of criteria for fulfillment for each conditionality. Under thematic objective 9 on social inclusion and combating the discrimination the ex-ante conditionalities include the existence of "national strategic policy framework for poverty reduction"[179] which as a fulfillment criteria include "measures for the shift from institutional to community-based care"[180]. It is set out under the investment priorities for the European Social Fund (ESF) and the European Regional Development Fund (ERDF) which is explicitly mentioning "the transition from institutional to community-based services"[181]. Further on, the conditionality 9.3 on the existence of "national or regional strategic policy framework for health"[182] is placed under the investment priorities for ESF and ERDF where ESF's investment priority is "enhancing the access to affordable, sustainable and high-quality services, including health care and social services of general interest"[183] and ERDF's again makes explicit mention of "the transition from institutional to community-based services"[184]. This investment priority with belonging ex-ante conditionalities are undoubtedly positioning the European Social Fund and the European Regional Development Fund as principal sources of EU funding for the Member States for development of community-based alternatives. These conditionalities with belonging fulfillment criteria also indicate that the EU is expecting to see the strategic orientation and commitment of the Member States towards the transition from institutional to community-based care if wishing to use the funds for these purposes. In addition to the first group of ex-ante conditionalities, there is the second group of general ex-ante

[179] *Ibid.* Annex XI, part I, point 9.1
[180] *Ibid.*
[181] *Ibid.*
[182] *Ibid.* Annex XI, part I, point 9.3
[183] *Ibid.*
[184] *Ibid.*

conditionalities which are cutting across all objectives and thematic priorities and the third one of them is on disability. This one assumes "the existence of an administrative capacity for the implementation and application of the CRPD in the field of ESI Funds"[185]. The belonging criteria for fulfillment refer to arrangements in place to consult with people with disabilities and their organizations in both the preparatory and implementation phases, the arrangements for the provision of training for staff members of the authority appointed to manage and control ESI Funds and the arrangements in place to monitor accessibility compliance[186]. It is notable here how confirmation of CRPD by the EU has to influence EU secondary law through the introduction of specific measurements and the mainstreaming of disability.

In addition to CPR as a general regulation of ESI Funds, there are specific regulations pertaining to afore listed component funds which are also making specific references to transition from institutional to community-based care.

ERDF Regulation concerns the fund which is tasked to "reinforce economic, social and territorial cohesion" and reduce regional imbalances.[187] It includes as an investment priority "promoting social inclusion, combating poverty and any discrimination" which mentions the investments in health and social infrastructure for the transition from institutional to community-based services[188]. In its initial report on CRPD implementation the European Commission has stated that ERDF should not be used for "building new residential institutions or the renovation and modernisation of existing ones" except in the cases when it can be justified if the interventions respond to "life-

[185] *Ibid.* Annex XI, part II, point 3
[186] *Ibid.*
[187] REGULATION (EU) No 1303/2013 (n 164), Article 2
[188] *Ibid.* Article 5 (9) (a)

threatening risks to residents" due to poor state of the infrastructure and even then such measures have to be part of the broader national strategy for deinstitutionalization[189].

ESF Regulation expressing the aims of the European Social Fund also directed towards strengthening the economic, social and territorial cohesion and addressing the social exclusion, discrimination and inequalities of marginalized communities make also an explicit mention of the transition from institutional to community-based care[190].

The potential of ESI Funds for helping countries in the process of deinstitutionalization is also recognized in the soft-law instruments of the EU in particular the European Disability Strategy 2010-2020 which recognizes that in the area of participation the Commission will work to "**promote** the transition from institutional to community-based care by: using Structural Funds and the Rural Development Fund to support the development of community-based services"[191] and will support national actions to "achieve the transition from institutional to community-based care, including use of Structural Funds and the Rural Development Fund for training human resources and adapting social infrastructure, developing personal assistance funding schemes, promoting sound working conditions for professional carers and support for families and informal carers"[192]. Wording "to promote" can be interpreted that the European Union does not have an obligation to undertake positive measures on CRPD Article 19 as discussed above but it still expresses the commitment for it in so far as it supports the Member States to do so whose competence it is.

[189] European Union, 'Initial Report of States Parties Due in 2012' (2014) CRPD/C/EU/1. para. 99
[190] REGULATION (EU) No 1304/2013 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL, Official Journal of the European Union, L 347/470 (17 December 2013), Article 8, para. 1
[191] European Disability Strategy (n 139), p.6, para.1
[192] *Ibid*. para.3

Although the introduction of ex-ante conditionalities and mainstreaming of disability in the general and specific regulations of ESI Funds certainly represents the step forward as compared with the previous budgeting period, it does not resolve the issue if the appropriate mechanisms to sanction the Member States when failing to comply, are not in place. These mechanisms will be discussed further in the next section.

The specific challenge in addressing the issue is the monitoring of usage of Structural Funds and spotting the inappropriate use of the funds. The projects which end up with the funds being allocated to the residential care institutions are not always easy to spot. The projects can envisage outright investments in the institutions in their objectives due to poor physical conditions of the infrastructure, planning to renovate or even extend the capacities of the institutions[193]. They can also include the objectives of development of community-based services which seemingly advance the right of people with disabilities to independent living and end up with creating smaller facilities with the same institutional culture[194]. Finally, the investments could also be directed to other purposes and still end up as financial support to the residential institutions. This has been noticed in the projects related to accessibility or improving the energy efficiency[195].

In relation to countries in accession to EU Membership, the EU is providing financial assistance through the Instrument for Pre-Accession Assistance (IPA II) as part of the EU's enlargement policy. The Regulation of IPA II is stipulating the specific objectives of the funding among which"

[193] Parker and Bulić (n 168).p.11-12
[194] Parker and Bulić (n 168).p.7, para.1
[195] Parker and Bulić (n 168).p.12, para. 3

"*promotion of social and economic inclusion, in particular of minorities and vulnerable groups, including persons with disabilities"*[196].

This financing instrument covers following countries: Albania, Bosnia and Herzegovina, Kosovo, the former Yugoslav Republic of Macedonia, Montenegro, Serbia, and Turkey.

Following the analogy with ESI Funds, IPA Funds should also not be used to support the residential institutions. Its potential for development of community-based care will be assessed in relation to Serbia in Chapter 4. It is worth mentioning that the usage of IPA funds does not entail fulfillment of any ex-ante conditionalities in relation to transition from institutional to community-based care. However, the thematic priorities for the assistance in relation to the objective on social inclusion include "enhancing access to affordable, sustainable and high quality services, such as healthcare and social services of general interest, including through the modernisation of social protection systems"[197] which can serve as a basis for funding the initiatives related to deinstitutionalization.

If IPA is to be regarded as sort of a development aid than the EU is under the legal obligation from the CRPD to render its development aid programs "inclusive of and accessible to 'persons with disabilities" according to Article 32[198]. IPA programs should be symmetrical and aligned with the ESI Funds[199] in terms of the safeguards for monitoring of its usage, corrective actions of the

[196] REGULATION (EU) No 231/2014 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL establishing an Instrument for Pre-accession Assistance (IPA II), Official Journal of the European Union, L 77/11, (11th March 2014), Article 2 (b) (iv)

[197] REGULATION (EU) No 231/2014 (n 188), Annex II (f)

[198] Article 32, UNCRPD

[199] Gerard Quinn and Suzanne Doyle, 'Getting a Life – Living Independently and Being Included in the Community. A Legal Study of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities.' (Office of the United Nations High Commissioner for Human Rights Regional Office for Europe 2012) p.61, para.6

European Commission and involvement of civil society in planning and implementation phases and more detailed analysis will ensue in Chapter 4.

3.2.2 EU mechanisms to enforce the right to live independently and being included in the community in the EU Member States

The changes that the EU has introduced in the set of regulations of ESI Funds placing the social inclusion of people with disabilities and transition from institutional to community-based care as the thematic objectives and investment priorities under the European Social Fund and the European Regional Development Fund as well as the recognition of the role of the ESI Funds in the process of deinstitutionalization given in the European Disability Strategy unequivocally represent positive developments. It highlights the issue and gives it a visibility in EU law at the same time trying to provide guidance for the EU Member States to reach the positive outcomes in the sense of making a community living a reality for people with disabilities. However, in order to assess the effectiveness of these measures, their enforcement mechanisms have to be explored further as well as the mechanisms in place to monitor and evaluate the usage of ESI funds in line with its priorities and the possible available remedies which can be used if the funds are not spent respecting EU law and CRPD principles.

The ESI funds are regulated and operated on the basis of the principle of shared management between the European Commission and the EU Member States. In the first place the European Commission has the role to review and approve the Operational Programmes of the Member States which state the plans and investment priorities for particular country and has to ensure that those are compliant with EU law and the CRPD as the CRPD is an integral part of EU legal order having the supremacy over EU secondary law. While recognizing this responsibility in its initial report on

CRPD implementation, the European Commission stated that the Member States are the ones responsible for implementation of OPs and selected projects[200]. The process of ESI Funds planning and implementation is largely decentralized and in the hands of EU Member States. The Member States are supposed to put in place the bodies at the national level of governance as part of the chain of management and control of ESI Funds. Their actions including the selection of projects funded through ESI Funds have to be considered as the implementation of EU law with the obligation to observe CRPD principles as they are bounded by EU's confirmation of the CRPD in so far as they are "interpreting and applying EU legislation"[201]. Considering the selection and implementation of ESIF funded projects by the Member States as EU law implementation is placing them under EU jurisdiction and opens the door to examine the obligations that the European Commission has under the CRPD in relation to projects supported through its funds. Article 6 of Common Provision Regulation states that: "Operations supported by ESI Funds shall comply with applicable Union law and the national law relating to its application ('applicable law')"[202]. It follows that all the "operations" related to ESI Funds planning and implementation has had to comply with the CRPD as applicable law.

The stance that the national measures taken in the process of implementation of the ESI Funds amount to the implementation of EU law finds its legal basis in the judgment of the ECJ in the case *Liivimaa Lihaveis MTÜ*[203]. In that case under the joint Operational Programme for using the ERDF the Monitoring Committee was formed following the ERDF regulations for the budgeting period 2007 – 2013, the body at the level of Member State in charge to select the projects and for

[200] European Union (n 189). para.100
[201] Butler (n 165).p.20, para.1
[202] REGULATION (EU) No 1303/2013 (n 164), Article 6
[203] *Liivimaa Lihaveis MTÜ* [2014] Court of Justice of the European Union C-175/13.

those purposes to establish its rules of procedure. Those rules of procedure did not allow for the complaints on the project results. The applicant whose project application was refused has complained to the national court and the national court asked ECJ for the clarification if such measure taken by the Member States complies with the General Regulation of ESIF and the European Charter of Fundamental Rights and its Article 47 on the right to an effective remedy[204]. The ECJ in determining whether the measure taken amounts to implementation of EU law stated that the measure referred to, establishment of the Monitoring Committee and its rules of procedures was envisaged in the secondary act of EU law and that the measure taken had the intention to implement EU law which it used as the criteria to establish that the measure of the Member State was implementing EU law and had to comply with the Charter[205]. Using the same analogy it can be inferred **that all the measures taken at the national level** to establish the bodies for management and control of **ESI Funds and the measures of implementation** following the rules set out in Common Provision Regulation[206] **amount to EU law implementation**.

As the CRPD is the part of EU legal order as stated above but having no direct effect the issue of how CRPD provisions from its Article 19 can be used and enforced arises in the context of inappropriate usage of ESI Funds. Based on the ECJ case-law elaborated above individuals cannot rely on CRPD provisions in national courts nor in the ECJ. The other remaining option is the use the CRPD indirectly through the EU Charter or EU secondary law as both will be interpreted in the manner consistent with the CRPD. In the previous sections, it was discussed why Article 26 of the Charter which the most closely resembles CRPD Article 19 does not have a direct effect. The consideration to use Article 26 of the Charter indirectly in a sense that the individual wishing

[204] The Charter of Fundamental Rights of the European Union (n 156), Article 47
[205] *Liivimaa Lihaveis MTÜ*, C-175/13, ECJ Judgement (17 September 2014). para. 63 - 66
[206] REGULATION (EU) No 1303/2013 (n 164)

to complain to the national court on the selected project for funding from ESI Funds which hinders community living relies on the provisions of ESI Funds related to transition from institutional to community-based care and social inclusion and then expecting the court bring into play Article 26 of the Charter would be doomed to fail as argued by the researchers because the ESI Funds regulations relied on does not fulfill the criteria for having a direct effect as in the implementation they need additional national measures[207].

The other option suggested by the scholars is to use other provisions of the Charter, in particular, Article 6 on the right to liberty and Article 21 on non-discrimination which includes disability as a ground because they are directly enforceable rights as their normative content is more specific and not vague as in Article 26[208]. For the interpretation of Article 6 and Article 21 of the Charter, it is important that ECJ is relying on the European Convention on Human Rights and Fundamental Freedoms and the case-law of ECtHR when interpreting the rights set out in the Charter. It does so because the rights from ECHR constitute the "general principles of the Union's law" as set out in TEU[209]. As the ECtHR is frequently relying on the CRPD when interpreting certain rights the CRPD could also find its way in EU law through reliance of the ECJ on ECtHR case-law[210]. These two Articles of the Charter can be of special significance if trying to make a claim on violation of the right to independent living if seen in the light of interpretation of CRPD Committee in the Guidelines on CRPD Article 14 where CRPD Committee stated that the involuntary placement in the residential institutions on the basis of disability constitutes discrimination and arbitrary deprivation of liberty[211]. It is on the basis of CRPD Committee's interpretation and the analysis of

[207] Butler (n 165).p.34, para.3
[208] Butler (n 165).p.35, para.1
[209] TEU (n 149), Article 6, para.3
[210] Butler (n 165).p.31, para.2
[211] Committee on the Rights of Persons with Disabilities, 'Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities' (n 24). paras. 4 and 8

relevant ECtHR case-law[212] that the individual would be more likely to challenge successfully the decision of the investing funds in the residential institutions on the basis of a breach of Article 6 and Article 21 of the Charter if read together with Article 26 and Articles 14 and the negative obligations under Article 19 of the CRPD[213]. If the individuals are to challenge the possible decisions to fund projects supportive of residential institutions than the obvious challenge arises to prove that the money is not actually directed for community-based care but to a form of segregation. Because of the tendency to replace the large-scale institutions with the smaller congregated settings in order to challenge such decisions it would be needed to resort to a definition of the institutions based on the institutional culture using the Guidelines of the European Expert Group[214] which would demand a demonstration that the service provided limits the choice and control of the individuals and to collect the data and evidences which can be difficult in the absence of adopted indicators discussed in the second chapter. It is more likely that the individual could challenge the funding decision if in the Operational Programme, Call for project proposals or the outline of the approved project it is outright stated that the project envisages the investments in the existing institutions which are evidenced as such in the state's welfare or health system. However, the research has shown that in the current budgeting period the most of the Operational Programmes incorporating the project on social inclusion are making a reference to community-based services but the problem lays in the fact that there are no enough details on type of those services and sometimes those turn out to be the small institutions which becomes evident only in the implementation phase[215].

[212] Butler (n 165).p.36 -43
[213] Butler (n 165).p.44, para.3
[214] Bulić (n 70).p.25, para.1
[215] Camilla Parker, Lilia Angelova-Mladenova and Ines Bulić, 'Working Together to Close the Gap Between RIGHTS and REALITY' (European Network on Independent Living – European Coalition for Community Living 2016).p.36, para.2

Another way of how the CRPD can be used for enforcement is by the acts of the European Commission. Those possible acts are set out as the recommendations in the Concluding Observations of CRPD Committee including the following: "to guide and foster deinstitutionalization, to strengthen the monitoring of the use of ESI Funds" and to "suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached"[216]. Those are the areas in which the responsibility of the EU is engaged and where the mechanisms for further improvements should be explored. In order to identify those mechanisms and how the Commission could put in practice the recommendations given by CRPD Committee it is necessary to offer a brief review of the mechanism of functioning of ESI Funds planning and implementation and the role of the European Commission. The starting point for this review is the Common Provision Regulation. As mentioned before the ESI Funds are operated on the basis of shared management between the European Commission and the Member States. The system is largely decentralized and it envisages that countries adopt the Partnership Agreement outlining the "strategy, priorities and arrangements for using the ESI Funds"[217] in line with the EU's policy goals and the Operational Programmes for specific funds which define the priorities and the activities. Both are subject to approval by the European Commission[218]. This is the first point where the Commission can and should pay due regard if these documents are making a reference to the transition from institutional to community-based care and if so to check if the ex-ante conditionalities related to it are fulfilled. The Commission through its position paper on Partnership Agreement has identified the transition from institutional to community-based care in 12 following countries: Bulgaria, Croatia, Czech Republic, Greece, Estonia, Hungary, Latvia,

[216] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of the European Union' (2015) CRPD/C/EU/CO/1. para. 51
[217] REGULATION (EU) No 1303/2013 (n 164), Article 2 (20)
[218] European Union (n 189).para.100

Lithuania, Poland, Romania, Slovenia, and Slovakia[219]. Thus, the ex-ante conditionality in relation to this thematic objective and funding priority apply to these countries. However, the research has shown that not all countries have fulfilled the ex-ante conditionality as they do not have the deinstitutionalization strategy in place[220] and what is, even more, they do not make commitments towards prohibition of investments into residential care. In some countries, there are planned investments into smaller congregated facilities for persons with disabilities under Operational Programmes[221].

The civil society including Disabled People's Organizations are supposed to be included in the process of elaboration of Partnership Agreements and Operational Programmes according to CPR[222] and that has been happening at the varying extent across the EU Member States. The practice shows that in those countries with the higher involvement of relevant civil society organizations at this stage the PAs and OPs included more clear references to deinstitutionalization and development of community-based services[223].

The operations of ESI Funds should be based on Partnership principle elaborated in the Code of Conduct on partnership and include civil society in all stages including "preparation, implementation, monitoring, and evaluation"[224].

The States also have to create management and control systems consisted of several bodies as prescribed by Common Provisions as mentioned above. The functions of these bodies are reviewed

[219] Camilla Parker and Ines Bulić Cojocariu, 'European Structural and Investment Funds and People with Disabilities in the European Union' (European Parliament's Policy Department for Citizens' Rights and Constitutional Affairs 2016).p.34, para.5
[220] Parker, Angelova-Mladenova and Bulić (n 215).p.35, para.4
[221] Parker, Angelova-Mladenova and Bulić (n 215).p.44, para.2
[222] REGULATION (EU) No 1303/2013 (n 164), Article 5
[223] Butler (n 165).p.56, para.1
[224] European Commission 'The European code of conduct on partnership in the framework of the European Structural and Investment Funds' (January 2014)

shortly so to identify the competences of the European Commission and those of the Member States. The role of the Managing Authority (MA) is to draft the Calls for project proposals and establish selection criteria and to conduct the prior check if the projects comply with the applicable law while Certifying Authority conducts financial checks and an additional layer of control if the applicable law is respected once the projects are approved. The Calls for proposals and the selection criteria should both contain the references to CRPD Article 19 positive and negative obligations but that depends on the awareness of the Member States. The problem can occur if these national bodies are not sufficiently aware that the CRPD should be considered as an applicable law and how does that translate into the propositions of the calls for proposals or selection criteria.

It is a duty of these two bodies to develop a complaint mechanism which means that the complaint system remains decentralized creating a somewhat paradoxical situation that if the complaint is to be submitted against the Member State who has approved the funding of residential care, it is a Member State which will receive and deal with it. The European Commission can receive the complaint but it only examines if the adequate procedural arrangements are in place in the Member States and return it to the Member State to decide on merits.

The Commission can also use soft mechanisms in terms of guidance for the States on the implementation of ESI Funds towards deinstitutionalization. As a response to the recommendation of CRPD Committee "to guide and foster deinstitutionalization" the Commission has issued the Guidance on ensuring the respect of the EU Charter when implementing the ESI Funds[225] and before that in cooperation with civil society a Toolkit on using the ESI Funds for the transition

[225] European Commission, 'Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds ('ESI Funds')', Official Journal of the European Union, C 269/1 (23 July 2016)

from institutional to community-based care[226] which is supposed to help in mitigating the problem of lack of awareness of national bodies in charge of planning and implementation of ESI Funds. However, the Guidance on the EU Charter does not make explicit reference on CRPD Article 19 obligations although it mentions the CRPD's supremacy over EU secondary law in Annex II[227] but fails to mention explicitly that all operations under ESI Funds amount to the implementation of EU law. Further on, the Guidance states that "EU law obliges Member States to implement the convention to the extent that its provisions fall within EU competence"[228]. As it was discussed above, the development of community-based services and the positive obligations under Article 19 of the CRPD fall under the competence of EU Member States. While the Guidance mentions the principle of "sincere cooperation" between the EU and its Member States in the implementation of all areas of the CRPD[229] it fails to mention how it relates to the operations of ESI Funds. It could have clarified that in the calls for proposals and the selection criteria due consideration has to be given to the implementation of positive obligations under CRPD Article 19 especially in those countries where the transition from institutional to community-based care is identified as a funding priority.

The Member States are obliged to set up the Monitoring Committees[230] which play a significant role as they are tasked with monitoring and evaluation of different stages of the planning and implementation of ESI Funds. They examine the performance of the operational programme, the evaluation plan, progress on the fulfillment of ex-ante conditionalities, they approve the selection criteria for the projects, annual and final implementation reports and amendment proposals for the

[226] Ines Bulić and Javier Guemes, 'Toolkit on the Use of EuropeanUnion Funds for the Transition from Institutional to Community-Based Care, Revised Edition'.
[227] European Commission Guidance (n 217), Annex II, para.2
[228] *Ibid.*
[229] *Ibid.*
[230] REGULATION (EU) No 1303/2013 (n 164), Article 47

operational programme, among the rest[231]. The Monitoring Committees include the civil society representatives in their composition as well as the European Commission representative but only in an advisory role[232]. The extent of the involvement of civil society and the impact vary significantly across the Member States at least for the two reasons. The first is the capacity and the possession of relevant expertise on behalf of civil society and Disabled People's Organizations and the other one is the quality of participation in terms of decision-making powers given to civil society through the rules of procedures of each Monitoring Committee as in some cases they don't have the voting powers which adversely affects their chances to influence any decisions and to be meaningfully involved[233]. Disabled People's Organizations remain little aware of the current possibilities to complain about the potential misuses of the ESI Funds[234].

If the Commission finds that the Partnership Agreements or Operational Programmes plan to invest in the residential institutions breaching the CRPD in that way it could take an action along with the Member State in the form of making an amendment of these documents[235]. The Commission is also supposed to check the fulfillment of ex-ante conditionalities including the one on the existence of a national strategic plan on deinstitutionalization. It should assess it in line with the requirements of CRPD Article 19 and if it finds a breach it can suspend payments[236]. The Commission is also checking if the Member States have in place the proper system of management and control and the found deficiencies in its functioning could also trigger the suspension of

[231] REGULATION (EU) No 1303/2013 (n 164), Article 110 (1) (2)
[232] REGULATION (EU) No 1303/2013 (n 164), Article 47 (3)
[233] Camilla Parker, Ines Bulić Cojocariu and Nataša Kokić, 'European Union Structural and Investment Funds and the Transition from Institutional Care to Community Living: Towards a More Effective Monitoring and Complaints System' (European Network on Independent Living 2017).p.14, para.2
[234] Parker, Bulić Cojocariu and Kokić (n 233).p.5, para.2
[235] REGULATION (EU) No 1303/2013 (n 164), Article 30
[236] REGULATION (EU) No 1303/2013 (n 164), Article 142(1)(e)

payments[237]. This is not limited to merely checking of the procedural arrangements in place but to examination for example if the system in place is such that it enables the selection of the projects which are not compliant with the EU Charter[238].

The next point for the intervention is in the phase of the implementation using the awareness-monitoring-enforcement approach[239] meaning that the Commission has to be supplied with enough information on selected projects by the State so to become aware of potential breaches, to monitor continuously the implementation and to be able and ready to enforce the compliance.

To trigger the suspension of payments the Commission should receive the "evidence resulting from the performance review for a priority that there has been a serious failure in achieving that priority's milestones relating to financial and output indicators and key implementation steps"[240]. Here the two issues are arising. The first one is the use of adequate output indicators that should be such to include data on the type and quality of the services in the projects related to the development of community-based services. Some of the indicators from the list of independent living indicators discussed in the second chapter of this analysis, especially those related to type and quality of community-based services, could be used for such purposes. Another issue is the issue of reporting as the Commission is almost entirely relying on the data reported by the Member States. The Managing Authorities are expected to submit the annual implementation reports on Operational Programmes to the Commission on the basis of "common and programme-specific indicators and quantified target values, as well as milestones"[241]. These reports have to be reviewed and approved by the Monitoring Committees prior to submission to the Commission. However, in

[237] REGULATION (EU) No 1303/2013 (n 164), Article 71 (1)
[238] Butler (n 165). p.65, para.3
[239] Butler (n 165).p.53, para.3
[240] REGULATION (EU) No 1303/2013 (n 164), Article 142 (f)
[241] REGULATION (EU) No 1303/2013 (n 164), Article 50 (2)

practice, these reports do not offer in-depth analysis of the selected projects from which it could be inferred how supportive to independent living or not these projects are[242]. If deficiencies are identified at this stage, the Operational Programme could be amended or the Commission could undertake the corrective actions. Again the use of the independent living indicators could be helpful here in terms of developing more elaborated reporting template which would include the questions related to independent living indicators if the transition from institutional to community-based care is included as a funding priority in particular country. Further on, the countries are to submit the periodic progress reports on the implementation of Partnership Agreements which should include the data on the fulfillment of ex-ante conditionalities[243] and civil society should also be included in this process.

Finally, the Managing Authorities are supposed to conduct three types of the evaluations of ESI funds: ex-ante – before the projects are implemented, on-going evaluations during the implementation phase and ex-post evaluations after implementation so to assess the effectiveness and the impact of the projects[244]. Evaluations conducted should be independent than authorities and the Commission is providing the guidance for the evaluation[245]. This is additional opportunity to use the programme-specific indicators which would include the independent living indicators to be used to assess the impact of the deinstitutionalization projects.

The European Commission has also expressed the commitment to interrupt, suspend or withdraw the funds when it is found that the spending is not in line with EU law[246]. However, in the previous

[242] Parker, Bulić Cojocariu and Kokić (n 233).p.12, para.5
[243] REGULATION (EU) No 1303/2013 (n 164), Article 52
[244] REGULATION (EU) No 1303/2013 (n 164), Articles 54 - 57
[245] REGULATION (EU) No 1303/2013 (n 164), Articles 54 (3)
[246] European Union (n 189).para.100

period, the Commission has never used this option[247] even when it was demonstrated that the funds were used or intended to be used for support to residential care. The Commission also has on its disposal to start the infringement procedure which is used in the case of "serious and persistent breaches of EU values"[248] if the corrective actions such as interruption, suspension or withdrawal of funds don't bring the results.

Despite the EU's confirmation of the CRPD and the new regulation of ESI Funds which introduced ex ante conditionalities as well as the new legal status of the EU Charter of Fundamental Rights as part of the Lisbon Treaty the individuals are still left with the little chances to obtain the judicial or administrative remedies in the cases of misuse of ESI Funds due to the constraints of CRPD's legal effects as well as the constraints of the current complaint system under ESI Funds Regulations.

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3.2.3 EU mechanisms to enforce the right to live independently and being included in the community in the countries in accession to EU membership

The countries which have set their political goal to join EU Membership have to undergo a long and extensive process of EU integrations through which they find themselves under heightened scrutiny by the European Commission on their human rights records. The focus of the analysis is the position, determinacy and prominence of the right to live independently and being included in

[247] Camilla Parker and Ines Bulić, 'Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges? ENIL–ECCL Shadow Report on the Implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union' (European Network on Independent Living – European Coalition for Community Living 2014).p.28, para.4

[248] TEU (n 149), Article 7

the community as a condition for the countries wishing to join the EU membership and the mechanisms the EU can apply to advance its implementation. Those countries are not subjects of EU law and are not under the jurisdiction of the European Court of Justice but the in order to join EU membership they have to fulfill a complex set of criteria known as Copenhagen criteria including political, economic and legal criteria. Those criteria include:

"stable institutions guaranteeing democracy, the rule of law, human rights and respect for and protection of minorities; a functioning market economy and the capacity to cope with competition and market forces in the EU; the ability to take on and implement effectively the obligations of membership, including adherence to the aims of political, economic and monetary union"[249].

The first stage in the course of European integrations includes stabilisation and association process and signing of the Stabilization and Association Agreement (SSA) between both the EU and its Member States and the country applying for membership, through which the country obtains the status of the potential candidate. The requirements of this stage are not within the scope of this research. The process of association to the EU is based on SSA and seeks to ensure that the country aligns its legislation with EU Acquis (the package of EU legislation) and prepares itself for the implementation. Upon fulfillment of the obligations stemming from SSA and the assessment by the European Commission followed with the approval by the Council of the European Union the country is awarded the candidate status while the opening of the accession negotiations depends on the recommendation by the European Commission, Council of the European Union and the decision of the European Council[250]. EU accession negotiations include the negotiations on

[249] See at: https://ec.europa.eu/neighbourhood-enlargement/policy/conditions-membership_en Accessed on 09th November 2017

[250] Danijela Božović and others, 'Guide for Monitoring the EU Accession Negotiations Process' (Belgrade Open School 2015).p.15, para.3

accepting and implementing EU acquis divided into 35 chapters where each of the chapters is being negotiated separately. The process entails three phases:

1. "analytical review of the legislation (screening);
2. The actual negotiations;
3. The conclusion of the Accession Treaty"[251].

In the current negotiation framework, the chapters 23 on Judiciary and fundamental rights and 24 on Justice, freedom, and security are given special importance in terms that they are the first ones to be opened and that the suspension of this chapters leads to the suspension of entire negotiations[252]. These chapters along with the Chapter 19 on Social Policy are also bearing special relevance for the rights of persons with disabilities.

The European Union through its policy of conditionality can advance and monitor human rights which fall out of the EU's competences in relation to its Member States creating in this way double standards for its Member States and countries in accession[253]. Therefore, the process of EU integrations where the accession to EU membership represents the "carrot" for countries aiming to join EU membership enables the EU to exercise not only legal means but political as well as in relation to these countries there are no such constraints of EU law such as in relation to EU's member states. The potential of this political leverage to advance the right to live independently and being included in the community will be examined in this section.

[251] Danijela Božović and others (n 250).p.18, para.3
[252] Danijela Božović and others (n 250).p.19, para.1
[253] Anneli Albi, 'Ironies in Human Rights Protection in the EU: Pre-Accession Conditionality and Post-Accession Conundrums' (2009) 15 European Law Journal 46.p.4, para.1

EU's policy of conditionality in relation to countries in accession to EU membership concerns the improvements in the areas of democracy, the rule of law, equality and respect of human rights as set out in the Lisbon Treaty[254].

The European Commission monitors regularly at the annual level the progress made by the potential candidate and candidate countries through its Progress Reports. Those reports reflect both on political and economic criteria and include the section on "human rights and the protection of minorities". It is exactly this criteria that will be examined here in relation to the prominence it gives to the process of deinstitutionalization of people with disabilities.

The arguments made against the efficiency of EU's policy of conditionality revolve around the questions of how voluntary the accession countries are adopting systemic changes towards fulfillment of criteria for membership bearing in mind that if the changes of institutional framework are not adopted on a voluntary basis but merely for the purposes of obtaining the accession to EU membership, the compliance may deteriorate after the accession happens as there are no any longer external incentives and such instruments for monitoring and intervention at the disposal for the European Commission once the country joins the membership.

EU's policy of conditionality is based on the method of external governance where the EU is exporting its already defined rules and the candidate country is supposed to adopt it before joining the membership[255]. What matters is if and how this rule transfer includes the transition from institutional to community-based care and if it does how efficient it is in doing so.

[254] TEU (n 149), Article 2 and Article 49

[255] Frank Schimmelfennig and Ulrich Sedelmeier, 'Governance by Conditionality: EU Rule Transfer to the Candidate Countries of Central and Eastern Europe' (2004) 11 Journal of European Public Policy 661. p.661, para.2

The policy of conditionality is based on promised and expected rewards so for the country at the receiving end of the rules of transfer there is an incentive for compliance with the bulk of rules. Its success largely depends on the perception of the candidate country in regards of the suitability of certain rules for its own context if it adopts those rules because it considers them as useful solutions for its context or it perceives them merely as a checkpoint towards the reward. [256]

Some authors are distinguishing between three models of EU rules transfer: the external incentive model, social learning model, and lesson-drawing model[257]. The features of these models will be reviewed briefly in order to identify which model is the most suitable to advance the right to live independently and being included in the community in the candidate country.

The core of the external incentive model are the rewards in the form of progress made in the process of EU integrations including but not limited to cooperation agreements, stabilization and association agreement, the status of the candidate country, openings of the negotiations, access to financial assistance and technical support and finally, the membership. The qualification for these incentives of rewards depends on the fulfilment of certain conditions for each. This affords the EU political leverage in the process of EU integrations. The country will adopt the rules if the rewards are outweighing the costs associated with the adoption of rules and following influencing factors have to be taken into account: "determinacy of conditions, the size and speed of rewards, the credibility of threats and promises, and the size of adoption costs"[258].

That means that deinstitutionalization should be clearly part of the human rights conditionality so that it leaves no doubt for the candidate country that the progress on deinstitutionalization one of

[256] Schimmelfennig and Sedelmeier (n 255).p.662, para.2
[257] Schimmelfennig and Sedelmeier (n 255).p.663, para.3
[258] Schimmelfennig and Sedelmeier (n 255).p.664, para.2

the criteria against which the country is being assessed in the process of EU accession. The credibility concerns the readiness of the EU to deliver on its promises in the case of compliance and readiness to stall the further progress if compliance is not met. In the context of the discussed topic, the EU should be ready to withhold the rewards in terms of the progress of EU integrations and financial assistance if there are no advancements in the process of deinstitutionalization. It should be born in mind that the cost for the EU to withhold the promises and rewards is higher as the process is advancing and nearing to an end because of the increased total investments over time both political and financial ones[259]. That might mean that further in the process of EU accession the EU can be less ready to sanction the country because of failures in deinstitutionalization.

The analysis of the 5th and 6th rounds of EU enlargement based on the Commission's progress reports has shown that there is no consistency applied in the EU's approach to the assessments of the progress of different candidate countries and no in-depth monitoring of compliance based on concrete benchmarks[260] leading to a somewhat vague conditionality policy with differing conditions towards different countries putting into question determinacy of conditions.

Next determinant of the rule transfer is the size of domestic costs of adoption. They could arise in the shape of welfare costs or power costs for certain domestic actors affected by the adopted rules[261]. Deinstitutionalization process encompasses the reform of welfare and health policies and significant transition costs as explained in the previous chapters and certain groups can often

[259] Schimmelfennig and Sedelmeier (n 255).p.666, para.1
[260] Dimitry Kochenov, *EU Enlargement and the Failure of Conditionality : Pre-Accession Conditionality in the Fields of Democracy and the Rule of Law.* (Austin [etc] ; Alphen aan den Rijn : Wolters Kluwer Law & Business, c2008). p.300, para.3
[261] Schimmelfennig and Sedelmeier (n 255).p.666, para.4

express their opposition to the process and stall it such as the staff of residential institutions and service providers affecting adversely the rule transfer.

Another model of rule transfer – social learning model is based on the voluntary adoption of rules due to a perception of the appropriateness of the rule for the local context and strong identification with the EU's identity, values, and norms. The rule is perceived as legitimate as it offers a solution which is acceptable and applicable to domestic context and stems from the standards which are in place also for the EU Member States and other international organizations[262]. This model has limited applicability to the adoption of rules which related to deinstitutionalization. On one hand deinstitutionalization is legitimate as it offers better outcomes for persons with disabilities and it is a norm of international human rights law but on the other hand, the development of community-based services are exceeding the EU's competences and EU member states themselves have varying success in the field.

Finally, the third model is based on lesson-drawing which implies that the country has recognized the existence of the problems in the particular policy area and it looks in EU countries for the solution applicable to the local context. This model is a voluntary one stemming from the internal needs for policy reforms. Its application to the field of deinstitutionalization is reflected in the wide recognition of the residential care as the problem for rights of persons with disabilities but is traditionally more recognized as a problem by civil society and persons with disabilities themselves and independent human rights bodies while the state actors are recognizing it as a problem at least declaratory. Consequently, the question that arises is how vigorous and decisive

[262] Schimmelfennig and Sedelmeier (n 255).p.668, para.2

are policy-makers to start looking for deinstitutionalization models abroad and to assess and use the potential solutions in the local context and place the issue on the top of their political agendas.

EU policy of conditionality refers to two areas of conditionality: democracy conditionality and acquis conditionality where the former includes the compliance with the EU's values and principles including human rights conditionality and the latter refers to the adoption of a specific EU's legal framework[263]. Democratic conditionality has brought some substantial results in the area of minority rights protection in the countries of Central and Eastern Europe which falls out of the EU's competences in the context of EU enlargement in 2004[264] and by the analogy it could be used to advance the right to live independently and being included in the community for persons with disabilities in the Republic of Serbia.

The European Commission in its document on Enlargement Policy has recognized the need to strengthen further the effective policies for the protection of the rights of people with disabilities in the countries in accession to EU membership[265]. However, the document remains vague on what does it mean to improve the effectiveness of the policies for people with disabilities and is making no reference on the transition from institutional to community-based care. That implies that determinacy of this condition is quite weak.

The potential of democratic conditionality in regards of deinstitutionalization will be examined in the next chapter along with the features of all three models of rule transfer on the basis of examples

[263] Schimmelfennig and Sedelmeier (n 255).p.669, paras 1 and 2
[264] Schimmelfennig and Sedelmeier (n 255).p.669, para.4
[265] COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT, THE COUNCIL, THE EUROPEAN ECONOMIC AND SOCIAL COMMITTEE AND THE COMMITTEE OF THE REGIONS, COM(2016) 715 final, '2016 Communication on EU Enlargement Policy'. (09th November 2016).p.29, para.2

of chosen national jurisdictions of Serbia and Croatia which are both sharing the experience of the process of accession to EU membership.

4 The state of implementation of Article 19: comparative analysis

This part of the analysis will offer the insight into the recent developments and state of implementation of CRPD Article 19 in Republic of Croatia and Republic of Serbia and will analyze the impact of EU integrations on the right to live independently and being included in the community. These two countries are sharing the common history as both were part of Socialist Federative Republic of Yugoslavia which dissolved in 1991 through the civil war which lasted until 1995 after which Republic Croatia obtained independence. Beside history, they are sharing the common features of a welfare system still relying highly on residential care facilities for people with disabilities as well as the similar challenges in the transition from institutional to community-based care. Apart from these commonalities, they were sharing a common political goal in terms of EU integrations and strivings to join the membership of the European Union. While Croatia has succeeded in this effort and acceded EU membership in 2013, Republic of Serbia has a status of candidate country and has recently started negotiations for EU membership. This chapter will also explore the role that the EU was or is playing in advancing the process of deinstitutionalization in these countries in terms of its policy of conditionality and external incentives such as financial assistance available for these countries including both the Instrument for Pre-Accession assistance and the European Structural Funds.

4.1 The implementation of Article 19 in Croatia

As a former part of the Yugoslavia Republic of Croatia inherited the same legacy of residential care like other former Yugoslav countries which have developed segregated residential care for people with disabilities under socialistic regime after Second World War characterized by highly

centralized welfare system including the centralized system of funding and care provision for people with disabilities[266]. According to official data, there are 114 residential institutions in Croatia including those for children and youth without parental care, children, and youth with behavioral disorders, children with developmental difficulties and adults with disabilities and those for people with psychosocial disabilities[267]. Out of this number of institutions, 71 are a state-run and total number of residents in all types of institutions is 12813 and more than a half pertains to people with disabilities[268]. The prevalence of institutional care becomes even more visible when compared to a number of beneficiaries of foster care in 2011: 250 children with disabilities, 668 adults with disabilities and 726 people with psychosocial disabilities[269].

The Republic of Croatia has started with the deinstitutionalization process soon after the war conflict (1991 - 1995) in 1997[270]. The process was initiated through external incentive and support and empowerment of domestic actors through collaborative effort of Open Society Mental Health Initiative, Croatia-based NGO Association for promotion of inclusion (API)[271] and University of Zagreb building knowledge and subsequently piloting first deinstitutionalization initiative aimed at one of the largest residential institutions – Center for Rehabilitation in Zagreb[272]. As a result of the community-based service of supported housing, piloted in this initiative and provided by NGO, has become part of the state system of social protection and financially supported by the

[266] Chiriacescu (n 29)
[267] Ministry of Health and Social Protection of the Republic of Croatia, 'Plan for Deinstitutionalization and Transformation of Social Welfare Homes 2011 - 2018'.(2010), p.6, para.2
[268] *Ibid.*
[269] Ministry of Health and Social Protection of the Republic of Croatia (n 267).p.6, para.3
[270] Judith Kleine, 'Briefing Paper Deinstitutionalization in Croatia: A Summary of Open Society Support'. (July 2014) p.2, para. 4
[271] API's foundation was supported by Open Society Mental Health Initiative
[272] Kleine (n 270).p. 3-4

government[273] although the government continued to favor state-run providers by allocating more funds to them[274].

The Republic of Croatia signed the CRPD in March 2007 and ratified it in August 2007 and has undergone the review of its initial state report on CRPD implementation in 2015. According to data used in the parallel reports on CRPD implementation in Croatia, in Croatian residential institutions for persons with disabilities, the most represented group are persons with psychosocial disabilities (3830), while the figure of 3, 182 accounts for children and adults with other types of disabilities[275]. Croatian government had elaborated 2011 – 2018 and adopted the Plan for Deinstitutionalization and Transformation of Social Welfare Homes[276] which includes 46 residential facilities but omits to include small private residential facilities funded by State, small family homes for up to 20 people and psychiatric hospitals offering long-term psychiatric care[277]. It is notable that the government has lack of understanding of the features of community-based care conducive of independent living and a lack of a vision for transition from institutional to community-based care as it regards "family homes"[278] and foster families for adults[279] where people are placed without given consent and without the right to challenge the decision, as desirable community-based solutions. Upon visiting such services, Croatian Ombudsman has noted the features of institutional care which continue to isolate and segregate the users of these

[273] *Ibid.*
[274] Kleine (n 270).p.4, para.2
[275] CROATIAN UNION OF ASSOCIATIONS OF PERSONS WITH DISABILITIES, 'ALTERNATIVE REPORT on the Implementation of the UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF CROATIA' (2014).para.46
[276] Ministry of Health and Social Protection of the Republic of Croatia (n 267).
[277] Human Rights Watch, 'Human Rights Watch Submission to the United Nations Committee on the Rights of Persons with Disabilities' (2014).p.5, para.2 and 3
[278] Law on Social Welfare 2017 (Official Gazette of the Republic of Croatia 157/13, 152/14, 99/15, 52/16, 16/17). Article 175
[279] *Ibid.* Article 183

services[280]. The Law on Social Welfare from 2011 envisages following social services:: assessment of needs, counseling, in-house support, psychosocial support, early intervention, integration in the education system, day-care, residential care and supported housing[281]. As mentioned, one of an essential services for independent living, personal assistance, is not envisaged.

The plan on deinstitutionalization has envisaged gradual annual decrease of number of residents and number of newcomers and entitlements to one or more support services in the community but the pace of development of range of community-based services did not follow the relocation targets set in the plan resulting in waiting lists for new admissions in all residential care facilities[282]. The targets are rather modest and have foreseen deinstitutionalization of 30% of persons with disabilities by the end of 2016 and only 20% of people with psychosocial disabilities until 2018 and the limit of 30[283]. Beside slow pace, the focus on people with milder disabilities is also problematic as the ones with high support needs are subjects of assessment of their "readiness" to move into the community[284].

Only 11 institutions are included in the relocation plans so far out of 46 residential facilities[285]. According to Government's data in the period from 1997 to 2012 only 308 persons were deinstitutionalized while in the period since the national plan on deinstitutionalization was adopted from 2014 to 2016, 948 people were deinstitutionalized out of which 217 persons with

[280] Disability Ombudsman of the Republic of Croatia, 'Parallel Report on the Implementation of the UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF CROATIA' (2014).p.27, para.3
[281] Law on Social Welfare (n 278). Article 74 (1)
[282] Disability Ombudsman of the Republic of Croatia (n 280).p.25, para.3
[283] Ministry of Health and Social Protection of the Republic of Croatia (n 267).
[284] Human Rights Watch (n 277).p.6, para.1
[285] p.26, para.4

psychosocial disabilities[286]. However, the concerns still remain on the scope and coverage of deinstitutionalization policy and the quality and range of alternatives in the community.

The absence of community-based services for people with psychosocial disabilities results in high rate of hospitalization of this group of people[287]. Forced psychiatric treatment is allowed by the Law on the protection of persons with mental disorders as people deprived of legal capacity can be admitted for a treatment on the basis of consent given by their guardian following the medical assessment of mental incapacity to give a consent which is not considered as involuntary admission[288]. In addition, involuntary treatments are allowed if person's disorder is endangering him/herself or the others contrary to the Guidelines of CRPD Committee on Article 14. There are more people with psychosocial disabilities residing in the social welfare institutions than in the psychiatric residential facilities[289].

Ombudsman's parallel report on the CRPD also notes the existence of resistance to the process of deinstitutionalization on behalf of guardians as well as the general population having negative attitudes towards people who are coming back in the community from residential institutions[290].

The community-based services remain underdeveloped and unevenly distributed across the State with the evident lack of "housing programmes, the programmes of health care, supported labour and employment"[291] and the lack of policy regulating the provision of personal assistance which

[286] Marija Pletikosa, 'THE PROCESS OF DEINSTITUTIONALIZATION IN CROATIA' (Working group Developing the Psychiatric Hospitals in Transition Alliance in Europe, Trieste, 16 December 2016).
[287] Disability Ombudsman of the Republic of Croatia (n 280).p.29, para.2
[288] Law on protection of persons with mental disorders 2015 (Official Gazette of the Republic of Croatia 76/14). Article 12
[289] Dragana Stanković, 'Establishment and Sustainability of the Deinstitutionalization Process and Development of Community-Based Services for People with Intellectual and Mental Disabilities in Serbia' (University of Belgrade, Faculty of Political Sciences 2016).p.88, para.2
[290] Disability Ombudsman of the Republic of Croatia (n 280).p.26, para.5
[291] CROATIAN UNION OF ASSOCIATIONS OF PERSONS WITH DISABILITIES (n 275).para.47

is limited only to people with "severe physical impairments" where it exists[292] and when provided its extent doesn't meet the needs of the user (80 hours per month)[293]. Services are mainly tied to the institutions so even people who were deinstitutionalized remain to use services which are founded and monitored by the institution[294] and social financial benefits are not big enough to enable people to afford housing rental and live independently.

The provision of independent living services by civil society organizations is based on project funding by the government which adversely affects the sustainability of such services[295] as well as the advocacy capacities of DPOs which are dependent on state funding. People with disabilities do not have choice and control over the support they are getting as the resources are directed to service providers rather than through personal budgets[296].

Progress is made in the field of legal capacity as the amendments of Family Law were adopted with the intention to start with the restoration of legal capacity envisaging that in the next 5 years all people deprived of legal capacity (currently around 18 000) get a judicial review and plenary guardianship is abolished[297]. Also, the Electoral law was changed enabling for the first time the voting rights to people deprived of legal capacity[298]. However, the Act still allows for the partial deprivation of legal capacity where the courts would specify the range of rights and decisions that person is still able to exercise. Assessments of persons' capacity remain medicalized and are done on the basis of the existing impairment and mental capacity[299]. The Act introduces the supporters

[292] Human Rights Watch (n 277).p.6, para.3
[293] Disability Ombudsman of the Republic of Croatia (n 280).p.27, para.8
[294] *Ibid.*
[295] CROATIAN UNION OF ASSOCIATIONS OF PERSONS WITH DISABILITIES (n 275).para.48
[296] CROATIAN UNION OF ASSOCIATIONS OF PERSONS WITH DISABILITIES (n 275).para.49
[297] Family Law 2015 (Official Gazette of the Republic of Croatia 75/14).
[298] Human Rights Watch (n 277).p.1, para.4
[299] *Ibid.* Article 234, para 3.

for decision-making but only for people who are deprived of legal capacity[300] which is a serious impediment for independent living of people with intellectual and psychosocial disabilities. Around 90% of residents of the institutions are deprived of legal capacity and appointed guardian decided where and with whom they are going to live[301].

The legal barriers for the process of deinstitutionalization include allowed involuntary placements and forced treatment, deprivation of legal capacity, restricted access to supporters in decision-making processes, the absence of legal regulations of personal assistance, the definition of institutions which is not based on institutional culture among the rest. Still, some notable advancements have happened in the DI process in Croatia over the years thanks to civil society advocacy and piloting of innovative community-based services as well as the foreign aid through which the partnership between civil society and the government was supported and encouraged. In 2012 new deinstitutionalization project in Croatia was started by API and Ministry for Social Policy and Youth supported by OSF with an aim to deinstitutionalize 400 people from two large residential facilities in different phases of transformation to community-based care with the commitment of OSF to cover the transitional costs of parallel running of systems of care by contribution of 3.3 million USD while the government investment was estimated at 30 million YSD[302]. The project is ongoing and the results so far show that 100 people were moved out of the institutions, staff was retrained in community-based care provision and several supported housing units were established[303]. Today API or its partners are providing the service of supported housing supported by public funds in 8 municipalities for 244 users[304]. In total supported housing is

[300] *Ibid.* Article 233, para 4.
[301] Human Rights Watch (n 277).para.2, p.6
[302] Kleine (n 270).p.8, para.2
[303] Kleine (n 270).p.10, para.1
[304] Stanković (n 289).p.92, para.4

provided for 407 people by civil society and 342 people by residential institutions which began providing this community-based service as part of the process of transformation according to data from 2015[305].

During the DI process in Croatia, the existence of "veto" player which were opposing to DI has become evident. As expected those were the staff of residential institutions and sometimes parents of the residents leading to a hesitation of the government and the failure to close down any institution up to date[306].

The Concluding observations of CRPD Committee on the implementation of the CRPD in Croatia puts emphasis on the recommendation to broaden the definition of "institutions" so to include the "small private institutions, wards for long-term care in psychiatric institutions and foster homes for adults and include them in the deinstitutionalization strategy"[307]. It also recommended the establishment of an adequate legal framework for the provision of personal assistance for persons with disabilities[308]. Despite the continued existence of the residential institutions in Croatia and narrow range and coverage of community-based services, the comparative analysis of deinstitutionalization process in the countries in the region (former Yugoslav countries) has shown that Croatia has made the most visible progress. EU accession process and its external incentives are recognized as one of the underlying factors of this partial success along with political will, technical support and import of know-how from abroad, piloting of community-based services

[305] Stanković (n 289).p.93, para.4
[306] Kleine (n 270).p.6, para.2
[307] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Croatia' (2015) CRPD/C/HRV/CO/1. para.29
[308] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Croatia' (n 307).para.30

which turned out successful, engagement with "veto players" (guardians and staff members) and empowerment and involvement of persons with disabilities themselves[309].

It is exactly the contribution of EU accession process that will be a subject of more detailed analysis to examine how much of the current state of implementation of Article 19 can be attributed to the EU's actions or inactions.

4.1.1 The contribution of EU accession to the process of deinstitutionalization in Croatia

The Republic of Croatia applied for EU membership back in 2003 and was negotiating EU accession from 2005 to 2011. It was admitted to EU membership in July 2013.

During the negotiation process, the matter of transition from institutional to community-based care was part of the agenda of negotiations which will be demonstrated through brief analysis of key strategic documents pertaining to the process of accession negotiations. After acceding membership, the Republic of Croatia became eligible to use the ESI Funds including for the purposes of social inclusion and the transition from institutional to community-based care as Croatia is one of 12 countries in which that was recognized among the funding priorities.

In 2007 while the negotiations were open the Republic the Republic of Croatia signed with the European Union The Joint Inclusion Memorandum on Social Inclusion which includes the commitment to address the insufficient development of community-based social services and the need for deinstitutionalization[310].

[309] Kleine (n 270).p.13, para.2
[310] 'JOINT MEMORANDUM ON SOCIAL INCLUSION OF THE REPUBLIC OF CROATIA'.p.21, point 3.5

The purpose of the Memorandum was to "prepare the country for full participation in the open method of coordination on social protection and social inclusion upon accession"[311] and to review the key policy areas of importance to modernise the system of social protection which were going to be the subject of the European Commission's monitoring in the years to come. Among the key challenges identified several ones were relevant to DI process and included the poor access to community-based services and the need to decentralize and deinstitutionalize social services and to include civil society in the process, political commitment towards DI, provision of training for service providers, physical access to infrastructure and buildings, legal capacity deprivation and cooperation between the government and civil society in service provision, introduction of the system of supported decision-making and personal assistance. The document is also making a number of references to independent living and choice and control of the people over the services. The recommendations expressly included the prohibition of building the new institutions, expansion of community-based services and the reduction of a number of residents[312].

As for the negotiation chapters, disability issues were covered under the Chapter 19 and its screening report had made an express recommendation to take into account the CRPD[313]. It also recommends briefly[314] that the attention should be paid to deinstitutionalization process and the development of community-based services.

In its last Progress Report for Croatia before the accession, the European Commission gave the remark that Croatia is sufficiently prepared in the area of social inclusion recognizing that "decentralization of social services is still at an early stage" and that Croatia needs to speed up the

[311] *Ibid*.p.1
[312] *Ibid*.p.59, para.3
[313] European Commission, 'Screening Report Croatia Chapter 19 – Social Policy and Employment' (2006).p.2, para.6
[314] *Ibid*.p.10, para.3

implementation of its national plan for deinstitutionalization[315]. From this opinion of the Commission it could be inferred that the Commission is not giving such a high prominence to the issue deinstitutionalization in the negotiations of the accession and it seemed satisfied with the fact that declaratory commitment by the government for DI is expressed and that the national strategy is in place without inquiring further on type of the measures introduced and exploration if such measures lead to a better quality of life for persons with disabilities.

Even before the accession, Republic of Croatia has adopted a National plan for DI (2011) and upon the accession belonging Operational plan for deinstitutionalization and transformation of institutions for social protection in Republic of Croatia 2014 – 2016 which has recognized the European Social Fund and the European Regional Development Fund as potential sources of funding for development of community-based care[316].

The Partnership Agreement on ESI Funds with the Republic of Croatia is underlining the flaws of the social welfare system giving the picture of the extent of residential care for persons with disabilities in Croatia and emphasizes the need for deinstitutionalization and the development of community-based services as the priority[317]. It clearly sets the aim of ESI Funds in Croatia for the transition from institutional to community-based care as well as the expected results with concrete goals and targets.

The Operational Programme under the "Investment for growth and jobs" goal makes references to the government's Operational plan for deinstitutionalization 2014 – 2016 and 32 institutions that

[315] European Commission, 'Comprehensive Monitoring Report on Croatia's State of Preparedness for EU Membership' (2012) COM(2012) 601 final. p.30, para.1
[316] 'Operational Plan of Transformation and Deinstitutionalization of Social Welfare Homes and Other Legal Entities Performing Social Welfare Activities in the Republic of Croatia for the Period 2014–2016'.p.15,para.1
[317] Partnership Agreement Republic of Croatia 2014. p.34, para.4

it envisages for transformation along with the development of community-based services[318]. The European Social Fund is seen as the principal source for the implementation of the Operational Plan. In addition, the Operational Programme states that ERDF would be used for the infrastructural interventions on the social welfare institutions in the process of transformation to community-based care but not to extend the long-term residential care and for the infrastructure interventions for service providers coming from civil society as well[319].

Currently, under ESI Funds there are two ongoing Calls for proposals, one aimed for the support of the transformation of residential institutions to provide community-based services[320] in line with the national Operational plan for DI and another one on the development of personal assistance service for persons with disabilities[321].

4.2 The implementation of Article 19 in Serbia

The reform of social protection system in Serbia has begun in the early 2000s encompassing the strategic orientation towards the transition from institutional to community-based care[322]. As a successor of Yugoslavia, Serbia has also inherited a legacy of a network of residential institutions stemming from a highly centralized system of social protection. Due to the highly centralized welfare system, the community-based services at the local level were not developed at all and the

[318] ESF Operational Programme the Efficient Human Potentials 2014-2020 2014. p.10, para.2
[319] *Ibid*.p.10, para.6
[320] The Call for proposals is available at: http://www.strukturnifondovi.hr/natjecaji/1381 Accessed on 10 November 2017
[321] The Call for proposals is available at: http://www.strukturnifondovi.hr/natjecaji/1312 Accessed on 10th November 2017
[322] Ljubomir Pejaković and Vladimir Zajić, 'Deinstitutionalization of Residential Institutions of Social Protection in Serbia' (Republic Institute for Social Protection 2014).p.3, para.1

care for persons with disabilities relied almost exclusively on the residential facilities. The network of residential institutions encompasses 17 residential institutions with the total of 5574 residents[323] designated for special categories of beneficiaries: children and youth with developmental disabilities, adults with intellectual disabilities, people with psychosocial disabilities and people with physical disabilities where people with intellectual and psychosocial disabilities comprise 93%[324]. The situation is especially dramatic in the institutions for children with disabilities as they are often large-scale (sometimes more than 300 residents) and mix children and adults because children grow older and remain in the institution as there are no possibilities to get back in the community.

Serbia approached the DI process with two goals: to develop new alternatives in the community so to prevent new institutional placements and to transform the existing institutions into more community-oriented services but at the same time reducing and keeping their residential capacity with a view that there are beneficiaries for whom the residential care is necessary[325]. This approach is in the sharp contrast with Article 19 of the CRPD and the stance of CRPD Committee stipulated in its recent General Comment on Article 19 that all persons with disabilities including the ones with severe impairments and high support needs have the right to live in the community[326].

Reforming efforts in the field of social protection since early 2000s included projects related to development of integral social protection models at the local level, development of standards of work of Centers for Social Work (CSW) at the local levels, transformation of residential facilities and development of alternatives in the communities, development of foster care and adoption

[323] *Ibid*. p. 11, para.4
[324] *Ibid*. p.22, para.1
[325] *Ibid*. p.3
[326] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para.21

strategies, protection of children from abuse and neglect as confirmed in the Strategy for the reform of social protection adopted in 2005[327]. The biggest progress in the field of DI in Serbia since 2001 was made in relation to children without parental care thanks to the development of foster care while children with disabilities didn't experience the benefits of this progress as in the period 2009 – 2013 83% of deinstitutionalized children were children without parental care and only 17% of children with disabilities[328].

The view of the Republic Institute for Social Protection on the next steps that need to be taken in the DI process in Serbia express in its report on DI in Serbia stipulates that the focus of future measures should be development of foster and family care, building the smaller residential capacities, the expansion of type, quality and number of services provided within the institutions and development of services at the community levels[329]. This "vision" is clearly contrary to the requirements of Article 19 of the CRPD as it envisages building and extending institutions and tying services to the buildings. CRPD Committee clearly states in the General Comment on Article 19 that: "…" *satellite" living arrangements that branch out from institutions, have the appearance of individual living (apartments or single homes) but revolve around institutions, should not be established"*[330].

The landmark Law on Social Protection was adopted in 2011[331] and envisaged broaden the range of social services. It also introduced the pluralism of social service providers enabling NGOs and private enterprises beside state-run providers to provide social services. The groups of social

[327] Strategy for the reform of social protection in the Republic of Serbia (Official Gazette of the Republic of Serbia 108/2005).
[328] Pejaković and Zajić (n 322).p.21, para.6
[329] Pejaković and Zajić (n 322).p.12, para.9
[330] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para. 49
[331] Law on Social Protection 2011 (Official Gazette of the Republic of Serbia 24/2011).

services included in the law are: assessment and planning, daily services in the community, support services for independent living, counseling, educative service and residential services[332] where independent living services include personal assistance and supported housing for persons with disabilities. The Law created the legal framework for the elaboration of minimum standards of quality of social services which are regulated through by-law acts for particular services and include infrastructural standards and functional standards. The Law also tried to decentralize the system of funding the social protection delegating the responsibility to fund social services to municipalities while the funding for residential care facilities remained as the responsibility of the relevant Ministry at the level of government. The idea was that the local municipalities establish, contract and support licensed local service providers for those services identified as a need in particular local community. However, the Law left this as a possibility rather than an obligation for local authorities so it at the complete discretion of local authorities if they will allocate budgets for social services at all. The financial incapacity is often an excuse for local authorities to justify the lack of community-based services at the local level. Thus, despite the intention of the law to decentralize the system of funding and provision of social services, the community-based services are mostly supported through the budget of Ministry for labor, employment and social policy for project funding of civil society which adversely affects the sustainability of services. Ultimately this has led to large discrepancies among municipalities concerning the extent, coverage, type, and quality of community-based services. This risk of high discrepancies between municipalities in the level of protection of the right to access independent living services where the responsibilities are shared between different level of governance is highlighted by EU Fundamental Rights Agency demanding vertical cooperation and coordination between different level of government in order

[332] *Ibid.* Article 49

to ensure that persons with disabilities enjoy the same access to support services regardless of the place of their residence[333].

According to official data in 12 out of 145 municipalities no social service was provided in 2015. When it comes to social services for persons with disabilities the most represented one is a day-care centre for children with disabilities (68 municipalities or 47% of municipalities), day-care for adults with disabilities (14%), personal assistance for children (21%), in-house support for children with disabilities (37%), personal assistance (12%), supported housing for persons with disabilities (9%), respite care (6%), counselling (20%)[334]. The extent of underdevelopment of community-based services is clearly seen on the coverage of the group of independent living services (personal assistance and supported housing) with the total number of users of 372 persons in 2015[335].

Up to date, the Republic of Serbia has not adopted comprehensive deinstitutionalization strategy nor does it show any intention to do so in the near future. Adopting deinstitutionalization strategy with clear indicators, benchmarks, allocated budget and timeline pertains to immediate obligations of the States Parties under Article 19 of the CRPD[336] and is recognized by EU FRA as the indicator of the political commitment of the State to advance DI process[337].

[333] 'From Institutions to Community Living Part I: Commitments and Structures' (European Union Agency for Fundamental Rights 2017) TK-01-17-811-EN-N. p.16, para.3
[334] Ivan Sekulović, 'Mapping the Social Services under the Jurisdiction of Local Self-government Units in the Republic of Serbia' (Social Inclusion and Poverty Reduction Unit of Government of the Republic of Serbia 2016).p.17 - 22
[335] *Ibid*. p.23, Table 6
[336] Committee on the Rights of Persons with Disabilities, 'General Comment on Article 19: Living Independently and Being Included in the Community' (n 22). para.39
[337] 'From Institutions to Community Living Part I: Commitments and Structures' (n 333). p.11 - 14

The vision or better said the lack of a vision of deinstitutionalization process in Serbia relies on transformation of institutions in terms of improvements of their conditions and the way how they work which means that the new community-based services could be provided by institutions and the services would be still tied to buildings limiting the choice and control of persons with disabilities over the support they get. In addition, this is creating the risk of establishing small-scale institutions and replicating the institutional culture as pointed out in the Alternative report on CRPD implementation by DPOs[338]. The replication of institutional culture in the small-scale institutions under the guise of transformation of residential institutions to provide community-based services has been demonstrated in the research of quality of life comparing the residents of the institutions, the users of the supported housing when provided by residential institutions in the process of transformation and the users of supported housing when provided by NGOs. Stark differences have been found between all three groups in domains of satisfaction, development of competences, empowerment, independent living and social participation. In all domains users of supported housing have scored better than residents or users of the supported housing when provided by the institution (in the domain of competences as twice as higher than residents and significantly higher than users of supported housing provided by the institutions). The users of supported housing are also more empowered and have a greater level of social participation – 73% are visiting social and cultural events at least once or twice a month as compared to 10% of the institutions' residents and 23% of users of supported housing provided by the institutions[339].

The same research has explored the attitudes of the staff of the residential institutions and has shown striking data that 65% of the staff members do not believe that the funds should be

[338] 'ALTERNATIVE REPORT ON THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF SERBIA' (Coalition of Disabled People's Organizations 2015).p.16,para.3
[339] Stanković (n 289).p.281, para.1

redirected to community-based care[340], 60% thinks that the people with high support needs cannot live independently in the community and should be institutionalized[341], more the one third thinks that people with intellectual and psychosocial disabilities should not be allowed to choose the place of residence and with whom they will live[342], while 55% has the opinion that legal capacity deprivation should not be abolished[343].

This implies that the process of transformation of residential institutions only leads to replication of the institutional culture in the small-scale services providing for the better conditions of the accommodation but failing to contribute to real independent living and participation in the community, largely due to maintenance of dependence on the services provided by the institution and paternalistic attitudes of staff members of residential institutions. That is why it is crucial for decision-makers to understand the difference between institutional care and community-based care and to adopt the definition of the institutions based on institutional culture rather than number of residents.

Undermining the pluralism of social service providers and independent living is visible in the lack of financial mechanisms and procedures demonstrated on the case of deinstitutionalized people from Sremcica residential institutions almost 10 years ago which became of users of supported housing provided by NGO Association for the promotion of inclusion from Belgrade. Despite their leave from the institution they are still being kept in the registry of the institution and their financial

[340] Stanković (n 289). p.273, para.5
[341] Stanković (n 289).p.274, para.2
[342] Stanković (n 289).p.276, para.3
[343] Stanković (n 289).p.277, para.2

assets are being directed by the Center for Social Work to the institution instead to them or the service provider of supported housing[344].

The main challenges in the DI process in Serbia are the lack of political commitment for DI process and lack of understanding what are the community-based services conducive of independent living, absence of comprehensive DI strategy, the gap between development of community-based service at the local level and planned transformation of the residential institutions, weak financial mechanisms for support of community-based services which undermines their sustainability, lack of coordination within the government, no monitoring mechanism in place for monitoring of the measures taken in DI process, favouring the residential services in terms of continued investments for provision of services based on "block treatment" instead of financing specific services in accordance with individual needs and the resistance of staff members of the institutions. The widespread practice of legal capacity deprivation is also adversely affecting the choice and control of persons with disabilities as more than 11000 people are deprived of legal capacity, most people with intellectual disabilities (45,3%) and psychosocial disabilities (31%) while only 33,6% of the residents of the institutions are not under guardianship[345]. The forced psychiatric treatments are allowed by the Law on the protection of people with psychosocial disabilities. A person can be forced for medical intervention without consent if being incapable to give consent what is assessed on the basis of mental incapacity and even without the consent of a guardian if having one if the person is endangering him/herself or the others[346]. This provision is amounting to an arbitrary

[344] 'ALTERNATIVE REPORT ON THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF SERBIA' (Coalition of Disabled People's Organizations 2015).p.17, para.3
[345] 'ALTERNATIVE REPORT ON THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN THE REPUBLIC OF SERBIA' (MENTAL DISABILITY RIGHTS INITIATIVE – SERBIA 2015).p.12 - 13
[346] Law on protection of persons wtih mental disorders 2013 (Official Gazette of the Republic of Serbia 45/13).

deprivation of liberty according to the Guidelines of CRPD Committee on Article 14 and is rendering deinstitutionalization of persons with psychosocial disabilities difficult.

In its Concluding observations on the implementation of the CPRD in the Republic of Serbia, CRPD Committee expressed its concerns in regards of lack of deinstitutionalization strategy, lack of availability of community-based services including personal assistance and continued investments of public funds in residential care[347]. On the basis of these findings, it recommended that the Republic of Serbia adopts the deinstitutionalization strategy and shifts the resources from residential care to development of community-based services and that it ensures greater involvement of DPOs in the development of alternatives in the community[348].

4.2.1 The contribution of EU accession to the process of deinstitutionalization in Serbia

The Republic of Serbia has been in the process of EU integrations since 2003. In 2009 it applied for membership formally and it obtained candidate status in 2012 and started accession negotiations in January 2014 after the Council's adoption of the Negotiating framework. In July 2016[349] it opened the Chapters 23 and 24 on Judiciary and fundamental rights and Justice, freedom and security. The screening report on Chapter 23 by the European Commission identifies the current situation and recommendations for further steps towards adoption and implementation of EU Acquis in this area. In the first part, the Screening report gives the overview of the institutional

[347] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Serbia' (2016) CRPD/C/SRB/CO/1.para.39

[348] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Serbia' (n 348).para.40

[349] 'GENERAL EU POSITION', Ministerial meeting opening the Intergovernmental Conference on the Accession of Serbia to the European Union, Brussels (21 January 2014)

and legal framework in place including in the area of human rights. In the second part, the report outlines the recommendations containing several specific ones on disability. The report calls for strengthening "the oversight of living conditions in social care institutions and psychiatric hospitals" mentioning no need for deinstitutionalization and it comments that the Law on the protection of people with psychosocial disabilities strengthened the legal framework while avoiding any criticism of it[350]. It briefly adds that "more attention is needed for the social integration of persons with disabilities"[351]. Concerning the rights of the children with disabilities, it recognizes "the lack of resources to guarantee the free choice of social welfare services"[352] and call for improvements of deinstitutionalization policy for children with disabilities[353].One of the recommendations strikes out as very concrete: "Adopt the Law aiming at protecting persons with mental disabilities in institutions of social welfare"[354]. The set of recommendations for the Chapter 23 by the European Commission shows that the European Commission paid too little attention for the obligations under the CRPD and its Article 19 and it fails to mention the transition from institutional to community-based care. It also sets out few surprising recommendations like oversight of the institutions and the adoption of the law on protection of the rights of residents acknowledging in that way that the residential institutions can continue to function even though they prevent people of an independent living. These recommendations are certainly missed the opportunity to express stronger call for comprehensive deinstitutionalization.

On the basis of recommendation obtained through screening the Government of Serbia elaborated the Action plan for Chapter 23 and under the section for protection of vulnerable groups it lists its

[350] 'Screening Report Serbia Chapter 23 – Judiciary and Fundamental Rights' (European Commission 2014) MD 45/14.p.34, para.7
[351] *Ibid.*
[352] Ibid.p.35, para.7
[353] *Ibid*.p.35, para.8
[354] Ibid.p.38, para.8

efforts in the field of DI of children and the development of foster care in cooperative project with UNICEF and it sets out the measure to evaluate the "existing resources in large and small residential institutions for children and drafting recommendations on the methods of their use in the process of transition from institutional to community care"[355] with an aim to reduce the capacities of two large-scale residential facilities. In addition, it also envisages to strengthen the capacities of professionals working in 4 residential institutions through "staff training for the provision of psychosocial support for service users' reintegration"[356] as part of DI process. In addition, the measure 3.6.1.26 envisages adoption the Law aiming at protecting persons with mental disabilities in institutions of social welfare in 2017[357] which has not happened until date. These measures are too weak and far from sufficient to advance seriously the process of deinstitutionalization. With such a loose commitments to the DI and approval of the European Commission, it is not likely that any serious progress will happen in the DI process in the context of EU accession negotiations.

The screening report on Chapter 19 on social policy includes the issues related to the social inclusion among the rest. This report explicitly mentions CRPD ratification by the EU and under the section on social inclusion gives a review of developments in the deinstitutionalization process and the reform of social protection recognizing unstable financing of community-based services, again failing to be more critical to the continuation of residential care for persons with disabilities. In the section with recommendations the European Commission gets more specific and makes several references to deinstitutionalization:

[355] Government of the Republic of Serbia, 'ACTION PLAN FOR CHAPTER 23'.p.277, point 3.6.2.7
[356] Ibid.p.277, point 3.6.2.8
[357] *Ibid*.p.268, point 3.6.1.26

"De-institutionalization process needs to be prepared very carefully, as the creation of sustainable and adequate alternative services takes time. Due attention should be paid to the quality of foster care and of small group homes. However, more importantly, measures should be taken to prevent institutionalization"[358] and

"De-institutionalisation of adults is lagging behind. More attention needs to be paid to the social integration of people with disabilities, including through the development of community-based support services..."[359]

Although the references to DI are there, it seems that the EU is sending mixed and vague messages in terms of recognizing "small group homes" as viable solutions which are in the essence contrary to the provisions of the CRPD Article 19 and recent General Comment on Article 19.

The Action plan for the Chapter 19 is not yet adopted and the Chapter remains yet to be opened. It remains to be seen if more serious commitments towards DI will be made under the Chapter 19 as the Action plan on Chapter 23 stated that the measures for the area of social integration of persons with disabilities will be elaborated in the Action plan under the Chapter 19.

The Republic of Serbia has been the beneficiary country of the Instrument for Pre-Accession Assistance ever since its establishment from the budgetary period 2007 – 2013 throughout the current one 2014 – 2020.

The European Commission monitors regularly the progress made in the areas where Serbia expressed commitment to made improvements in the process of EU negotiations. In its most recent Progress Report it expresses the concerns over the practice of involuntary confinements and no

[358] 'Screening Report Serbia Chapter 19 – Social Policy and Employment' (European Commission 2016) MD 11/16.p.13, para.1
[359] *Ibid*.p.13,para.2

progress in the area of deinstitutionalization[360], the lack of access to education of children with disabilities living in the institutions[361], access to services for persons with disabilities and the failure to align the institutional treatment of persons with intellectual and psychosocial disabilities with international standards[362]. This implies that the issue of deinstitutionalization is on the agenda in the process of EU accession negotiations.

Throughout the IPA program for Serbia, it was not always clear both for the European Commission and Serbian government what kind of obligations are arising from the CRPD and its Article 19 for both parties. In 2011 the European Commission had published a tender call for the "works on (re)construction and adaptation of 6 residential care institutions for persons with mental disability and mental illness"[363] to support Serbian Ministry of Labour, Employment and Social Policy in this endeavor. The value of the tender was 300.000 EUR. Such investment would represent the breach of Article 19 of the CRPD. It was only after the pressure was put to the European Commission by civil society and domestic and international actors that this problematic call got cancelled[364]. As a result, the new tender call was announced afterward by the European Commission with changed contract description and heightened amount to 2 million EUR. The new tender aimed at "preparation of a transformation plan for residential and psychiatric institutions"; development of a range of quality community-based services in support of deinstitutionalization

[360] 'Serbia 2016 Report' (European Commission 2016) SWD(2016) 361 final.p.61, para.2
[361] *Ibid*.p.63, para.2
[362] *Ibid*.p.63, para.3
[363] RS-Belgrade: IPA — preparation of documentation for the (re)construction and/or adaptation of 6 residential institutions 2011/S 21-032516 Location: Europe (non-EU) — Serbia Service procurement notice, Section 7. Available at: http://europa.rs/tenderi/zatvoreni/2014/EuropeAid_130668_1_Procurement.pdf
[364] Quinn and Doyle (n 199).p.61, para. 3

of persons with mental disability and mental illnesses and a support to a grant scheme to fund local actors to develop and implement community-based services[365].

The contribution of EU's financial assistance will be assessed on the example of multiannual project financed by the European Commission worth around 5 million of EUR titled "Enhancing the position of residents in residential care institutions for persons with mental disability and mental illness and creation of condition for their social inclusion in the local community" better known as "Open Arms Project" implemented from 2012 to 2015[366]. The project has involved 11 social welfare residential institutions and 5 psychiatric hospitals and involved partnership of the Ministry of Labor, Employment and Social Policy and the Ministry of Health as two key state actors for the reform of institutional care.

The purpose of the project was to enhance the social inclusion of people with intellectual and psychosocial disabilities and to enable their deinstitutionalization through the transformation of residential institutions with the goal to improve the quality of services and to support the development of community-based social and health services[367].

The project activities were focused on development of deinstitutionalization program, development of transformation plans for the residential institutions involved in the project, elaboration of feasibility study for transformation of psychiatric hospitals, development of legal reform proposal for development of community-based care, delivering a training package for the

[365] RS-Belgrade: IPA — enhancing the position of residents in residential care institutions for persons with mental disability and mental illness and creation of conditions for their social inclusion in the local community 2011/S 200-324809 Location: Europe (non-EU) — Serbia Service procurement notice, Section 7. Available at: http://europa.rs/tenderi/zatvoreni/2011/EuropeAid_131330_1_Procurement.pdf

[366] The Delegeation of the European Union to the Republic of Serbia, 'Database of funded projects'. Available at: http://mapa.euinfo.rs/home/details/145 Last accessed on 10th November 2017

[367] *Ibid.*

staff members of residential institutions, sub-granting scheme for community-based services (19 projects supported worth 2.3 million EUR).

The transformation plans for each of 11 institutions involved included a detailed plan following the assessment of the residents' needs, institution's capacities, the type of services to be provided, budget and the timeline. The final report upon completion of the project has shown that until the end of the project 160 people were deinstitutionalized and 600 staff members were trained [368]. The project has submitted the feasibility study for the DI of psychiatric care to the Ministry of Health which ordered the study but until now the Ministry has not followed up on it nor it has officially adopted it as a policy document[369]. The report also states that there is no adequate leadership from the level of government for the DI process and notes that there is enough money in the system for the transition to community-based care but the problem is the existing system of funding which does not allow that the funds follow the users and their needs[370]. Among the noted problems it also emphasizes the importance of vertical cooperation in terms of coordination between the government and local authorities both in terms of delegating responsibilities and funds. Within the project, a detailed national plan for deinstitutionalization was developed in coordination with the working groups for DI of the Ministry of Health and Ministry for Labour, employment and social policy which was supposed to be the basis for the national strategy on DI. Although the Plan was submitted to both Ministries, it has never been officially adopted by the government after the project was completed.

[368] Monika Gabanyi, 'Final Report of the project "Enhancing the Position of Residents in Residential Care Institutions for Persons Wiht Mental Disability and Mental Illness and Creation of Condition for Their Social Inclusion in the Local Community"' (Hifab, Bolt International Consulting, Society of Social Psychiatry and Mental Health i Pro mente oö 2015) 11SER01/11/11.p.6, para.6

[369] *Ibid*.p.8, para.4

[370] Ibid.p.10, para.2-3

The individual plans for the transformation of the institutions show that the transformation can be completed for 29 years, while 9 out of 11 institutions can complete it within 15 years the largest one would need time until 2043[371]. It is predicted that for this period of time "1961 people would be deinstitutionalized while 1566 would get back to their families or in some other way"[372]. It remains unclear what is then the meaning of "deinstitutionalization" if the ones coming back to their families are not considered as "deinstitutionalized" and what is "the other way" in which the remaining people would go out. It is estimated that the cost of the process of transformation would be 16.733.029 EUR[373].

After the duration of the project both working groups for DI within both of the Ministries have practically ceased to operate. As for the process of transformation of residential institutions, the report on the project has recognized that sustainability is the issue in all 11 institutions and until now no further progress has been made.

This case study is proving that without the firm political commitment of the key actors in society for the DI process available EU funds could easily be wasted. That is why the European Commission should introduce specific ex-ante conditionality for usage of IPA funds using the analogy with the ESI Funds. The key ex-ante conditionality should be the existence of national DI strategy with clear and concrete indicators, targets and benchmarks and the timeline in line with the recommendation of CRPD Committee stipulated in the Concluding observations on the implementation of the CRPD in the Republic of Serbia[374].

[371] Ibid.p.15, para.4
[372] *Ibid.*
[373] *Ibid.*
[374] Committee on the Rights of Persons with Disabilities, 'Concluding Observations on the Initial Report of Serbia' (n 348). para.40

4.3 Common lessons from DI processes in Serbia and Croatia

The models of deinstitutionalization applied in these two countries which are sharing the same legacy of institutional care for persons with disabilities display some striking commonalities which are in essence preventing the people with disabilities to participate fully in the life of the communities. Both countries have chosen the path to keep the residential institutions running but to gradually decrease the number of residents and to transform the institutions to become providers of community-based services. However, in both countries that includes the perception that there are people with severe disabilities who are incapable to live in the community and for whom the only possible care is the residential care. This attitude is largely contradicting with the obligations under Article 19 and independent living principle which should be applicable to all regardless of the type and severity of impairment. Such approach is necessarily incurring double-running costs, both for maintained residential care and for community-based services and consequently is costly. The Croatian national plan for deinstitutionalization is giving the choice for the institutions: to decide if they are going to close down, to transform in the community-based support centers or to keep double-running system including both residential capacities and community services. Something similar is imagined for the residential institutions for children with disabilities in Serbia and it is logical that the institutions when given such a choice will choose to run parallel systems of support. Such system is flawed for several reasons. Firstly, it impedes the principle of plurality of service providers which is the essence of social protection reform in both countries favoring state-run providers over the ones from civil society and the private sector. In both countries, the system of financing of the residential institutions is linked with the central level of government while the financing of community-based services is delegated to municipalities without clear

obligation to do it. Without accompanying decentralization of funds, such approach is resulting in a scarce availability of community-based services and large discrepancies between municipalities. Secondly, it undermines the choice and control of people with disabilities over the type and the extent of support they get. The services remain tied with the buildings and the funding goes through service providers, in the worst case – residential institutions, leaving little choice for persons with disabilities to freely choose the service in accordance to their individual needs. In addition, the risk to replicate institutional culture in terms of the content of the service and the way how it is provided remains high. Both countries have not gone far in putting in place the funding mechanism that would allow the funds to follow the person instead of the service providers.

Although it is perceived that EU accession process has played a significant role in advancing the process of deinstitutionalization in Serbia and Croatia the analysis of the European Commission's screening reports for negotiation Chapters 19 and 23 and Progress Reports show that the European Commission is recognizing that institutional is a human rights issue that needs to be addressed but it doesn't apply the CRPD's approach consistently when drafting the recommendations for the countries in accession and it does not regard the absence in the progress on deinstitutionalization as the issue due to which the negotiations could be suspended or stalled. That implies that determinacy of the deinstitutionalization as a condition for the membership is not clear which puts into question the potential and efficiency of democratic conditionality in this area. On the other hand, the EU's financial assistance has proved to be an important instrument to support the process of deinstitutionalization. However, not the same standards of safeguards apply to ESI Funds and the Instrument for Pre-Accession Assistance. For IPA funds there are no ex-ante conditionalities like in ESI Funds which can lead to inefficient spending of IPA funds missing the opportunity to advance some long-term changes.

Conclusion

Even though the CRPD does not have a direct effect in EU law it still creates the legal obligations for the EU and is an integral part of EU's legal order[375]. In the context of usage of the ESI Funds, the CRPD certainly creates the negative obligations in terms of preventing the funds to be invested in the forms of institutional care due to its supremacy over secondary sources of EU law. As the right to live independently and being included in the community is the matter of shared competences between the EU and its Member States the question is what competences the EU has. According to subsidiarity principle, the EU should act only if "the objectives of the action could not be sufficiently achieved by the Member States and the Union can better achieve the action, because of its scale or effects"[376]. It is not likely that the EU could respond to positive obligations under CRPD Article 19 issuing the harmonized legislation on community-based services due to the divergence of welfare systems across the EU Member States and variety of potential measures through which States could implement these positive obligations. That means that the EU can only guide the Member States in the area, provide financial assistance and make sure that its funds are not used to perpetuate segregation and isolation of persons with disabilities referring both to ESI Funds and its external action funds such as the Instrument for Pre-Accession Assistance. In this way, the EU seeks to harmonize gradually the fulfillment of its objectives in the human rights field through the promotion of sustainable solutions and good practice examples and monitoring of usage of its funds without legislating in the field. Besides, the EU **should also revise its Declaration of Competence** that it had put together when it confirmed the CRPD and include new

[375] Butler (n 165).p.46, para.4
[376] TFEU (n 103), Article 5 (3)

sources of EU law which bear relevance for CRPD implementation and explain more clearly how are those sources of law engaged with the obligations from the CRPD.

While there are avenues for the individuals on the basis of ESI Funds Regulations and the EU Charter of Fundamental Rights, to challenge the decisions of funding the projects supportive of residential institutions it is strikingly difficult to do so, in the first place because it would be difficult to demonstrate that the funds are not used in line with CRPD Article 19 as the most of the programmes include as the objective social inclusion and the development of community-based services prima facie.

Although the CRPD does not impose the obligation for the EU to take action in the field of shared competences, if the EU does so, the CRPD does not create only negative obligations but the positive as well so to ensure that the measure taken not only avoids violation of the right but that it leads to fulfillment. That would mean that the European Commission will have to strengthen its monitoring mechanisms and get more involved in the aspect of addressing the potential complaints. The measures taken by the Commission might also include the provision of technical support and guidance to the Member States on the transition from institutional to community-based care and undertaking of corrective measure when it is determined that the inappropriate spending has taken place.

Considering the vastly differing outcomes across EU countries in the transition from institutional to community-based care, it is highly desirable that the EU acts further in the field of shared competences. Although the commitment to allocate the Structural Funds for a transition from institutional to community-based care has become visible in the ESF Regulation, the monitoring and the complaint procedures are still left within the responsibility of EU Member States.

The following recommendations for the improvement of the mechanisms of monitoring, reporting and complaints systems are stemming from the analysis above and identified gaps which are causing the occasional misuses of the ESI Funds contrary to CRPD Article 19:

- **Heightened scrutiny of fulfillment of ex ante conditionalities** by the European Commission for the countries which envisage in their Partnership Agreements the transition from institutional to community-based care with the special emphasis on the ex ante conditionality on the existence of national deinstitutionalization strategy with concrete targets, benchmarks and timeline in line with the General Comment on CRPD Article 19. If the ex-ante conditionality is not fulfilled within the given deadline the European Commission should be ready to undertake corrective actions it has at its disposal including the interruption or suspension of the payments.
- **Improvements of the complaint mechanisms** – the current complaint mechanism for ESI Funds operations is largely decentralized as it envisages the submissions of the complaints to the Managing Authorities. In the event of complaint submission to the European Commission, the Commission is only examining if the procedural arrangements for complaints are in place and returns the complaint to the Managing Authority. The practice has shown that the greater involvement of the Commission in consideration of complaints may bring better outcomes. The European Expert Group on the transition from institutional to community-based care had alarmed the European Commission informally upon receiving the information of the call for a proposal which envisages the support to residential institutions. The European Commission intervened with the Managing Authority and the call for proposals was changed as a result[377]. The new complaint mechanism for the new budgeting period 2021 – 2028 should resemble the

[377] Parker, Bulić Cojocariu and Kokić (n 233).p.27, para.7

court hierarchy and the two-level examination of the complaints. The Managing Authority could act as the first instance and if the complaining is not satisfied how the complaint is resolved it could submit it further to the European Commission which would examine it on merits and its decision would be the final one.

- **Strengthening the financial and technical support to civil society to take part in all stages of ESI Funds implementation according to the Code of Conduct on partnership** including the participation in the work of Monitoring Committees, preparation and assessments of call for proposals, preparations of annual implementation reports on OPs, progress reports on PAs and evaluations of the programmes[378].
- **Modifications of the requirements for annual implementation reports on the Operational Programmes and Progress reports on Partnership agreement** so to include more details on the projects related to deinstitutionalization on the basis of which the European Commission could infer the extent to which the project supports independent living and community inclusion. The usage of programme-specific indicators for Article 19 should be considered as the reporting requirement using the set of indicators developed by EU Fundamental Rights Agency and the Commissioner for Human Rights of Council of Europe;
- **Issuing the guidelines for evaluation of the projects** related to the deinstitutionalization for the States implementing programmes funded by the EU funds which would focus on evaluating the quality of life and the satisfaction of users – persons with disabilities and their families and the extent to which they have choice and control to choose where they will live and what type and the extent of the support they will get.

[378] Code of Conduct on Partnerships (n 213), Articles 13 - 17

In relation to the Instrument for Pre-Accession assistance which is on disposal for countries in the process of EU accession, it should also ensure that IPA funds are not used to perpetuate the segregation and isolation of persons with disabilities. **IPA Regulation should be revised and should also include ex-ante conditionalities on CRPD implementation framework and more importantly on the existence of national deinstitutionalization strategy.** Such strategy should be qualitatively assessed by the European Commission so to make sure that it does not envisage the investments in the residential care and replication of institutional culture by building smaller institutions and congregated facilities.

In the process of EU accession, the EU should pay due regard to the process of deinstitutionalization especially under negotiations chapter 23 on Judiciary and fundamental rights and chapter 19 on Social policy. Firstly, the European Commission should be clearer on setting the deinstitutionalization and the progress made in it as a condition in the process of EU accession and it should ensure that its conditionality relies on the requirements Article 19 of the CRPD according to the recent General Comment. Secondly, it should ensure the credibility of conditionality by being ready to withdraw the "rewards" if the country fails to fulfill its commitments by being ready to suspend or withdraw IPA funds for projects in this area and even to stall the negotiations of relevant chapters.

While in the relation between the EU and its Member States the EU cannot enforce the positive obligations under Article 19 in its Member States due to the limitations of EU law it could provide the guidance and monitor states' compliance and make sure that its funds are not used for the investments in the residential care. In relation to the countries in the process of EU accession, the EU has the potential to advance the right to live independently and being included in the community through its policy of conditionality. However, it does not seem that this leverage was

used enough in the past. First, the deinstitutionalization as a condition in the process of accession negotiations was not strongly determined and the EU has not introduced clear indicators and benchmarks against which it could measure the progress of the country. On the other hand, the external incentives offered by the EU in the form of financial assistance did contribute to the progress in the field but the impression is not to the extent it could have. The empowerment of domestic actors including civil society seemed to be efficient but not enough in the context of lack of the political commitment by the State. Thus, more stringent requirements towards state actors would be needed if the chance to advance the right to live independently and being included in the community is not to be missed in the process of EU accession negotiations.

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