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THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES AND THE TRANSFORMATION OF SOCIAL CARE IN THE CZECH REPUBLIC

(The right to live independently and be included in the community under Article 19 of the CRPD and the obligations of the Czech Republic)

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LIST OF ABBREVIATIONS

- CESCR UN Committee on Economic, Social and Cultural Rights
- CRPD Convention on the Rights of Persons with Disabilities
- CRC UN Convention on the Rights of the Child
- ECHR European Convention on Human Rights and Fundamental Freedoms
- ECtHR European Court of Human Rights
- HRC UN Human Rights Committee
- ICCPR International Covenant on Civil and Political Rights
- ICESCR International Covenant on Economic, Social and Cultural Rights
- RevCS European Social Charter (revised)

INTRODUCTION

Fifty years ago, Erving Goffman in his work "Asylums" described "total institutions" and critically evaluated their impact on the lives of people with mental disabilities. For fifty years, we have been aware of the fact that inmates spending their daily lives in large segregated institutions are suffering socially, their lives are controlled and they live in complete isolation from the world outside the walls. As a sociologist and an anthropologist, Goffman completely disregarded the legal aspects of this situation. However, his work does have importance to lawyers as it reveals systematic discrimination against people with mental disabilities based on segregation and fear of unreason. It is obvious that personal and family lives of people living behind the walls of an institution are subject to limitations and privacy of individuals is compromised due to the rules, obligations and commands imposed by the institution and, to a large extent, to its practical needs. Only a few years ago, cage beds were a common practice of "tranquilizing" inmates of such institutions in the Czech Republic, and various rumours describing the horrors of degrading and inhuman treatment are still afloat. Another important question is whether life in such institutions can still be referred to as "voluntary" if the system is based on a strange fiction of a "voluntary" agreement on social services between institutions and persons who are mostly deprived of legal capacity, as is the case in the Czech Republic. All the above aspects have a significant legal dimension.

Institutionalization and overt segregation of people with intellectual disabilities were not considered as a human right issue until recently. The rights of people with disabilities started to gain more public attention as late as in the 1990's, and this process resulted in the adoption of the breakthrough UN Convention on the Rights of Persons with Disabilities in 2006. Our work is dealing with the right to live in the community and with the States' obligations laid down in the Convention on the Rights of Persons with Disabilities. It deals with the issue of persons with disabilities in terms of respect, protection and fulfilment of the rights of this significantly marginalized group.

The aim of our work is to identify specific elements of the right to live in the community and of the corresponding obligations of the Czech Republic. As to the methodology used, we will focus first on the analysis of international law to help us understand the meaning of the "right to independent living" and of the fact that life in the community is a prerequisite to the realization of this right. Then, we will focus on the concept of obligations in the theory of international law and its application in the practice of international organizations, notably of the UN Committee on Economic, Social and Cultural Rights. A correct definition of the obligations and their elements is a key prerequisite of conceptualization of the right to independent living.

¹ Goffman, E. Asylums: Essays on the Social Situation of Mental Patients and Other Inmates. Anchor Books: New York, 1961.

Conceptualization is understood to mean the process of specification and definition of the elements of the rights and the corresponding obligations which are a prerequisite for living independently. The conceptualization of the right to live independently will help us identify the specific elements and the corresponding obligations of the Czech Republic arising from the right to be included in the community which are a key prerequisite of the transformation of social care in the Czech Republic.

The term "people with intellectual disabilities" used in this paper comprises a wide group of people with disabilities including a group of people with mental and psychosocial disabilities.² The reason for that is the fact that the social services transformation process in the Czech Republic and in particular the pilot project is focused almost exclusively on the group of people with mental disabilities living in institutions for people with disabilities.³ However, we would like to draw attention to the fact that the following conclusions apply also to other areas, such as deinstitutionalization of psychiatric care or residential care for the elderly.

The author would like to thank his colleagues from the League of Human Rights and the Mental Disability Advocacy Center, namely to Zuzana Durajová, Barbora Rittichová, Denisa Slašťanová and David Zahumenský, for their support and comments. He would also like to acknowledge the expert comments provided by his colleague Jan Fiala from the Disability Rights Centre, which helped correct many inaccuracies in his work. And, last but not least, the author would like to thank David Kopal and other trainees, volunteers and colleagues.

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² WHO Resource book on mental health. Human rights and legislation. Stop exclusion, dare to care. WHO: Geneva, 2005, pp. 22 to 23

³ Compare the list of institutions involved in the pilot transformation project on the following pages and their target group: www.trass.cz

DE-INSTITUTIONALIZATION OF CARE FOR PEOPLE WITH MENTAL DISABILITIES IN INTERNATIONAL DOCUMENTS ON HUMAN RIGHTS

In order to be able to clearly define the right to live in the community, we will have to somewhat simplify this concept and establish the areas it actually covers. A relevant definition was proposed by Krieg who says that the debate over deinstitutionalization and the development of community-based services has been associated with three types of rights:

- i) the right of the individual to receive treatment;
- ii) the right to treatment in the least restrictive setting;
- iii) the right to freedom from harm.4

We will build on Krieg's definitions; however, we are going to deal with the right of the individual to receive treatment marginally and only in relation to the second type of right to treatment in the least restrictive setting or, in other words, the right to live in the community. The right to freedom from harm is related to the quality of treatment, and our work does not cover this aspect. In our text below, we will focus on the question of whether, and if so how, the right to live in the community (or, in a broader sense, the right to independent living) is defined in the international law. A separate chapter dedicated to the European Convention on Human Rights deals mostly with the right of individuals to personal freedom, taking into account the case-law of the European Court of Human Rights.

⁴ Krieg, R.G. An interdisciplinary look at the deinstitutionalization of the mentally ill. Social Science Journal 38 (2001), pp. 367–380.

The Universal Declaration of Human Rights and the UN International Covenants

The Universal Declaration of Human Rights, adopted by the United Nations in 1948 in response to the horrors of World War II, is a landmark document in the modern history of protection of natural human rights. This global catalogue of fundamental human rights and freedoms can be described as "universal" as it makes no distinction between" civil and political rights" on the one hand and "economic, social and cultural rights" on the other - it covers both these categories without making any differences. Rights related to the right to live in the community can be found in several provisions of the Universal Declaration. For example, Article 5 states that "no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment", Article 6 declares that "everyone has the right to recognition everywhere as a person before the law", Article 12 protects privacy. An important article in relation to the right to live independently is also Article 13 which states that "everyone has the right to freedom of movement and residence within the borders of each state". This provision must be read in conjunction with Article 25 of the Declaration, under which "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services ... "The right of persons with disabilities to live independently therefore means that they are free to choose their residence, provided there is a choice, i. e. that there are alternatives to institutional care. In other words, the exercise of these rights assumes the existence of the necessary social measures enabling life in the community.

In 1966, two international covenants were adopted which, for political reasons, artificially separated the so-called political and civil rights from economic, social and cultural rights. However, both these Covenants have a common history with the Universal Declaration of Human Rights. The **Covenant on Civil and Political Rights** highlights the so-called aspect of social cooperation associated with the life in the community which is the core of certain rights. According to Degener and Quinn⁶, the examples of these are the right to freedom of association (Article 22), family rights (Article 23), the right to be protected as a child (Article 24) and the right to privacy (Article 17). According to the **Covenant on Economic, Social and Cultural Rights**, the right to live in the community is subject to social, health and economic aspects of life of people with disabilities and it is related mainly to the right to social security (Article 9), the right to an adequate standard of living (Article 11) and the right to health (Article 12).

Let us focus first on the rights provided for in the Covenant on Civil and Political Rights (hereinafter referred to as the "ICCPR") in terms of their relevance to institutional social care. These include in particular the prohibition of torture, cruel, inhuman or degrading treatment or punishment (Article 7 of the ICCPR), which

⁵ The purpose of this work is not to address in detail the relationship between the categories of civil and political rights and of economic, social and cultural rights. Please refer to the relevant literature, in particular Fredman, S. Human Rights Transformed. Oxford: Oxford University Press, 2008.

⁶ Degener, T., Quinn, G. (eds.) The current use and future potential of United Nations human rights instruments in the context of disability. New York & Geneva: UN, 2002, p. 57.

protects also people with disabilities living in institutions. According to Degener, a violation of Article 7 of the ICCPR may occur for example if disabled persons are "warehoused" in institutions. Quinn⁹ argues that also a deliberate policy to treat persons with disabilities under separate arrangements simply for the sake of administrative convenience might amount to second class citizenship and is thus at least arguably "degrading" as per Article 7 of the ICCPR. Another relevant provision relates to the right to liberty of person (Article 9 of the ICCPR) and protects also people with disabilities involuntarily placed in institutional care. 10 The UN Human Rights Committee, for example, pointed out that Article 9 Paragraph 4 of the ICCPR, which provides for the right to check the lawfulness of deprivation of liberty by a court, applies to all cases of deprivation of personal liberty. In the Czech Republic, there are obvious cases of involuntary hospitalization as defined in the Czech Civil Procedure Code; however, even the placement of a person deprived of legal capacity or with a limited legal capacity in an institution providing social services on the basis of his/her guardian's decision can be considered to constitute deprivation of personal liberty. Institutional care is also related to the right of persons to be treated with humanity and with respect for their dignity (Article 10 of the ICCPR). 11 Article 17 of the ICCPR protects the right to privacy, and precisely the privacy of people with disabilities in institutional settings is subject to significant limitations. People with disabilities living in institutions often share a room with many other people and their personal space is limited by the space of their roommates. Single rooms are rare. Disabled persons in institutional care are also subject to other disciplinary restrictions such as a fixed daily schedule, and they have to accept the involvement of many others in their private lives (doctors, therapists, personal assistants, etc.). The right to privacy is therefore difficult to protect, especially in an institutional setting. 12

Let us now shift our focus to the **Covenant on Economic, Social and Cultural Rights** (hereinafter referred to as the "**ICESCR**"), from which we will primarily derive the right to living independently. The Pact was adopted in 1966, came into effect in 1976 and in the same year it became legally binding for Czechoslovakia. The right to live independently, expressed in terms of deinstitutionalization of institutional care, is as such inferable from the ICESCR, which is important for the definition of the obligations of States and of their nature (as discussed below). The right of people with disabilities to living independently is based primarily on the right to health, the right to social security, the right to adequate standard of living, the right to housing, the right to work and the right to education.

⁷ Cf. Human Rights Committee. General Comment No. 20: Replaces General Comment No. 7 concerning prohibition of torture and cruel treatment or punishment (Article 7): . 03/10/1992., Paragraph 2.

⁸ Degener, T., Quinn, G. (eds.) The current use and future potential of United Nations human rights instruments in the context of disability. New York&Geneva: UN, 2002, p. 55.

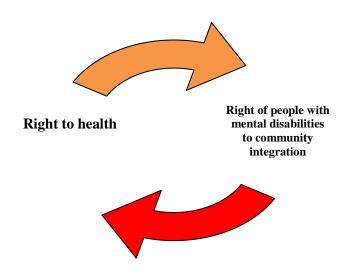
⁹ Quinn, G. The International Covenant on Civil and Political Rights, in Degener, T., Koster-Dreese, Y. (eds.) Human Rights and Disabled Persons, Doredrecht, Martinus Nijhoff, 1995, p. 84.

¹⁰ Cf. Human Rights Committee. General Comment No. 8: Right to liberty and security of persons (Art. 9): . 06/30/1982., Paragraph 1.

¹¹ Cf. Human Rights Committee. General Comment No. 21: Replaces General Comment No. 9 concerning humane treatment of persons deprived of liberty (Art. 10): . 04/10/1992., Paragraph 2.

¹² Cf. Degener, T., Quinn, G. (eds.) The current use and future potential of United Nations human rights instruments in the context of disability. New York&Geneva: UN, 2002, p. 57.

The key right in terms of deinstitutionalisation of social care is the right to the enjoyment of the highest attainable standard of physical and mental health (Article 12 of the ICESCR). This right implies "the right to have access to, and to benefit from, those medical and social services which enable persons with disabilities to become support their social integration." 13 The right to health was independent and [...] linked to deinstitutionalization by Paul Hunt, the UN Special Rapporteur on the Right to Health. In his 2005 report¹⁴, he derives the right to community integration from the right to health. He emphasized the general "application of this right to all persons with mental disabilities" and the value of integration, which "supports their dignity, autonomy, equality and participation in society." 15 According to Hunt, the right to integration comprises also a preventative element which consists in preventing institutionalization. Institutionalization renders persons with mental disabilities vulnerable to human rights abuses and damages their health on account of the mental burdens of segregation and isolation. Hunt also emphasized the strengthening element of integration because it is "an important strategy in breaking down stigma and discrimination against persons with mental disabilities." In his report to the UN Commission on Human Rights, he concluded that "the segregation and isolation of persons with mental disabilities from society is inconsistent with the right to health, as well as the derivative right to community integration, unless justified by objective and reasonable considerations, grounded in law and subject to independent scrutiny and determination." ¹⁷



An independent way of life of people with disabilities depends on their economic status in society. People with disabilities constitute a significant group of people at risk of poverty; in the developing world, they are often the poorest of the poor in terms of income, but in addition their need for income is greater than that of ablebodied people, since they require money and assistance to try to live normal lives. Therefore, it is essential that the State adopts appropriate social policy instruments

¹³ Committee on Economic, Social and Cultural Rights: General Comment No. 5. Persons with disabilities: . 12/09/1994, Paragraph 34.

¹⁴ Hunt, P. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. E/CN.4/2005/51, Report of 11 February 2005.

¹⁵ Ibid., Paragraph 85.

¹⁶ Ibid., Paragraph 85.

¹⁷ Ibid., Paragraph 86.

¹⁸ Sen, A. Idea of Justice. London: Penguin books, 2009, p. 258.

ensuring them a standard of living sufficient for them to lead independent lives. The ICESCR provides for the right to social security, including the right to social insurance, in its Article 9. In 1994, the UN Committee on Economic, Social and Cultural Rights (hereinafter referred to as "CESCR" or "the Committee"), adopted its General Comment No. 5 dealing with the rights of persons with disabilities. 19 In its comment on the right to social security (see Article 9 of the ICESCR), the Committee stated that "institutionalization of persons with disabilities, unless rendered necessary for other reasons, cannot be regarded as an adequate substitute for the social security and income-support rights of such persons." The Committee emphasized the community dimension of the income-support by its requirement that "as far as possible, the support provided should also cover the needs of individuals (who are overwhelmingly female) who undertake the care of a person with disabilities." while such persons do not necessarily have to be family members.²¹ Amartya Sen points out the connection between the impairment of income-earning ability, which can be called "the earning handicap" and the difficulty in converting incomes and resources into good living ("the conversion handicap"). According to Sen, the earning handicap tends to be reinforced and magnified precisely by the conversion handicap.²

The right to social security under Article 9 of the ICESCR must be understood in conjunction with other social rights, in particular the right to an adequate standard of living under Article 11 of ICESCR. This right includes other rights, namely the right to "food, clothing, housing and to the continuous improvement of living conditions". In addition to the obligation to ensure that persons with disabilities have access to this group of rights, i.e. access to adequate food, accessible housing and other basic material needs, the Committee also emphasized the obligation to ensure the availability of "support services, including assistive devices" that will "assist them to increase their level of independence in their daily living and to exercise their rights." The right to adequate standard of living of people with disabilities therefore includes an obligation of the State to create a system of support and assistance with the goal of increasing the level of independence of people with disabilities in their daily living, which must also be understood as independence of care provided by a total institution.

A very important right in this context is the right to housing. Under Article 11 of the ICESCR, the right to housing means the right to "adequate" housing; the interpretation of this article should not be restrictive, and this right should rather be interpreted as the "right to live in security, peace and dignity". According to the Committee, this view is based at least on two reasons. In the first place, the right to housing is integrally linked to other human rights and to the fundamental principles upon which the ICESCR is premised. The interpretation of the term "housing" can be inferred from the concept of "the inherent dignity of the human person" from which the rights in the Covenant derive. Most importantly, "the right to housing should be

¹⁹ Committee on Economic, Social and Cultural Rights: General Comment No. 5. Persons with disabilities: . 12/09/1994.

²⁰ Ibid, Paragraph 29.

lbid, Paragraph 28. Cf. also Committee on Economic, Social and Cultural Rights: General Comment No. 19. The right to social security (Art. 9), E/C.12/GC/19, Paragraph 20.
 Sen, A. Idea of Justice. London: Penguin books, 2009, p. 258.

²³ Committee on Economic, Social and Cultural Rights: General Comment No. 5. Persons with disabilities: . 12/09/1994, Paragraph 33.

ensured to all persons irrespective of income or access to economic resources."24 The Committee stressed in particular the aspect of accessibility of housing to people with disabilities. The Committee says that disadvantaged groups "must be accorded full and sustainable access to adequate housing resources", while such disadvantaged groups as "the elderly [...], the physically disabled, [...] the mentally ill [...] and other groups should be ensured some degree of priority consideration in the housing sphere. Both housing law and policy should take fully into account the special housing needs of these groups." ²⁵ The Committee further identified certain aspects of the right that must be taken into account when assessing the "adequacy" of the housing, namely:

- a) Legal security of tenure:
- b) Availability of services, materials, facilities and infrastructure;
- c) Affordability;
- d) Habitability;
- e) Accessibility;
- f) Location:
- g) Cultural adequacy.²⁶

If we read Article 11 of the ICESCR as a whole and in conjunction with other provisions of the ICESCR (in particular Articles 9 and 2 of the ICESCR), and if we take into account the importance of this right in connection with the general principles of the CRPD (Article 3 (a) of the CRPD) and certain other rights (Articles 9 and 19 of the CRPD), we will arrive at the conclusion that in case of people with disabilities, the right to adequate housing involves the right to live in the community rather than in institutional settings. Any other interpretation would lead to absurd conclusions. Therefore, the obligation of the State to ensure the accessibility of the right to adequate housing under Article 11 (1) of the ICESCR should be understood as the right to housing in the natural environment of the community.

Another right worth mentioning which cannot be realized in institutional settings is the right to education (Article 13 of the ICESCR). According to Article 13 of the ICESCR, the States should recognize equal primary, secondary, tertiary and lifelong educational opportunities for children, youth and adults with disabilities in "integrated settings", i.e. in mainstream schools.²⁷ Education within an institution cannot be inclusive.28

The Convention on the Rights of the Child and the transformation of institutional care for children with mental disabilities.

²⁴ Committee on Economic, Social and Cultural Rights: The right to adequate housing (Article 11 (1)): . 12/13/1991., Paragraphs 6, 7. ²⁵ Ibid., Paragraph 8.

²⁶ Ibid., Paragraph 8.

Committee on Economic, Social and Cultural Rights: General Comment No. 5. Persons with disabilities: . 12/09/1994, Paragraph 35.

²⁸ The issue of (non-) education of children with mental disabilities in institutions was addressed by the European Committee of Social Rights in MDAC v. Bulgaria, Complaint No . 41/2007, decision of the ECSR of 3 June 2008. The Committee concluded that the situation constituted a violation of the right to education and of non-discrimination as defined in the RevCS.

In 1989, the United Nations General Assembly adopted the Convention on the Rights of the Child (hereinafter referred to as the "CRC"), which entered into force on 2 September 1990. On 6 February 1991, the CRC entered into force in the Czech and Slovak Republics. The Convention on the Rights of the Child explicitly provides also for the rights of children with disabilities. An important point is the general provision of Article 2 of the CRC prohibiting discrimination against children, which explicitly mentions "disability" as a prohibited ground for discrimination. The Committee on the Rights of the Child considers this mention to be unique, perhaps because it was the first explicit mention of disability as a ground for discrimination in international law. What is the reason for this? The answer is obvious. According to the Committee on the Rights of the Child, it can be explained simply by the fact that children with disabilities belong to one of the most vulnerable groups.²⁹ The crucial provision is Article 23 of the CRC which provides for the rights of children with disabilities. According to Article 23, Paragraph 1 of the CRC, children with disabilities "should enjoy a full and decent life in conditions which ensure dignity, promote selfreliance and facilitate the child's active participation in society." According to the Committee on the Rights of the Child, this provision should be considered as the leading principle for the implementation of the CRC with respect to children with disabilities and all the measures taken should be directed towards this goal. The core message of this provision is that children with disabilities should be included in the society.30

The UN Committee on the Rights of the Child has often expressed its concern at the high number of children with disabilities placed in institutions. In its General Comment No. 9, it addresses in detail the issue of their institutionalization. According to the UN Committee on the Rights of the Child, the "quality of care provided, whether educational, medical or rehabilitative, is often much inferior to the standards necessary for the care of children with disabilities." The Committee further stated that this situation is due either to lack of identified standards or lack of implementation and monitoring of these standards. Institutions are also a particular setting where children with disabilities are more vulnerable to mental, physical, sexual and other forms of abuse as well as neglect and negligent treatment. The Committee therefore urged States parties to use the placement in institution only as a "measure of last resort, when it is absolutely necessary and in the best interests of the child." Attention should be paid to "transforming existing institutions" while the Committee recommends to focus on small residential care facilities organized around the rights and needs of the child. It should also result in developing national

²⁹ Committee on the Rights of the Child. General Comment No. 9 (2006). The rights of children with disabilities. CRC/C/GC/9, 27 February 2007, Paragraph 8. The Committee defined certain measures that should be taken by the States to prevent discrimination against children with disabilities:

a) Include explicitly disability as a forbidden ground for discrimination in constitutional provisions on non-discrimination and/or include specific prohibition of discrimination on the ground of disability in specific anti-discrimination laws or legal provisions.

b) Provide for effective remedies in case of violations of the rights of children with disabilities, and ensure that those remedies are easily accessible to children with disabilities and their parents and/or others caring for the child.

c) Conduct awareness-raising and educational campaigns targeting the public at large and specific groups of professionals with a view to preventing and eliminating de facto discrimination against children with disabilities.

³⁰ Ibid., Paragraph 11.

Committee on the Rights of the Child: General Comment No. 9. The rights of children with disabilities. CRC/C/GC/9, 27 February 2007, Paragraphs 47-49.

standards for care in institutions and in establishing rigorous screening and monitoring procedures to ensure effective implementation of these standards.³²

The UN Committee on the Rights of the Child expressed concern at the fact that children with disabilities are not heard in placement processes. In general, decisionmaking processes do not attach enough weight to children as partners, even though these decisions have a far-reaching impact on the child's life and future. The Committee emphasized the need for participation of children with disabilities in "the evaluation, separation and placement process in out-of-home care."33 In the Czech Republic, children with disabilities are excluded from the decision-making process in the area of social services: typically, they are placed in residential social care institutions on the basis of the decisions of their legal guardians (mostly their parents). The exception from this rule is institutional care in homes for disabled persons in compliance with the Czech Family Act No. 94/1963 Coll. or Article 48 (3) of the Social Services Act No. 108/2006 Coll. The decision to place a child in a health care facility, particularly in a psychiatric hospital for children, also depends fully on his/her legal guardians. Lack of consent by the child is not considered a reason for initiating a process of involuntary hospitalization. This practice contradicts the interpretation of the Convention on the Rights of the Child, and it should be expressly provided for in the national law, which so far does not give clear guidance on this issue.

At the conclusion of its Comment, the UN Committee on the Rights of the Child urged the States "to set up programmes for de-institutionalization of children with disabilities," which can be interpreted as urging them to adopt adequate social policies. At the same time the Committee noted that children with disabilities should be "re-placed within their families, extended families or foster care system. Parents and other extended family members should be provided with the necessary and systematic support/training "for successfully including their child back into their home environment.³⁴

The right to live independently in the Convention on the Rights of Persons with Disabilities

The landmark document defining the right to live independently and be included in the community is the Convention on the Rights of Persons with Disabilities (hereinafter referred to also as the "CRPD"). It is one of the fastest negotiated treaties - the preparatory work at the UN lasted five years - from 2001 to December 2006. In March 2007, the Convention was opened for signature and it came into force on 3 May 2008.

The entire Convention is built on the principle of independence, which is a cornerstone of all rights of people with disabilities. According to Paragraph n) of its Preamble, the States recognize "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own

³² Ibid., Paragraph 47.

³³ Ibid., Paragraph 48.

³⁴ Ibid., Paragraph 49.

choices." Independence is also defined as the first [sic!] general principle of the Convention. According to Article 3 (a), the Convention is based on the principle of "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons." Independence is also explicitly emphasized in the crucial Article 9 (Accessibility) as well as in other provisions.

Independent living in the sense of de-institutionalization and inclusion in the community is expressly guaranteed by Article 19 of the CRPD. The first draft version of the right to live independently was submitted to the delegations for discussion in January 2004. According to this draft:

Draft Article 15 (original):"Living independently and being included in the community"

- 1. States Parties to this Convention shall take effective and appropriate measures to enable persons with disabilities to live independently and be fully included in the community, including by ensuring that:
 - a) persons with disabilities have the equal opportunity to choose their place of residence and living arrangements;
 - b) persons with disabilities are not obliged to live in an institution or in a particular living arrangement;
 - c) that 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;
 - d) community services for the general population are available on an equal basis to persons with disabilities and responsive to their needs.
 - e) persons with disabilities have access to information about available support services.

Leibowitz notes that the original draft affirmed the aspect of choice.³⁵ The UN discussion on this draft clearly reflected the freedom to choose one's living arrangements, including the option whether to reside in an institutional facility. However, the German delegation emphasized that the right to live in the community entails two aspects - the freedom of choice and the right to an adequate standard of living as set forth in Article 11 of the ICESCR. The implications of this for people with disabilities are that they do not have a choice to live outside of an institution even if they are not committed to an institution by police or other forces. The question of forced institutionalization is a separate issue. The German delegation therefore proposed that Paragraph 1 should be reformulated so that "persons with disabilities have their equal freedom to choose their own living arrangements. This freedom includes the right not to reside in an institutional facility." Paragraph 2 should be also reformulated to reflect Article 11 of the ICESCR to make it obvious that the states recognize the right of persons with disabilities to an adequate standard of living "which enables persons with disabilities to live independently."³⁶

³⁶ As for the discussion and proposals of the German delegation see http://www.un.org/esa/socdev/enable/rights/wgsuma15.htm

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³⁵ Leibowitz, T. Living in the Community – Disentangling the Core Right. Paper presented at the Colloquium on Disability Law and Policy, April 2010, University of Galway.

The Working Group did not deal with the right to live independently any further during its fifth session, but it resumed the discussion on its text and the modifications proposed namely by the European Union³⁷ and by the representatives of NGOs³⁸ during its sixth session in August 2005. The discussions during the sixth session resulted in a proposal to emphasize the aspect of liberty of movement and freedom of choice³⁹; another text was drafted during the seventh session in early 2006 which reflected in particular the comments of NGOs. 40 Leibowitz comments that one aspect common to the earlier formulations was the absence of the right at the core of the Article. The unequivocal right of all persons to live in the community was added only after concerted effort by civil society and supporting governments, who argued that like every substantive article of the CRPD, this article should affirm a right, and that the right at the base is linked, but not synonymous with, liberty of movement or choice. Rather, it is the inalienable right to live in the community not subject to proving one's "ability," "eligibility" or "entitlement". 41 The final formulation of Article 19 includes this "right" and also the equal right of all persons with disabilities to live in the community:

Article 19 Living independently and being included in the community

States Parties to this 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.

According to Leibowitz, the article clearly negates forced institutionalization: "Persons... have the opportunity to choose their place of residence... and are not obliged to live in a particular living arrangement" (Article 19(a) of the CRPD). But it

³⁸ Proposals made by international organizations are available at: http://www.un.org/esa/socdev/enable/rights/ahc5contngos.htm

http://www.un.org/esa/socdev/enable/rights/ahc7israel.htm, or NGO comments available at: http://www.un.org/esa/socdev/enable/rights/ahc7contngos.htm

³⁷ Proposals made by the Governments are available at: http://www.un.org/esa/socdev/enable/rights/ahc5contgovs.htm

³⁹ Cf. the Report of the Chairman to the (original) Article 15 (14). The report is available at: http://www.un.org/esa/socdev/enable/rights/ahcstata19ssrepchair.htm

Cf. the comments of International Disability Caucus (IDC). The comments are available at:

http://www.un.org/esa/socdev/enable/rights/ahcstata19sevscomments.htm#idc

41 Leibowitz, T. Living in the Community – Disentangling the Core Right. Paper presented at the Colloquia on Disability Law and Policy, April 2010, University of Galway, p.6 Cf. the Israel Position Paper, available at:

also negates institutional life *per se*, even if not formally coerced; an institution by its essence defines a group apart from the community, thereby contributing to the group's isolation and segregation, in contrast with the obligation to "facilitate...full inclusion and participation in the community... and...prevent isolation and segregation..." (Article 19(b) of the CRPD). As a system, an institution overrides the personhood and choices of the individuals living within it – in breach of the obligation to enable "...choices equal to others..." Leibowitz also states that the article's emphasis that community based services must support living and inclusion in the community and prevent isolation and segregation from the community (Article 19(b)) clarifies that locating an institution geographically within the community or even downsizing it into a common housing format (for example an apartment building) that does not have the outwardly appearance of an institution do not suffice; so long as the characteristics of an institution prevail – a group governed by a system that applies to all or most areas of life. 42

Life in the community in UN soft law documents

The above provisions and their interpretations are general and relate to the transformation of institutional care for people with both intellectual and psychosocial disabilities. These are the so-called *hard law* documents, which means that they are legally binding for the States and the States are obliged to meet their commitments ensuing from such conventions. On the other hand, some of the documents adopted by the UN have the nature of *soft law* documents - they contain recommendations and are important in terms of interpretation and application. Let us now focus on the latter documents whose importance should not be underestimated.

In December 1971, the United Nations General Assembly adopted the **Declaration** on the Rights of Mentally Retarded Persons. 43 According to Article 4 of the Declaration, "whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life. "It clearly follows from the above wording that the focus of care for persons with intellectual disabilities lies primarily in the community. Institutionalization can be considered a last resort measure emphasizing both the need of "proximity" of the institution to the person's home and also the qualitative aspect of the service which should be provided in surroundings and other circumstances as close as possible to those of normal life. The right to independent living is emphasized also in the **Declaration on the Rights of Disabled Persons** of 1975.⁴⁴ According to Paragraph 9 of the Declaration, disabled persons "have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities." [...] If the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age".

⁴² Ibid., pp. 6-7.

⁴³ 2856 (XXVI). Declaration on the Rights of Mentally Retarded Persons, A/RES/26/2856, 20 December 1971

⁴⁴ 3447 (XXX). Declaration on the Rights of Disabled Persons, A/RES/30/3447, 9 December 1975

In December 1976, the UN General Assembly proclaimed the year 1981 International Year of Disabled Persons, which opened the issue of the rights of people with disabilities at the United Nations level. A major milestone was the adoption of the **World Programme of Action Concerning Disabled Persons** by the UN General Assembly in 1982. According to Paragraph 18 of the Programme, "large institutions should be avoided. Specialized institutions, where they are necessary, should be organized so as to ensure an early and lasting integration of disabled persons into society." More specific is Paragraph 75 of the Programme, which states that "many persons with disabilities are not only excluded from the normal social life of their communities, but in fact confined in institutions. While the leper colonies of the past have been partly done away with and large institutions are not as numerous as they once were, far too many people are today institutionalized, when there is nothing in their condition to justify it."

Another UN *soft law* document addresses specifically the issue of mental health care and it therefore relates particularly to psychiatric care. These are the **Principles for the protection of persons with mental illness** adopted by the UN General Assembly in 1991, known as the MI Principles. Life in the community is governed by Principle 3, under which "every person with a mental illness shall have the right to live and work, as far as possible, in the community." Rosenthal and Sundram emphasize that Principle 3 - the right to community integration or the right to "social independence" is not linked to whether or not a person receives mental health treatment. The community dimension of treatment is similarly governed by Principle 7 which states that every patient "shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives," and also "shall have the right to return to the community as soon as possible".

The World Conference on Human Rights held in Vienna in 1993, stressed the universality of all human rights and fundamental freedoms which unconditionally apply also to persons with disabilities. Under the adopted Declaration, known as the Vienna Declaration, every person "has the same rights to life and welfare, education and work, living independently and active participation in all aspects of society. Persons with disabilities should be guaranteed equal opportunity through the elimination of all socially determined barriers [...] which exclude or restrict full participation in society."⁴⁸ Still in Vienna in May 1993, the states called upon the United Nations to prepare the draft Standard Rules. A few months later, in December 1993, the UN General Assembly adopted the **Standard Rules on the Equalization** of Opportunities for Persons with Disabilities. 49 The Standard Rules guarantee also the right to independent living. According to their preamble, "intensified efforts are needed to achieve the full and equal enjoyment of human rights and participation in society by persons with disabilities." The rules apply to all persons with disabilities and the community dimension is emphasized in all aspects dealt with by the Rules

⁴⁵ General Assembly Resolution A/RES/37/52 of 3 December 1982.

Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles), A/RES/46/119, adopted on 17 December 1991.

Rosenthal, E., Sundram, C., J. The Role of International Human Rights in National Mental Health Legislation. WHO: Geneva, 2004, p. 33.

⁴⁸ Vienna Declaration and Programme of Action. World Conference on Human Rights. Vienna, 14-25 June 1993. A/CONF.157/29, 12 July 1993, Paragraphs 63-65.

⁹ Standard Rules on Equalization of Opportunities for Persons with Disabilities, A/Res/48/49

(accessibility, education, employment, social security, family life and personal integrity, culture, recreation and sports, religion).

European Council Area: the European Convention on Human Rights and Fundamental Freedoms and the European Social Charter (revised)

The European Convention on Human Rights and Fundamental Freedoms (hereinafter the "ECHR") signed in 1950 is a fundamental legally binding instrument codifying the fundamental human rights and freedoms in the European area. ECHR represents a catalogue of fundamental rights and freedoms; the protection of these rights and the interpretation of the ECHR is the responsibility of the European Court of Human Rights (hereinafter the "ECtHR" or "the Court"), based in Strasbourg. ECHR does not explicitly establish the right to independent living or the right to health, from which the right to live in the community could be inferred. However, even so, it still has its importance in terms of institutionalization of people with disabilities.

The most important rights relating to institutional care are the following ones: the right to life (Article 2), the prohibition of torture, inhuman or degrading treatment (Article 3), the right to liberty of person (Article 5) and the right to respect for private and family life (Article 8). From the interpretation of these rights in the ECHR decisions, certain standards protecting the rights of people living in institutions can be inferred as well as the issue of legal regulation of involuntary institutionalization. Let us now take a brief look to the importance of these provisions in relation to institutional social care.

As regards the right to life guaranteed in Article 2 of the ECHR, the Court interprets this right to include not only the obligation of the States not to deprive anyone of life, but also to effectively investigate cases of death (the so-called procedural or formal aspect). ECtHR emphasized this element in relation to the social services in its *Dodov v. Bulgaria*⁵⁰ judgment, in which the Court inferred the state's obligation to adopt provisions regulating the activities of the staff providing care to people with disabilities. The importance of this decision for service providers, and in particular for the States, lies in the fact that the ECtHR positively inferred the duty of the States to make regulations leading to adoption of appropriate measures for the protection of patients' lives.⁵¹ Although in the case of Mr Dodov's mother, the negligent act was committed by a medical orderly, the ECtHR does not see any reason why the requirement to regulate the activities of public health institutions should not encompass such staff, in so far as their acts may also put the life of patients at risk, the more so where patients' capacity to look after themselves is limited, as in the present case. 52 It is therefore important that the state introduces adequate legislation regulating the obligations of social workers and other employees

⁵⁰ *Dodov v. Bulgaria,* application No. 59548/00, decision as of 17 January 2008. The case concerned the facts surrounding the disappearance and presumed death of Mrs Stoyanova, Mr. Dodov's mother, who suffered from Alzheimer's disease and lived in a nursing home located on a busy boulevard in Sofia. The disappearance occurred in 1995 when Mrs Stoyanova went to see a doctor accompanied by a medical orderly from the nursing home who left her alone for several minutes. During this time, Mrs Stoyanova disappeared.

⁵¹ Ibid., Paragraph 80.

bid., Paragraph 81.

of social service providers providing such services in natural community settings where the risk of disappearance or death is greater than in institutional settings.

Institutional care represents a risk of infringement of the right not to be subjected to torture or to inhuman or degrading treatment. This right is protected under Article 3 of the ECHR and it has also substantive and procedural aspects. The Court is aware of the vulnerability of people with mental disabilities in institutions, and it calls for increased vigilance in reviewing whether there has been a violation of Article 3 of the ECHR.⁵³ A person suffering from severe disability was subjected to degrading treatment for example when she was held in conditions where she was complaining of the cold, the bed prepared for her was inappropriate and she was unable to use the toilet or to wash herself without serious problems.⁵⁴

Let's now turn our attention to another issue - the problem of deprivation of liberty. So far, there is no explicit case law of the ECtHR relating to the issue of institutionalization of people with mental disabilities, and we will therefore focus only on certain aspects which can be inferred from the decision-making practice of the Court. The first question is when a person with mental disabilities can be institutionalized.

In its Witold Litwa v. Poland⁵⁵ judgment, the ECtHR stated that deprivation of liberty is "such a serious measure that it is only justified where other, less severe measures have been considered and found to be insufficient to safeguard the individual or public interest which might require that the person concerned be detained". 56 It can therefore be inferred that less restrictive alternatives to institutional care should prevail over institutionalization, assuming that institutionalization constitutes deprivation of liberty. This brings us to the key question – what situations qualify as deprivation of liberty of person, and whether the provision of institutional residential social services can be considered as "deprivation of liberty of person" within the meaning of Article 5 of the ECHR.

To determine whether there has been a deprivation of liberty, both objective and subjective criteria have to be met.⁵⁷ The objective criteria include the type, duration, effects and manner of implementation of the measure in question.⁵⁸ A relevant factor in case of care for people with mental disabilities is also the fact, whether the staff exercise complete and effective control over the care of a person with mental disability⁵⁹, while it is not determinative whether the institution is "locked" ⁶⁰ As regards the subjective criteria, it is an issue of the "consent" to the confinement. A person may give a valid consent to his/her confinement only if he/she is capable of consenting. 61 Where a person is capable of consenting, the consent to his/her

⁵³ Herczegfalvy v. Austria, application No. 10533/83, judgment of 24 September 1992, para 82.

⁵⁴ Price v. the United Kingdom, application No. 33394/96, judgment of 10 July 2001, para 30.

⁵⁵ Witold Litwa v. Poland, application No. 26629/95, judgment of 4 April 2000.

⁵⁶ Ibid., para 78.

⁵⁷ Storck v. Germany, application No. 61603/00, judgment of 16 June 2005, para 74.

⁵⁸ Guzzardi v. Italy, application No. 7367/76, judgment of 6 November 1980, para 92.

⁵⁹ H.L. v. the United Kingdom, application No. 45508/99, judgment of 5 October 2004, para 91.

lbid., para 92. Cf. also the Ashingdane v. the United Kingdom judgment, application No. 8225/78, judgment of 28 May 1985. The Court inferred that the guarantees under Article 5 apply also to accommodation on an unlocked ward.

⁶¹ Storck v. Germany, application No. 61603/00, judgment of 16 June 2005, paras 76-77.

confinement may be inferred from the fact that the person does not object. 62 However, escape or attempted escape can be also considered as lack of consent. 63 "Capacity" is not a question of "legal capacity", i.e. even a person deprived of legal capacity may have the capacity to express his/her disagreement with institutional care. 64

What would be the importance of the possible conclusion that provision of institutional care amounts to deprivation of liberty under Article 5 of the ECHR? In its *Winterwerp v. the Netherlands* judgment, the European Court of Human Rights⁶⁵ defines the conditions of "lawfulness" of the deprivation of liberty which should be met in such a case, namely: i) the mental disorder must be reliably established, ii) the mental disorder must be of a kind or degree warranting compulsory confinement, and iii) the validity of continued confinement depends upon the persistence of such a disorder. Lawfulness overlaps with the requirement of a procedure prescribed by law, i.e. deprivation of liberty is only possible on the basis of a certain procedure which is sufficiently clearly defined under domestic law.⁶⁶

An act of deprivation of liberty is subject to other important safeguards such as the right to have the lawfulness reviewed by a court pursuant to Article 5 (4) of the ECHR and the right to compensation pursuant to Article 5 (5) of the ECHR, if the deprivation of liberty was unlawful. The purpose of the review of deprivation of liberty is protection against arbitrariness, since both the protection of the physical liberty of individuals and their personal security is at stake. The applicants have attempted to argue before the Court that detention constitutes arbitrariness if it was preventable by the provision of community services. However, the ECtHR did not respond to this argument. Are also as a court pursuant to Article 5 (4) of the ECHR, if the ECHR is a court pursuant to Article 5 (5) of the ECHR, if the deprivation of liberty is protection of the physical liberty of individuals and their personal security is at stake. The applicants have attempted to argue before the Court that detention constitutes arbitrariness if it was preventable by the provision of community services. However, the ECtHR did not respond to this argument.

However, let us go back to the question of the review. The Court stated that the act of deprivation of liberty is subject to review ⁶⁹ and that he person detained must have a right of recourse to a court. ⁷⁰ The review must be of judicial character and provide appropriate guarantees ⁷¹; it is essential that the person concerned should have access to a court and the opportunity to be heard either in person or through some form of representation. ⁷² A person of unsound mind compulsorily confined for an indefinite or lengthy period is thus entitled, at any rate where there is no automatic periodic review of a judicial character, to take proceedings at reasonable intervals before a court to put in issue the lawfulness of his/her detention. ⁷³ The consent of the guardian with the institutionalization of a person deprived of legal capacity does not exclude the review of the deprivation of liberty. ⁷⁴

⁶² H.L. v. the United Kingdom, application No. 45508/99, judgment of 5 October 2004, para 93.

⁶³ Storck v. Germany, application No. 61603/00, judgment of 16 June 2005, paras 73, 76.

⁶⁴ Shtukaturov v. Russia, application No. 44009/05, judgment of 27 March 2008, para 108.

⁶⁵ Winterwerp v. the Netherlands, application No. 6301/73, judgment of 24 October 1979, para 39.

⁶⁶ Kawka v. Poland, application No. 25874/94, judgment of 9 January 2001, para 49.

Varbanov v. Bulgaria, application No. 31365/96, judgment of 5 October 2000, para 58.

⁶⁸ Kolanis v. the United Kingdom, application No. 517/02, judgment of 21 September 2005, para 12; Johnson v. the United Kingdom, application No. 22520/93, judgment of 24 October 1997.

Kolanis v. the United Kingdom, application No. 517/02, judgment of 21 September 2005, para 80.
 Winterwerp v. the Netherlands, application No. 6301/73, judgment of 24 October 1979, para 55.

Megyeri v. Germany, application No. 13770/88, judgment as of 12 May 1992, para 22.

Winterwerp v. the Netherlands, application No. 6301/73, judgment of 24 October 1979, para 60. X v. the United Kingdom, application No. 7215/75, judgment of 5 November 1981, para 52.

⁷⁴ Shtukaturov v. Russia, application No. 44009/05, judgment of 27 March 2008, para 125.

The decision which was probably the most closely related to the issue of deinstitutionalization was in *Marzari v. Italy*⁷⁵ when the Court dismissed a complaint as inadmissible. The applicant alleged a violation of his right to respect for his private life under Article 8 of the ECHR. The applicant complained about the eviction and about the local administrative authorities' failure to provide him with accommodation adequate to his disability. Unfortunately, the Court did not consider the merits of the complaint, but in its decision on admissibility it defined an important principle. EctHR stated that "although Article 8 does not guarantee the right to have one's housing problem solved by the authorities, a refusal of the authorities to provide assistance in this respect to an individual suffering from a severe disease might in certain circumstances raise an issue under Article 8 of the Convention because of the impact of such refusal on the private life of the individual."

We can therefore conclude that the EctHR did not provide a clear answer whether it is possible to infer the right to live in the community; on the other hand, however, it did not strictly deny such a conclusion. With regard to the *Marzari* judgment, it rather seems that the Court might be inclined to consider the case of the right to live in the community as part of the right to respect for one's private life or home. This paves the way for a potential strategic litigation in the future.

And, finally, let us focus on the second fundamental treaty of the Council of Europe - the **European Social Charter (revised)** adopted in 1996. In its Article 15, the revised Charter expressly provides for the right of persons with disabilities to independence, social integration and participation in the life of the community. According to the introductory sentence of Article 15, the States undertake, "with a view to ensuring [...] the effective exercise of the right to independence, social integration and participation in the life of the community", in compliance with Article 15 (3) "to promote their full social integration and participation in the life of the community...." The Explanatory Report states that, as compared to the original text of the Charter, the protection of the disabled has been extended as it no longer applies only to vocational rehabilitation. The words "effective exercise of the right to independence" contained in the introductory sentence to the provision imply, *inter alia*, that disabled persons should have the right to an independent life.⁷⁶

The right to live independently in the Council of Europe's *soft law* documents

The recommendatory documents of the Council of Europe are important for the formulation of policies relevant to the transformation of institutional care and also for the interpretation of the Council of Europe's *hard law* documents. We basically distinguish two types of declarations in relation to the entity adopting such a declaration or recommendation. These entities are the Council of Europe Parliamentary Assembly and the Committee of Ministers of the Council of Europe. The key recommendations are those of the Committee of Ministers. The

⁷⁵ Marzari v. Italy, application No. 36448/97, decision of 4 May 1999.

Explanatory Report to the revised European Social Charter, Paragraph 63. The report is available at: http://conventions.coe.int/treaty/en/Reports/Html/163.htm

Parliamentary Assembly plays an important role in the case of the rights of persons with disabilities; in the past, it for example addressed the Committee of Ministers to call for the adoption of the Recommendation on the Rights of Persons with Disabilities. This was the case for example in 1981⁷⁷; by that time, however, the response of the Committee of Ministers was not yet significant.

In 1992, the Committee of Ministers of the Council of Europe adopted the first comprehensive recommendation on the rights of persons with disabilities, namely the **Recommendation No. R (92) 6 on a Coherent Policy for People with Disabilities as of April 1992.** This is a very important recommendation which replaced an earlier Resolution AP (84) 3 on a coherent policy for the rehabilitation of disabled people as of 1984. The above resolution was based on the paradigm of medical rehabilitation and on the policy of institutionalization of people with disabilities. The new Recommendation is based on the principle of independent living and full integration into society. 80

According to the basic principles of this Recommendation, the policy in favour of people with disabilities or who are in danger of acquiring them should aim at the following basic goals: a) preventing or eliminating disablement and alleviating its consequences; b) guaranteeing full and active participation in community life; c) helping them to lead independent lives according to their own wishes. A particularly important part in terms of transformation of institutional care is Section VIII of the Recommendation entitled "Social integration and environment." This section includes recommendations relating to housing. Its Point 4 defines specific steps enabling the people with disabilities "to live independently [...] and be integrated in society." According to Point 4.1. of the Recommendation: a) all new housing accommodation should be accessible and adaptable; b) subsidies and/or tax exemption benefits should be granted to adapt existing housing; c) architects and building constructors should receive training on adaptations to houses and buildings for people with disabilities; d) proper access should be provided.

A month later, in 1992, the Parliamentary Assembly of the Council of Europe adopted the **Recommendation 1185 (1992) on rehabilitation policies for the disabled**,⁸¹ which also responds to the paradigm shift. In this Recommendation, the Parliamentary Assembly called on the governments of the member states to "strive for and encourage genuine active participation by disabled people in family life, the community and society, and in the organisation of their own lives", more specifically by "reinforcing home services and assistance to families, with special attention being paid to severely disabled people and dependent elderly people".

⁷⁷ Parliamentary Assembly Recommendation 925 (1981)

⁷⁸ Recommendation No. R (92) 6 of the Committee of Ministers to Member States on a Coherent Policy for People with Disabilities. The Recommendation was adopted by the Committee of Ministers on 9 April 1992 at its 474th meeting.

⁷⁹ Resolution AP(84)3 on a coherent policy for the rehabilitation of disabled persons of 17 September 1984.

Degener, T., Disabled persons and human rights: the legal framework, p. 36, In Degener, T., Koster-Dreese, Y. (eds.) Human rights and disabled persons: essays and relevant human rights instruments, Dordrecht-Boston-London: Martinus Nijhoff Publishers, 1995.

⁸¹ Parliamentary Assembly Recommendation 1185 (1992) on rehabilitation policies for the disabled

The year 2003 was declared the European Year of People with Disabilities by the European Commission. The Council of Europe Parliamentary Assembly responded by adopting **Recommendation 1592 (2003) Towards full social inclusion of people with disabilities.** In this Recommendation, the Committee of Ministers of the Council of Europe called *inter alia* for the adoption of an Action Plan. An interesting document in terms of transformation is the report for the Parliamentary Assembly prepared by László Surján, rapporteur of the Social, Health and Family Affairs Committee, including the relevant Recommendation. In his report he emphasized that the existence of large residential institutions is an obstacle to the inclusion of people with disabilities, especially those with mental disabilities. He did not deal with other inclusion issues such as custody, inclusive education or the right to engage in work.

The Action Plan called for by the Parliamentary Assembly in its 2003 Recommendation was adopted by the Committee of Ministers of the Council of Europe three years later. In the Recommendation Rec(2006)5 on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015,⁸⁴ the Committee of Ministers stressed the universality, indivisibility and interdependence of all human rights and fundamental freedoms and the need for people with disabilities to be guaranteed their full enjoyment without any discrimination, taking into account *inter alia* the EHCR and the European Social Charter (revised). The Recommendation thus in this point further developed the ideas contained in the Vienna Declaration adopted in 1993.

Section 3.8 of the Action Plan focuses in considerable detail inter alia on According to Point 3.8.1. of the transformation of institutional care. Recommendation, this action line focuses on measures "enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live." The Recommendation clearly states that this requires "strategic policies which support the move from institutional care to community-based settings ranging from independent living arrangements to small group homes." However, according to the Council of Europe, "full independent living may not be a possibility or a choice for all individuals. In exceptional cases, care in small, quality structures should be encouraged as an alternative to living in an institution." The Recommendation emphasizes also the interdependence of individual aspects of transformation of care for persons with disabilities, as "independent living policies are not just confined to living arrangements, but are also dependent on the accessibility of a broad range of services, including transport. The success of such policies requires a mainstream approach to the planning, development and delivery of mainstream services to ensure they also respond to the needs of individuals with disabilities with cross-agency support to ensure a co-ordinated approach." Specific actions by member states are defined in Point 3.8.3 as follows:

⁸² Parliamentary Assembly Recommendation 1592 (2003) Towards full social inclusion of people with disabilities.

⁸³ Surján, L. Towards full social inclusion of persons with disabilities, Report Social, Health and Family Affairs Committee 2002, doc. 9632.

⁸⁴ Recommendation Rec(2006)5, the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, adopted by the Committee of Ministers on 5 April 2006.

- i. To ensure a co-ordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life;
- ii. to develop and promote housing policies which enable people with disabilities to live in suitable housing in their local community;
- iii. to support formal and informal help, making it possible for people with disabilities to live at home:
- iv. to recognise the status of carers, by providing them with support and relevant training;
- v. to have the needs of families as providers of informal care thoroughly assessed, especially those with children with disabilities or caring for persons in need of a high level of support, with a view to providing information, training and assistance, including psychological support, to enable life within the family, paying particular attention to the reconciliation of private and professional life and to gender equality;
- vi. to ensure community-based quality service provision and alternative housing models, which enable a move from institution-based care to community living;
- vii. to ensure that individuals can make informed choices with the assistance, when appropriate, of a skilled advocacy service;
- viii. to promote schemes which will allow disabled people to employ personal assistants of their choice;
- ix. to provide complementary services and other facilities, for example day centres, short-stay centres or self-expression groups, offering suitable forms of therapy, to give people with disabilities and their families periods of support and respite;
- x. to provide people with disabilities, in particular those in need of a high level of support, with tailored support provision, including advocacy, in order to reduce any risk of social exclusion;
- xi. to implement the relevant provisions included in Recommendation No. R (96) 5 of the Committee of Ministers to member states on reconciling work and family life.

In 2010, the Committee of Ministers of the Council of Europe adopted the Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities, 85 which is aimed at a specific target group and deals in a considerable detail with the process of transformation of institutional care for children with disabilities. We can specifically outline the following basic principles on which the Recommendation is built and which are enshrined in international legal instruments:

- 1. All children have rights, hence disabled children have the same rights to family life, education, health, social care and vocational training as all children.
- 2. All disabled children should live with their own family, which is the natural environment for the growth and well-being of a child, unless there are exceptional circumstances which prevent this.
- 3. Parents have the primary responsibility for the upbringing and development of the child. They should choose how to meet their child's needs as long as their decisions are informed by, and seen to be in, the child's best interests.

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⁸⁵ Recommendation CM/Rec(2010)2 of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities

- 4. In all actions concerning children the best interests of the child take precedence over other considerations and this principle should be upheld in relation to children with disabilities.
- 5. If a family or a service fails to work in a disabled child's best interests, or if a disabled child is being abused or neglected, the state, acting through its public agencies and within general child protection frameworks, should intervene to protect the child and make sure that his or her needs are met. In these exceptional circumstances, if care is to be provided outside the family, such care should be welcoming, well regulated and designed to maintain family ties.
- 6. The state has a responsibility to support families so that they can bring up their disabled child at home and, in particular, to create the necessary conditions to implement a better reconciliation of family and working life. The state should therefore finance and make available a range of high-quality services from which the families of children with disabilities can choose assistance adapted to their needs.

STATE OBLIGATIONS IN THE THEORY OF INTERNATIONAL LAW

The doctrine concerning the nature of the legal obligations imposed on states by the Covenants on Human Rights has undergone an important development over the few decades since both the Conventions came into force, and more or less stabilized in the 1990s. However, certain aspects are still subject to discussions: both the doctrine and the practical application are critical e.g. towards the so-called *minimum core obligation*. For the correct definition of the nature of the obligations of the Czech Republic under the UN Convention on the Rights of Persons with Disabilities,

⁸⁷ Cf. the judgment of the South African Constitutional Court in: Republic of South Africa v. Grootboom (1) 2001 (1) SA 46 and namely in: Khosa and Mahlaule v. Minister for Social Development 2004 (6) BCLR 569, paras 34-35.

⁸⁶ Young., K. The Minimum Core of Economic and Social Rights: A Concept in Search of Content. The Yale Journal of International Law, Vol. 33, 2008, pp. 151-163.

specifically of the right to live in the community, it is useful to look at the development of the opinions of the legal doctrine on the nature of state obligations.

Probably the most common and relatively simple typology of obligations is their classification as positive or negative. Negative obligations require the state to refrain from certain acts, whereas positive obligations assume certain positive liability. This so-called duty distinction is advocated e.g. by Cécile Fabre⁸⁸. On the basis of this dichotomy, some authors make a distinction between negative rights (which include civil and political rights) and positive rights (typically social rights). This classification of obligations to positive and negative was one of the reasons why the UN established two international covenants instead of the originally planned single document, the *Bill of Rights*. At present, this classification of rights has been subject to criticism. ⁹¹

As part of the discussion on the responsibility of the States under international law in the U.N. International Law Commission (hereinafter referred to as "ILC), Mr Roberto Ago⁹², Special Rapporteur, presented in 1977 two kinds of obligations denominated as "obligations of specific conduct" and "obligations requiring to achieve a particular result". A simplified definition of the obligations of specific conduct says that they require the State to adopt a particular course of conduct in the form of an action or omission. In other words, the States are obliged to take, or refrain from taking, certain legislative, executive or judicial measures. The obligations requiring to achieve a particular result indicate the result to be achieved and give the State discretion as to the means of achieving this result.

In 1990, the Committee on Economic, Social and Cultural Rights in its General Comment No. 3 on the nature of the obligations ensuing from Article 2 of the ICESCR⁹³ referred to obligations of conduct and obligations of result as defined by the UN International Law Commission. However, it did not use this typology in its other Comments and it did not develop it any further in relation to social rights. According to Sepúlveda, the dichotomy between "obligations of conduct" and "obligations of result" is apparent in civil law systems, particularly in the French system. However, the use of these notions at the international level is much less

⁸⁸ Cf. Fabreová, C. Ústavní zakotvení sociálních práv. Praha: Filosofia, 2004, p. 17-19 (orig. C. Fabre: Social Rights under the Constitution – the quoted text was based on the Czech translation of Ms Fabre's lecture)

⁸⁹ Cf. e.g. Donnelly, J. Universal Human Rights in Theory and Practice. 2nd edition. Cornell University Press, 2003, p. 30. However, although Donelly speaks about the distinction between negative and positive rights, he in fact challenges this simplistic dichotomy using a reference to Henry Shue.

⁹⁰ For an extensive discussion of the reasons for this most unfortunate division of rights into two Covenants see e.g. the work challenging the widespread belief that Western countries have been antagonistic to social rights: Donnelly, J., Whelan, D., J. The West, Economic and Social Rights, and the Global Human Rights Regime: Setting the Record Straight. Human Rights Quarterly, 29, 2007, pp. 908-949.

⁹¹Fredman, S. Human Rights Transformed. Oxford: Oxford University Press, 2009, p. 69; Fabreová, C. Ústavní zakotvení sociálních práv. Praha: Filosofia, 2004, pp. 17-19 (orig. C. Fabre: Social Rights under Constitution); Arambulo, K. Strengthening the Supervision of the International Covenant on Economic, Social and Cultural Rights: Theoretical and Procedural Aspects. Oxford: Hart, 1999.

⁹²Ago, R. Sixth report on State responsibility by Mr. Roberto Ago, Special Rapporteur - the internationally wrongful act of the State, source of international responsibility. A/CN.4/302 and Add.1, 2, 3. Yearbook of the International Law Commission: 1977, vol. II(1)

⁹³ Cf. The nature of state obligations (Article 2(1): . 14/12/90. CESCR General Comment 3, 1990, Paragraph 1.

clear and it cannot be classified as an adequate characterization of the obligations arising from human rights.94

In 1980, Henry Shue⁹⁵ published a work which has significantly affected the human rights discourse. Shue arrived at the conclusion that any basic right can be assessed in terms of a very simple tripartite typology of interdependent duties. He refused the usual assumption held at that time that for every right there is a single correlative duty, thereby challenging the positive/negative dichotomy of rights. 96 Shue was the first one to define a set of three governments' duties arising from the human rights: i) to avoid depriving; ii) to protect from deprivation; iii) to aid deprived. 97 Later, he amended his work ⁹⁸ and modified some of his conclusions. ⁹⁹

There are other authors who further developed the typology of obligations based on Shue's work. These include in particular Asbjørn Eide, UN Special Rapporteur for the Right to Food, who in his 1987 report to the UN Commission on Human Rights presented a very important and influential typology of obligations. 100 Eide specifically defined three types of obligations:

- the obligation to respect i)
- ii) the obligation to protect
- iii) the obligation to fulfil

Later, he added a fourth obligation "to facilitate", placing it between the obligation to protect and the obligation to fulfil. By adding the obligation to fulfil, Eide, like Shue, challenged the positive/negative dichotomy of the rights as a false and misleading description of the nature of the human rights obligations. 101 The importance of Eide's work is reflected in the fact that his terminology was accepted by the UN Committee on Economic, Social and Cultural Rights for its General Comments (cf. below).

The obligation to respect: States should, at the primary level, respect the resources owned by the individual, her or his freedom to find a job of preference, to make optimal use of her/his own knowledge and the freedom to take the necessary actions and use the necessary resources - alone or in association with others - to

⁹⁴ Cf. Sepúlveda, M. The nature of the obligations under the International Covenant on Economic, Social and Cultural Rights. Antwerp: Intersentia, 2003, s. 184-185. Our work does not aim to deal with the suitability of this dichotomy and/or the suitability of any other typology in more detail. For more detailed specification of the grounds for criticism please refer to the relevant works.

Shue, H. Basic Rights: Subsistence, Affluence and U.S. Foreign Policy. Princeton: Princeton Unviersity Press, 1980, p. 51. Shue introduced his different concept of dividing the duties - trichotomy for the first time in his 1979 work. Cf. Shue, H. Rights in the Light of Duties, In Brown, P., Maclean, D. (eds.) Human Rights and U.S. Foreign Policy. 1979, Lexington Mass: Lexington Books, pp. 65-82.

Cf. Sepúlveda, M. The nature of the obligations under the International Covenant on Economic, Social and Cultural Rights. Antwerp: Intersentia, 2003, p. 158.

Shue, H. Basic Rights: Subsistence, Affluence and U.S. Foreign Policy. Princeton: Princeton University Press, first edition, New Jersey, 1980, p. 52 an.

³ Shue, H. The Interdependence of Duties, p. 85, In: Alston., P., Tomasevski, K. (eds.), The Right to Food. Utrecht: Martinus Nijhoff, 1984.

Shue, H. Basic Rights: Subsistence, Affluence and U.S. Foreign Policy. Princeton: Princeton University Press, 2nd. Edition, New Jersey, 1996.

Eide, A. E/CN.4/Sub.2/1987/23

101 Cf. Eide, A. Realization of Social and Economic Rights and the Minimum Threshold Approach, (1989) 10 Human Rights Law Journal 35.

satisfy his or her own needs. The State cannot, however, passively leave it at that. Third parties are likely to interfere negatively with the possibilities that individuals or groups otherwise might have had to solve their own needs. 102

Obligation to protect: When defining this secondary level, Eide was building on the obligation to respect. According to him, this level requires active protection against other, more assertive or aggressive subjects - more powerful economic interests, such as protection against fraud, against unethical behaviour in trade and contractual relations, against the marketing and dumping of hazardous or dangerous products. According to Eide, this protective function of the State is widely used and is the most important aspect of State obligations with regard to economic, social and cultural rights, similar to the role of the State as protector of civil and political rights. ¹⁰³

Obligation to facilitate: Requires the states to facilitate opportunities by which the rights listed can be enjoyed. It takes many forms, some of which are spelled out in the relevant instruments. As an example, Eide states Article 11 (2) of the ICESCR.¹⁰⁴

Obligation to fulfil: This fourth level requires that the States fulfil the rights of those who otherwise cannot enjoy their economic, social and cultural rights. This fourth level obligation increases in importance with increasing rates of urbanization and the decline of group or family responsibilities. Eide states as an example obligations towards the elderly and disabled, which in traditional agricultural society were taken care of by the family. This level is important during emergencies, e.g. when the conditions for survival are temporarily disrupted (as a result of, for example, severe drought or flood, armed conflict or the collapse of economic activities within particular regions of a country). This obligation may consist of the direct provision of basic needs such as food or resources which can be used for food (through direct food aid or social security) when no other possibility exists. 106

Besides the now already classical trichotomy of obligations, there are also typologies based on four types or levels of obligations. Such a typology was introduced in 1984 by van Hoof¹⁰⁷, and later in 2000, by Steiner and Alston¹⁰⁸. The significance of the two above works lies mainly in the formulation of the fourth obligation "to promote", which was adopted later in Article 4 of the CRPD. We will therefore focus on the concept of this obligation in the works of the above authors.

104 Ibid., Paragraph 52(c)

Eide, A. The right to adequate food and to be free from hunger, E/CN.4/Sub 2/1999/12, 1999, Pagaragraph. 52(a).

¹⁰³ Ibid., Paragraph 52(b)

¹⁰⁵ Ibid., Paragraph 52 (d)

Eide, A. Universalisation of human rights versus globalisation of economic power, In: Coomans, F., et al. (eds.) Rendering justice to the vulnerable: liber amicorum in honour of Theo van Boven. The Hague: Kluwer Law International, p. 111.

Hoof, G., J., H. van. Legal nature of economic, social and cultural rights: a rebuttal of some traditional views, In: Alston, P., Tomasevski, K. (eds.) The right to food. Utrecht: Martinus Nijhoff Publishers, 1984, pp. 106-108.

Steiner, H., Alston, P. International Human Rights in Context: Law, Politics, Morals. New York: OUP, 2000, pp. 180-185.

According to van Hoof¹⁰⁹, this type of obligation encompasses measures aimed at long-term goals, for instance, the duty on the part of the government to set training programmes. This obligation can only be achieved progressively or over the long term. Steiner and Alston¹¹⁰ understand the obligation to promote as referring to bringing about changes in public consciousness or perception or understanding about a given problem or issue. Like the duty of protection, it generally requires the state to expend funds and create the institutions that are necessary to promoting acceptance of the right. Thus a state's duty to promote often involves public education.

Sepúlveda¹¹¹ agrees with the inclusion of the "duty to promote" as an independent duty within the original typology. While the "duty to promote" requires positive actions of a long-term character and, according to Sepúlveda, it may therefore be considered to be included in the "duty to fulfil" and even in the "duty to protect", it can be viewed as distinct in nature from these other duties which also entail positive actions. Admittedly, when States take measures to comply with one level of duty, these measures might at the same time serve to comply with the duty to promote. For example, in aiming to comply with the duty to protect the right to adequate housing, States might promote the rights of tenants, or in attempting to protect the right to the highest attainable standard of health they may promote consumers' rights. While such promotional activities are only one of the ways that States have to comply with their duties, it is possible to say that the requirement to "promote" human rights is not solely an ancillary obligation. According to Sepúlveda, the obligation to promote has taken on an independent character and all human rights should be viewed as imposing this level of obligation. Certainly, individuals would be better protected if States were to take active measures to promote human rights. However, it is not possible to have effective protection of human rights if individuals are unaware of their rights and the mechanisms available to protect them.

Formulation of the obligations of States in the UN covenants

In the previous section, we have briefly discussed the international law doctrine which significantly influenced the activities of the quasi-judicial bodies established as the control mechanisms to review the implementation of UN conventions on human rights. In the context of our work, important opinions are those of the Human Rights Committee (hereinafter referred to also as the "HRC"), and in particular those of the Committee on Economic, Social and Cultural Rights (hereinafter referred to also as the "CESCR"). Since 1989, the Committees have been issuing General Comments in which they interpret the individual provisions set out in the Covenants. These Comments have an important interpretive significance. Below we focus on the terminology relating to the obligations under both Covenants and on the interpretation contained in the General Comments.

¹⁰⁹, G., J., H. van. Legal nature of economic, social and cultural rights: a rebuttal of some traditional views, In: Alston, P., Tomasevski, K. (eds.) The right to food. Utrecht: Martinus Nijhoff Publishers, 1984, pp. 106-108.

Steiner, H., Alston, P. International Human Rights in Context: Law, Politics, Morals. New York: OUP, 2000, p. 184.

Sepúlveda, M. The nature of the obligations under the International Covenant on Economic, Social and Cultural Rights. Antwerp: Intersentia, 2003, p. 166.

Before we proceed to the analysis itself, we would like to point out that the wording of the obligations in the treaties on human rights is inconsistent and therefore somewhat confusing. For example, Kratochvíl¹¹² draws attention to the formulation of the obligations of States in the European Convention on Human Rights and Fundamental Freedoms. In its Article 1, the Convention uses a different expression to determine the States' obligations. Instead of the obligation to "respect and ensure" the rights used in the ICCPR the Convention uses the term "secure". Indeed, the European Court of Human Rights did not have any problems with the word "secure" and in many cases, it even revealed various implicit positive obligations contained in various articles of the Convention.

International Covenant on Civil and Political Rights

The obligations ensuing from the Covenant on Civil and Political Rights are defined in Article 2 (1) of the Covenant:

"Each State Party to the present Covenant undertakes to **respect** and to **ensure** to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

According to the Human Rights Committee, the legal obligations under Article 2(1) of the Covenant are both negative and positive in nature and are of immediate nature rather than of progressive implementation. Article 2 requires that States Parties adopt legislative, judicial, administrative, educative and other appropriate measures in order to fulfil their legal obligations. The obligation to respect is traditionally associated with the negative obligation of the State not to interfere, while the obligation to ensure, on the other hand, has a clearly positive aspect of undertaking a certain activity. This brief explanation should be sufficient for the moment, as we will focus below on the structure of the commitments defined in relation to the so-called social rights; however, our ambition is to cover the obligations ensuing from all rights, regardless of their more or less artificial categorization.

International Covenant on Economic, Social and Cultural Rights

The Covenant on Economic, Social and Cultural Rights regulates rights which are typically of progressive realization. In some cases, the Covenant regulates even rights which are not achievable over time. One of these is the right to continuous improvement of living conditions provided for in Article 11, Paragraph 1 of the ICESCR. As to the definitions of the obligations, the wording significantly differs from the ICCPR. Under Article 2(1) of the ICESCR:

. .

¹¹² Kratochvíl, J. Sociální práva v Evropské úmluvě na ochranu lidských práv a Mezinárodním paktu o občanských a politických právech. Thesis. Prague: UK, 2010, p. 23.

HRC General Comment No. 31 The Nature of the General Legal Obligation Imposed on States Parties to the Covenant, CCPR/C/21/Rev.1/Add. 13, 26 May 2004, Paragraphs 5-7.

"Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."

The obligations under Article 2(1) of the ICESCR have been given a detailed theoretical examination in the CESCR General Comments. The Committee dealt with the obligations for the first time in the General Comment No. 3, where it applied the dichotomy between obligations of conduct and obligations of result as defined by the International Law Commission, and defined also obligations of immediate nature, terming them as "general legal obligations". The Committee later abandoned this dichotomy and introduced its own independent typology.

The CESCR's conclusions were confirmed and further developed also by experts in international law, namely in the Limburg principles and in the Maastricht Guidelines. In 1986, a group of experts in international law met in Limburg (the Netherlands) and formulated a set of principles on the implementation of the ICESCR. This handbook, known as the **Limburg Principles**, is an important tool to determine the obligations ensuing from social rights which, to a certain extent, operationalizes the conclusions of the CESCR. These principles were further developed during the 1997 meeting of experts in Maastricht (the Netherlands) who formulated the Guidelines on Violation of Economic, Social and Cultural Rights (**Maastricht Guidelines**). While these documents are not binding, they serve as an interpretive guidance in relation to Article 38 (1) (d) of the Statute of the International Court of Justice.

In 1999 the CESCR published its General Comment No. 12 (The right to adequate food), in which it identified three levels of obligations: to **respect**, to **protect** and to **fulfil**, including two sub-levels of the obligation to fulfil. CESCR further developed this trichotomy in its General Comment No. 13 (The right to education), in which it formulated the third sub-level obligation to fulfil. The types or levels of obligations can be defined as follows:

- i) Obligation to respect
- ii) Obligation to protect
- iii) Obligation to fulfil
 - a) Obligation to facilitate
 - b) Obligation to provide
 - c) Obligation to promote¹¹⁷

According to Craven, ¹¹⁸ this approach provides a detailed analytical framework enabling a better understanding of the State's obligations in the context of human

114 CESCR General Comment 3. The nature of States parties obligations (Art. 2, para. 1 of the Covenant), para. 1.

Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, Maastricht, January 1997.

The Limburg Principles on the Implementation of the International Covenant in Economic, Social and Cultural Rights, UN doc. E/CN.4/1987/17.

Sepúlveda, M. The nature of the obligations under the International Covenant on Economic, Social and Cultural Rights. Antwerp: School of Human Rights Research series; No. 18, 2003, p. 239.

rights. At the same time, it serves to counteract some of the traditional assumptions that categorically separate economic, social and cultural rights from civil and political rights. Other authors are critical of this approach, e.g. Koch¹¹⁹ who criticizes a certain rigidity of this approach, supporting rather the approach of the European Court of Human Rights which infers negative and positive obligations from both civil and social human rights on a case-by-case basis.

Let us first briefly focus on the time aspect of the obligations, i.e. on the issue of progressive realization of social rights and on whether the obligations of immediate nature are inferable as well, on the issue of availability of resources which is closely linked to progressive realization and, finally, on the definition of the so-called normative framework or elements of social rights.

Time aspect of obligations: Immediate nature or progressive realization?

The CESCR addressed the issue of progressive realization of rights as expressed in Article 2(1) of the Covenant on Economic, Social and Cultural Rights "with a view to achieving progressively the full realization of the rights" and the issue of whether it is possible to infer from the ICESCR also obligations of immediate nature. The Committee stressed that progressive realization means that the full realization of all economic, social and cultural rights will generally not be able to be achieved in a short period of time. Nevertheless, the recognition of this progressive realization should not be misinterpreted as depriving the obligation of all meaningful content. According to CESCR, the progressive realization imposes on the State an obligation to move as expeditiously and effectively as possible towards that goal. 120

However, the progressive realization of social rights, which include the right to live in the community, does not mean that the state has no obligations of immediate nature. In the General Comment No. 3, CESCR clearly stated that ICESCR imposes various obligations which are of immediate effect¹²¹, namely: i) non-discrimination, ii) obligation "to take steps" with a view to achieving full realization of the right and iii) minimum core obligation of each right and iv) obligation to monitor the extent of the realization.

In 2009, the CESCR issued its General Comment No. 20 on non-discrimination. The Committee stressed that non-discrimination is an immediate obligation and it stated that discrimination must be eliminated both formally and substantively. According to CESCR, both direct and indirect forms of differential treatment can amount to discrimination. The Committee also stressed that States should pay increased attention to discrimination in the private sphere and to systemic discrimination. It is the systemic discrimination which is relevant for people with

¹¹⁸ Craven, M. The International Covenant on Economic, Social, and Cultural Rights. A perspective on its Development. Oxford: Oxford University Press, 1995, p. 110.

Koch, I., E., Dichotomies, Trichotomies or Waves of Duties? (2005) 5 Human Rights Law Review, 100-103.

¹²⁰ Ibid., Paragraph 9.

¹²¹ Ibid., Paragraph 2.

General Comment No. 20, Non-Discrimination in Economic, Social and Cultural Rights (Article 2(2), E/C.12/GC/20.

disabilities. As for the permissible scope of differential treatment, the CESCR stated that differential treatment will be viewed as discriminatory unless the justification for differentiation is reasonable and objective. 123

According to the Committee, the obligation to take steps means that the State must immediately take steps which are deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the Covenant by all appropriate means, including particularly the adoption of legislative measures. According to CESCR, legislation is highly desirable and in some cases may even be indispensable. The Committee stated as an example the combating of discrimination and also fields such as health, the protection of children and mothers, and education. Among the measures which might be considered appropriate, in addition to legislation, is the provision of judicial remedies and administrative, financial, educational and social measures.

Table No. 1: Summary of obligations of immediate nature and of progressive realization

Obligations of immediate nature	Obligations of progressive realization
 Non-discrimination Undertaking to take steps Minimum core obligation Monitoring the (non-) realization of the rights Respect and protect the rights 	 Obligation to move as expeditiously and effectively as possible Obligation to use the available resources efficiently Obligation to use the resources to the maximum

The CESCR is also of the view that obligations of immediate nature include the so-called minimum core obligation. This obligation ensures the satisfaction of, at the very least, minimum essential levels of each of the rights. Thus, for example, a State party in which any significant number of individuals is deprived of essential foodstuffs, of essential primary health care, of basic shelter and housing, or of the most basic forms of education is, *prima facie*, failing to discharge its obligations under the ICESCR. The CESCR is trying to provide in its General Comments a rather

¹²³ The CESCR adopted the methodology used by the European Court of Human Rights. In relation to people with disabilities, cf. *Glor v. Switzerland*, application No. 13444/04, judgment of 30 April 2009.
¹²⁴ CESCR General Comment No. 3, Paragraph 3.

¹²⁵ Ibid., Paragraph 5.

¹²⁶ Ibid., Paragraph 7.

The issue of "minimum core" is subject to a lively debate both in the academic circles and in important courts. Cf in particular Fredman, S. Human Rights Transformed. Oxford: Oxford University

comprehensive definition of minimum core obligations relating to each right. And, finally, the CESCR includes in obligations of immediate nature also the obligation to monitor the extent of the realization, or more especially of the non-realization, of economic, social and cultural rights. 128

These obligations of immediate nature include also the obligation to respect and protect the rights, i.e. the negative obligation of the State to refrain from interfering with, or curtailing, the enjoyment of social rights, while protecting individuals and groups from violations of their rights by third parties.

What is the meaning of "maximum of available resources" or "maximum extent of resources"?

By adopting the Convention on the Rights of Persons with Disabilities, each State Party undertook to "take measures to the maximum of its available resources" with a view to achieving the full realization of the rights contained in the Convention. The fulfilment of these obligations implies expending funds that must be "maximum available" for the State. According to the Maastricht Guidelines, the failure of the State to do so constitutes a violation of an obligation stemming from international law. 129 This obligation is closely related to the immediate obligation to take steps, or "adopt measures" as worded in the CRPD. However, there is a question – what does "maximum of available resources" mean and how can we establish whether the state actually expends the "maximum of its available resources"?

In her work, Sepúlveda¹³⁰ analyses the indicators developed by the CESCR in order to provide the most objective assessment of the implementation of the ICESCR. The principal indicator is a comparative analysis of the financial resources spent by the State in expenditures related to economic, social and cultural right and those which are not related to the implementation of the ICESCR. If there have been significantly more funds allocated to non-related areas, such as military defence, than to Covenant-related expenditures such as health or education, it is considered as an indicator of non-compliance. The CESCR also compares the money spent by the State Party in the implementation of a specific Covenant right and that which is spent for the same item by other States with the same level of development – for example, expenditure on education in the Czech Republic compared to that in the Slovak Republic or Hungary. And, finally, the Committee can find a violation when the State has not spent funds allocated to a certain area, e.g. to social services, or reallocates them to another chapter, due to corruption.

Fredman in her work on social rights advocates a methodology which to some extent overlaps with the less structured CESCR indicators. The methodology is based on the assessment of three elements,, namely: i) the sufficiency of government spending; ii) the equity of spending patterns; and iii) the efficiency of

Press, 2009, pp. 84-87 and the famous Grootboom judgment of the Constitutional Court of South Africa.

CESCR General Comment No. 3, Paragraph 11.

¹²⁹ Cf. Maastricht Guidelines, Guideline No. 15.

¹³⁰ Sepúlveda, M. The nature of the obligations under the International Covenant on Economic, Social and Cultural Rights. Antwerp: Intersentia, 2003, pp. 316-319.

spending.¹³¹ **Sufficiency** is assessed by comparing actual expenditure with a benchmark figure, such as the proportion of GDP, or of total government spending. The World Health Organization has suggested that health spending should comprise 5% of GDP. A state which spends less would be in violation of the duty to utilize maximum available resources.¹³² Regarding **equity**, it is also measurable if spending is inequitable as between genders, classes, regions, or ethnic groupings, the government would be in breach of its duty. This can be illustrated by the Mexican example, in which it was shown that the richest regions in Mexico had received significantly more of the health spending than the poorer.¹³³ **Efficiency** of spending is more difficult to assess. But where a sum has been clearly budgeted and not used, a very strong argument can be made to compel a government to fulfil its obligations. As an example Fredman pointed out situation in India, when starvation deaths were occurring even though adequate food was being held in storage;¹³⁴ from practice of the CESCR it is for example General Observations regarding Colombia, when the state failed to spend allocated resources on social expenses.¹³⁵

We can therefore conclude that the State clearly has an obligation to spend funds to implement the rights of people with disabilities, and therefore also their right to live in the community. The funds must be spent to the maximum of the State's available resources taking into account sufficiency, equity and efficiency.

Basic elements of individual rights (the 4-A scheme)

The tripartite distinction between the obligation to respect, to protect and to fulfil is not the only analytical tool which can be used in order to clarify the content of States' obligations, particularly in the field of social, economic and cultural rights entailing certain obligations to ensure that individuals have the resources which allow them access to certain social goods such as housing, education, or health services. Another other option to classify the obligations of the State is the 4-A scheme developed in 1999 by Katarina Tomasevski, the UN Special Rapporteur on the Right to Education. We will briefly focus on the history of this scheme and of its acceptance.

Tomasevski, building on the analysis of international law¹³⁷ national constitutional documents, the practical impact of formal recognition of the right to

Schutter, O. International Human Rights Law.. Cambridge: Cambridge University Press, 2010, p. 253.

¹³¹ Fredman refers to the work "Hofbauer, H., Blyberg, A., Krafchik, W. Dignity Counts. Fundar, 2004. The work Dignity Counts is available at: http://www.internationalbudget.org/files/Dignity_Counts_english1.pdf

¹³² For a more detailed analysis of the possibility to compare spending to GDP and the Government expenditure structure, including comparison of the proposed and the actual spending, cf. Hofbauer, H., Blyberg, A., Krafchik, W. Dignity Counts. Fundar, 2004, pp. 35-39,.

¹³⁴ Fredman, S. Human Rights Transformed. Oxford: Oxford University Press, 2009, p. 82.

¹³⁵ Cf. Concluding Observations Colombia, E/1996/22, Paragraph 181.

¹³⁷ The States' obligations relating to education of children are based on three fundamental pillars: a) the State is obliged to enable all children to benefit from primary education; b) the State can enforce access to school and school attendance by making primary education compulsory, and c) it is

education in different countries, analysis of the enforceability of the right to education and on the available case law, developed a comprehensive structure of the State's obligations ensuing from the recognized right to education - the so-called "4-A scheme". According to Tomasevski, the state must ensure education to be a) Available, b) Accessible, c) Acceptable and d) Adaptable. 138 Education must thus be available to everyone, accessible to all, acceptable for pupils and parents and adaptable to the needs of learners. 139

This scheme is partly derived from an older CESCR General Comment No. 4 on the right to adequate housing 140 and the CESCR General Comment No. 12 on the right to adequate food 141. The scheme designed by Tomasevski was taken over in the same year by the CESCR in its General Comment No. 13.142 The Committee referred directly to the Preliminary Report of the UN Special Rapporteur on the Right to education and to its earlier General Comments No. 4 and No. 12. The 4-A scheme was taken over also by national human rights institutions 143 and by legal experts. 144 In June 2008, the European Committee of Social Rights (ECSR) used the above defined criteria to assess the fulfilment of the state's obligations arising from the right to education. In its decision in Mental Disability Advocacy Center (MDAC) v. Bulgaria, ECSR directly referred to the General Comment No. 13 of the Committee on Economic, Social and Cultural Rights (CESCR) and pointed out that under the European Social Charter, all education provided by states must fulfil four criteria as follows.

Table No 2: Summary of the states' obligations

	Availability	Accessibility	Acceptability	Adaptability
Obligation to respect				
Obligation to protect				

necessary to ensure that primary education is free of charge. The last obligation is not shared among all regional human rights treaties; however, the second obligation, which emphasizes also respect of parental freedom of choice, is shared among all documents. Preliminary report of the Special Rapporteur on the right to education of 13 January 1999, E/CN.4/1999/49, Paragraph 50.

E/CN.4/1999/49, Paragraph 50.

¹³⁹ Coomans, F. Justiciability of the right to education. Erasmus Law Review, Vol. 2, Issue 04, 2009, p.

<sup>427.

140</sup> In its General Comment No 4 (The right to adequate housing (Art.11 (1)), the Committee defined availability, affordability, several factors relating to the right to adequate housing which include availability, affordability, accessibility and cultural adequacy.

¹⁴¹ In its General Comment No 12 (The right to adequate food (Art.11)) the Committee set out the following elements of the right to adequate food: a) availability; b) aceptability and c) accessibility.

¹⁴² General Comment no. 13. The right to education (Art.13), E/C.12/1999/10.

Defensoria del Pueblo, El derecho a la educación en la Constitución, la jurisprudencia, y los instrumentos internationales. 2003; Human Rights Commission. The Right to Education: A Discussion Document, New Zealand Plan of Action for Human Rights. 2003.

¹⁴⁴ Cf. e.g. Schutter, O. International Human Rights Law.. Cambridge: Cambridge University Press, 2010, pp. 253-257; Coomans, F. Justiciability of the right to education. Erasmus Law Review, Volume 02, Issue 04, 2009, pp. 427-443.

Obligation to fulfil (facilitate)		
Obligation to fulfil (provide)		
Obligation to fulfil (promote)		

According to Coomans, 145 however, this scheme is appropriate for including elements that do not directly relate to a certain right as a human right but to certain policy issues and the role of state and local authorities in a specific matter. The common feature of the four A's is that all dimensions relate to the obligation of governments to respect, protect and implement a certain right. De Schutter believes that the 4-A's scheme describes the characteristics of the "good" or "service" that the individual right-holder has a right to: the respect/protect/fulfil framework describes the different obligations of the State either not to interfere with the enjoyment of that good or service, or to regulate private actors, or to facilitate access to that good or service by market mechanisms, or in certain cases to provide it. He therefore proposes to combine both these dimensions to the following matrix.

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¹⁴⁵ Coomans, F. Justiciability of the right to education. Erasmus Law Review, Vol. 2, Issue 04, 2009, p. 427.

CONCEPTUALIZATION OF THE RIGHT TO INDEPENDENT LIVING

In the previous chapter, we defined the theoretical basis of the obligations and elements of human rights as defined by the Committee on Economic, Social and Cultural Rights. Under this scheme, which can be comprehensively expressed in a table (see Tab. 1), the CESCR conceptualises specific rights by trying to provide an exact definition of all relevant elements of the respective rights and also its own perception of the State obligations to respect, protect and fulfil. Besides the above mentioned table, it is necessary to take account of the *minimum core obligation;* this is another concept the Committee strives to define in its Comments as clearly as possible. As noted above, a violation of the minimum core obligation constitutes *prima facie* a violation of the relevant right.

The right to independent living

Article 19 of the CRPD provides a general definition of the right to live independently and be included in the community. However, Article 19 itself does not specifically define the right to independent living but rather the right to live in the community; in its precise wording "equal right of all persons with disabilities to live in the community" while emphasizing the aspect of choice. The plural used in the phrase "with choices" implies that persons with disabilities have the right to choose from several options to fulfil their own idea of implementing their right to live in the community.

The right to independent living is broader than the right to live in the community as it includes many partial rights including the right to live in the community itself. In order to be able to define the right to live in the community, namely the obligations and elements arising thereof, we are going to look at the obligations and elements of those obligations that are part of the right to independent living. In our analysis, we are going to focus on social rights, as the General Comments of the CESCR provide a comprehensive theoretical basis to be built on.¹⁴⁶

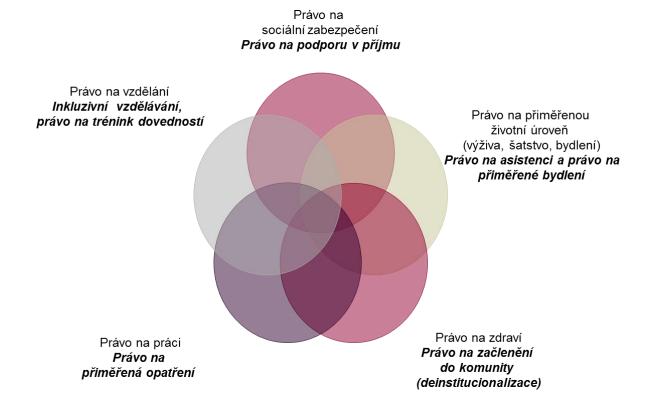
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¹⁴⁶ We hope the reader will kindly forgive us for not including in our analysis political and civil rights such as the right to vote and to be elected, which is also a very important prerequisite for independent living.

Independent living is related to the right to health because the highest attainable level of physical and mental health is a prerequisite of full "independence" understood as the ability to live according to one's own wishes. The prerequisite of independent living is a certain standard of living, i.e. the fulfilment of the right to an adequate standard of living (food, clothing and housing). This is related to the issue of social security of people with disabilities - simply because in order to be able to live independently it is necessary to have sufficient funds. These can be provided either by the social security system (however, with the drawback of creating dependence on it), or by providing conditions for independent work which may in some cases replace or supplement the social security benefit system. This leads us to the right to work which is important not only in terms of economic independence, but also in terms of self-esteem of persons with disabilities. Self-esteem is the basis of the enabling aspect of this right. The right to work is important also in terms of acceptance of otherness by those surrounding the person with disability, i.e. by the majoritarian society. This phenomenon is the basis of the strengthening aspect of the right to work. A similar situation arises in case of the right to education which is associated with the right to work because education determines career prospects. In addition, the right to education has also an enabling and a strengthening element, both of which go beyond social rights. This can be illustrated on the example of the voting rights or of the right of association.

The right to independent living can thus be conceptualized with regard to partial social rights. In the diagram below, independent living is expressed as an intersection of circles representing individual rights.¹⁴⁷

¹⁴⁷ We are aware of the fact that this diagram is simplistic and that it can be argued that there are also different intersections. However, we can consider it sufficient for the purpose of this work.



Elements of the right to health, social security, work and education

Let us now consider in greater detail the elements of the right to health, to social security, to work and to education as defined in the CESCR's General Comments. As we stated above, this framework consists of the 4-A scheme which can be applied universally; therefore, the following definitions will help us formulate specific elements of the right to live in the community, or, in the words of Article 19 of the CRPD, the right to being included in the community.

The right to health

The elements ensuing from the right to work were defined by the CESCR in its General Comment No. 14.¹⁴⁸ This framework was later adopted for example by the African Commission on Human and Peoples' Rights¹⁴⁹, and emphasized also by Paul Hunt in his report on the right to health. Hunt stated that this analytical framework applies to mental health as well as related support services, while each component has close synergies with international mental disability standards.¹⁵⁰ The right to health in all its forms and at all levels contains the following interrelated and essential elements, the precise application of which will depend on the conditions prevailing in a particular State party. The Committee defined the following elements of the right to health: i) availability, ii) accessibility iii) acceptability and iv) quality of health services, facilities, goods and programmes.

Availability of the right to health means that functioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party. The precise nature of the facilities, goods and services will vary depending on numerous factors, including the State party's developmental level. They will include, however, the underlying determinants of health, such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action Programme on Essential Drugs. ¹⁵¹ In the area of mental health, accessibility includes adequate numbers of mental health-related facilities and support services and adequate numbers of medical and other professionals trained to provide these services. For some persons with certain psychiatric disabilities, an adequate supply of essential medicines, including essential psychotropic medicines on WHO's List of Essential Medicines, should also be available. ¹⁵²

In general, **accessibility** of the right to health means that health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State. Accessibility has four overlapping dimensions: i) non-discrimination, ii) physical accessibility; iii) economic accessibility and iv) information accessibility.

Non-discrimination means that health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the

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¹⁴⁸ General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4.

¹⁴⁹ Cf. Resolution of the African Commission on Human and Peoples' Rights, ACHPR/Res. 141 (XXXXIIII)08: Resolution on Access to Health and needed Medicines in Africa.

Hunt, P. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. E/CN.4/2005/51, Report of 11 February 2005, Paragraph 46.

of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4, Paragraph 12. Hunt, P. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. E/CN.4/2005/51, Report of 11 February 2005, Paragraph 46 (a).

population, in law and in fact, without discrimination on any of the prohibited grounds. States may need to take affirmative action to ensure equality of access for all individuals and groups; states should also ensure that persons with disabilities get the same level of medical care within the same system as other members of society. 154

Physical accessibility assumes that health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups. Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities. According to Hunt, physical accessibility has especially important implications for community-based care. ¹⁵⁶

Economic accessibility (affordability) implies that health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.¹⁵⁷

And, finally, *information accessibility* includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality. Hunt emphasizes that this entitlement is often denied to persons with mental disabilities because they are wrongly judged to lack the capacity to make or participate in any decisions about their own treatment and care. Information on health and other matters, including diagnosis and treatment, must be accessible to persons with mental disabilities, and the parents of children with mental disabilities. ¹⁵⁹

The **acceptability** element requires that all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements. They must also be designed to respect confidentiality and

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¹⁵³ General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4, Paragraph 12. Hunt, P. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. E/CN.4/2005/51, Report of 11 February 2005, Paragraph 46 (b).

of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4, Paragraph 12. Hunt, P. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. E/CN.4/2005/51, Report of 11 February 2005, Paragraph 46 (b).

¹⁵⁷ General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4, Paragraph 12. ¹⁵⁸ Ibid.

Hunt, P. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. E/CN.4/2005/51, Report of 11 February 2005, Paragraph 46 (b).

improve the health status of those concerned. As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically **appropriate and of good quality.** This requires, *inter alia*, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation. 161

The right to social security

The obligations of States ensuing from the right to social security right were defined by the CESCR in its General Comment No. 19. The Committee's definition of the framework of the right to social security differs from the standard 4-A scheme. However, even this definition, all elements are identifiable. As to the right itself, the CESCR emphasized that in interpreting these aspects, it should be borne in mind that social security should be treated as a social good, and not primarily as a mere instrument of economic or financial policy. ¹⁶³

Availability (social security system) means that the right to social security requires, for its implementation, that a system, whether composed of a single scheme or variety of schemes, is available and in place to ensure that benefits are provided for the relevant social risks and contingencies. The Committee relatively clearly defined its understanding of the notions of **social risks and contingencies**. According to the CESCR, the social security system should provide for the coverage of the following nine principal branches of social security: 165 a) Health care; b) Sickness; c) Old age; d) Unemployment; e) Employment injury; f) Family and child support; g) Maternity; h) Disability; i) Survivors and orphans.

Another element defined by the Committee is **adequacy**. Benefits, whether in cash or in kind, must be adequate in amount and duration in order that everyone may realize his or her rights to family protection and assistance, an adequate standard of living and adequate access to health care, as contained in articles 10, 11 and 12 of the Covenant. States parties must also pay full respect to the principle of human dignity and the principle of non-discrimination, so as to avoid any adverse effect on the levels of benefits and the form in which they are provided. Methods applied should ensure the adequacy of benefits. The adequacy criteria should be monitored regularly to ensure that beneficiaries are able to afford the goods and services they require to realize their Covenant rights. ¹⁶⁶

In terms of **accessibility**, the Committee partly differs from the traditional definitions and it defines the following four overlapping dimensions: i) coverage; ii) eligibility; iii) affordability; iv) participation and information and v) physical access.

General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4, Paragraph 12.

¹⁶² General Comment No 19. The right to social security (Article 9), E/C.12/GC/19, Paragraph 20.

¹⁶³ Ibid., Paragraph 10.

¹⁶⁴ Ibid., Paragraph 11.

¹⁶⁵ Ibid., Paragraph 12.

¹⁶⁶ Ibid., Paragraph 22.

Coverage means that all persons should be covered by the social security system without discrimination on any of the prohibited grounds. The social security system should cover especially individuals belonging to the most disadvantaged and marginalized groups. As to the eligibility dimension, the CESCR stipulates that the qualifying conditions for benefits must be reasonable, proportionate and transparent. The withdrawal, reduction or suspension of benefits should be based on grounds that are reasonable, subject to due process, and provided for in national law. Affordability means that a social security scheme based on contributions assumes that those contributions should be stipulated in advance. The direct and indirect costs and charges associated with making contributions must be affordable for all, and must not compromise the realization of other Covenant rights. Participation and information expresses the obligation to involve the beneficiaries of social security schemes in the administration of the social security system. The system should be established under national law and ensure the right of individuals and organizations to seek, receive and impart information on all social security entitlements in a clear and transparent manner. The last dimension defined by the CESCR is the physical access. Benefits should be provided in a timely manner and beneficiaries should have physical access to the social security services in order to access benefits and information, and make contributions where relevant. Particular attention should be paid in this regard to persons with disabilities, so that they, too, can have access to these services.

The right to work

According to the CESCR, the right to work contains the same interdependent and essential elements as the right to health – i.e. availability, accessibility, acceptability and quality. In its General Comment No. 18, the CESCR combines acceptability and quality in a single point. 167

Availability means that the States must have specialized services to assist and support individuals in order to enable them to find available employment. Unlike in other general comments, the Committee did not define individual dimensions of **accessibility**. However, we can clearly conclude that it is a dimension of: i) non-discrimination, ii) physical accessibility iii) information accessibility. Let us now take a closer look at the individual dimensions as defined by the CESCR.

According to the Committee, Article 2 (2) and Article 3 of the Covenant prohibits any discrimination in access to and maintenance of employment, which has the intention or effect of impairing or nullifying exercise of the right to work on a basis of equality. According to Article 2 of ILO Convention No. 111, States parties should "declare and pursue a national policy designed to promote, by methods appropriate to national conditions and practice, equality of opportunity and treatment in respect of employment and occupation, with a view to eliminating any discrimination in respect thereof". Many measures, such as most strategies and programmes designed to eliminate employment-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information. The Committee recalls that, even in times of severe

 $^{^{\}rm 167}$ The Right to Work. General Comment No. 18, E/C.12/GC/18.

resource constraints, disadvantaged and marginalized individuals and groups must be protected by the adoption of relatively low-cost targeted programmes. *Physical accessibility* is one dimension of accessibility to employment as explained in Paragraph 5 of General Comment No. 5 on persons with disabilities. Accessibility includes the right to *seek*, *obtain and impart information* on the means of gaining access to employment through the establishment of data networks on the employment market at the local, regional, national and international levels;

Acceptability and **quality** cover the right of the worker to just and favourable conditions of work, in particular to safe working conditions, the right to form trade unions and the right freely to choose and accept work.¹⁶⁸

The right to education

The elements of the right to education represent the 4-A model scheme as defined above. The individual elements were outlined by the UN Special Rapporteur on the Right to Education, Katarina Tomasevski, and later adopted by the CESCR in its General Comment No. 13.¹⁶⁹

Availability means that functioning educational institutions and programmes have to be available in sufficient quantity. What they require to function depends upon numerous factors, including the developmental context within which they operate; for example, all institutions and programmes are likely to require buildings or other protection from the elements, sanitation facilities for both sexes, safe drinking water, trained teachers receiving domestically competitive salaries, teaching materials, and so on; while some will also require facilities such as a library, computer facilities and information technology;

Educational institutions and programmes have to be **accessible** to everyone, without discrimination. According to the CESCR, accessibility of the right to education has three overlapping dimensions: i) non-discrimination, ii) physical accessibility and iii) economic accessibility.

The principle of *non-discrimination* means that education must be accessible to all, especially the most vulnerable groups, in law and fact, without discrimination on any of the prohibited grounds. *Physical accessibility* means that education has to be within safe physical reach, either by attendance at some reasonably convenient geographic location (e.g. a neighbourhood school) or via modern technology (e.g. access to a "distance learning" programme); *Economic accessibility* means that education has to be affordable to all. This dimension of accessibility is different in relation to primary, secondary and higher education; only primary education shall be available "free to all". States parties are required to progressively introduce free secondary and higher education;

The form and substance of education, including curricula and teaching methods, have to be **acceptable** (e.g. relevant, culturally appropriate and of good

¹⁶⁸ Ibid., Paragraph 12.

¹⁶⁹ General Comment No. 13. The right to education (Article 13), E/C.12/1999/10.

quality) to students and, in appropriate cases, parents; and finally, the **adaptability** element means that education has to be flexible so it can adapt to the needs of changing societies and communities and respond to the needs of students within their diverse social and cultural settings. ¹⁷⁰

The States' obligations arising from the right to health, social security, work and education and their violations

The fulfilment of specified elements of certain social rights is a prerequisite of the fulfilment of a more general right to independent living. We are now going to focus on the specific obligations defined by the CESCR, taking into account the typology specified above. Specifically, we are going to deal with those ensuing from the right to health, whose connection to deinstitutionalization was explained by Paul Hunt. We are further going to deal with the obligations ensuing from the right to social security, the right to work and, finally, the right to education. We will omit the right to housing because this typology was not yet used by the CESCR in its General Comment No. 7. We however believe that even so, this analysis will be sufficient to define the obligations ensuing from the right to live in the community.

The right to health

The right to health is laid down in Article 25 of the Universal Declaration of Human Rights, in Article 12 of the International Covenant on Economic, Social and Cultural Rights and in Article 25 of the Convention on the Rights of Persons with Disabilities. The right to health is related also to the right to habilitation and rehabilitation provided for in Article 27 of the Convention on the Rights of Persons with Disabilities. The obligations ensuing from the right to health were defined by the CESCR in its General Comment No. 14.¹⁷¹

In particular, States are under the obligation to **respect** the right to health by refraining from denying equal access for all persons to preventive, curative and palliative health services, by abstaining from enforcing discriminatory practices as a State policy and by abstaining from imposing discriminatory practices relating to women's health status and needs. Furthermore, the obligation to respect includes an obligation to refrain from prohibiting or impeding traditional preventive care, healing practices and medicines. States should also refrain from marketing unsafe drugs and from applying coercive medical treatments, unless on an exceptional basis for the treatment of mental illness or the prevention and control of communicable diseases. Such exceptional cases should be subject to specific and restrictive conditions, respecting best practices and applicable international standards, including the Principles for the Protection of Persons with Mental Illness (the so-called MI Principles). In addition, States should refrain from limiting access to contraceptives and other means of maintaining sexual and reproductive health, from censoring, withholding or intentionally misrepresenting health-related information, including

¹⁷⁰ Ibid., Paragraph 6.

General Comment No. 14 (2000), The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), E/C.12/2000/4.

sexual education and information, as well as from preventing people's participation in health-related matters. ¹⁷²

Violations of the obligation to respect are those State actions, policies or laws that contravene the standards set out in article 12 of the ICESCR and are likely to result in bodily harm, unnecessary morbidity and preventable mortality. Examples include the denial of access to health facilities, goods and services to particular individuals or groups as a result of *de jure* or *de facto* discrimination; the deliberate withholding or misrepresentation of information vital to health protection or treatment and the suspension of legislation or the adoption of laws or policies that interfere with the enjoyment of any of the components of the right to health. A violation of the obligation is also the failure of the State to take into account its legal obligations regarding the right to health when entering into bilateral or multilateral agreements with other States, international organizations and other entities, such as multinational corporations.¹⁷³

The obligation of the States to **protect** the right to health includes, inter alia, the duties of States to adopt legislation or to take other measures ensuring equal access to health care and health-related services provided by third parties. It is necessary to control the marketing of medical equipment and medicines by third parties and to ensure that medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct. States are also obliged to take measures to protect all vulnerable or marginalized groups of society. States should also ensure that third parties do not limit people's access to health-related information and services.¹⁷⁴

Violations of the obligation to protect follow from the failure of States to take all necessary measures to safeguard persons within their jurisdiction from infringements of the right to health by third parties. This category includes such omissions as the failure to regulate the activities of individuals, groups or corporations so as to prevent them from violating the right to health of others; the failure to protect consumers and workers from practices detrimental to health, e.g. by employers and manufacturers of medicines or food; the failure to discourage production, marketing and consumption of tobacco, narcotics and other harmful substances; the failure to protect women against violence or to prosecute perpetrators; the failure to discourage the continued observance of harmful traditional medical or cultural practices; and the failure to enact or enforce laws to prevent the pollution of water, air and soil by extractive and manufacturing industries. 175

The obligation to **fulfil** requires States parties, *inter alia*, to give sufficient recognition to the right to health in their national political and legal systems, preferably by way of legislative implementation, and to adopt a national health policy with a detailed plan for realizing the right to health. States must ensure provision of health care, including immunization programmes against the major infectious diseases, and ensure equal access for all to the underlying determinants of health, such as nutritiously safe food and potable drinking water, basic sanitation and

173 Ibid., Paragraph 50.

¹⁷² Ibid., Paragraph 34.

¹⁷⁴ Ibid., Paragraph 35.

¹⁷⁵ Ibid., Paragraph 50.

adequate housing and living conditions. Public health infrastructures should provide for sexual and reproductive health services, including safe motherhood, particularly in rural areas. States have to ensure the appropriate training of doctors and other medical personnel, the provision of a sufficient number of hospitals, clinics and other health-related facilities, and the promotion and support of the establishment of institutions providing counselling and mental health services, with due regard to equitable distribution throughout the country. Further obligations include the provision of a public, private or mixed health insurance system which is affordable for all, the promotion of medical research and health education, as well as information campaigns, in particular with respect to HIV/AIDS, sexual and reproductive health, traditional practices, domestic violence, the abuse of alcohol and the use of cigarettes, drugs and other harmful substances. States are also required to adopt measures against environmental and occupational health hazards and they are required to formulate, implement and periodically review a coherent national policy to minimize the risk of occupational accidents and diseases, as well as to provide a coherent national policy on occupational safety and health services. 176

The obligation to *fulfil* (*facilitate*) requires States *inter alia* to take positive measures that enable and assist individuals and communities to enjoy the right to health. States parties are also obliged to *fulfil* (*provide*) a specific right contained in the Covenant when individuals or a group are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal. The obligation to *fulfil* (*promote*) the right to health requires States to undertake actions that create, maintain and restore the health of the population. Such obligations include: (i) fostering recognition of factors favouring positive health results; (ii) ensuring that health services are culturally appropriate and that health care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups; (iii) ensuring that the State meets its obligations in the dissemination of appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices and the availability of services; (iv) supporting people in making informed choices about their health.¹⁷⁷

Violations of the obligation to fulfil occur through the failure of the State to take all necessary steps to ensure the realization of the right to health. Examples include the failure to adopt or implement a national health policy designed to ensure the right to health for everyone; insufficient expenditure or misallocation of public resources which results in the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalized; the failure to monitor the realization of the right to health at the national level, for example by identifying right to health indicators and benchmarks; the failure to take measures to reduce the inequitable distribution of health facilities, goods and services; the failure to adopt a gender-sensitive approach to health. And, last but not least, a violation of this obligation is also the failure to reduce infant and maternal mortality rates. ¹⁷⁸

The right to social security

¹⁷⁶ Ibid., Paragraph 36.

¹⁷⁷ Ibid., Paragraph 37.

¹⁷⁸ Ibid., Paragraph 51.

The right to social security is laid down in Article 22 of the Universal Declaration of Human Rights, in Article 19 of the International Covenant on Economic, Social and Cultural Rights and in Article 28 of the Convention on the Rights of Persons with Disabilities. The obligations of the States ensuing from the right to social security were defined by the CESCR in its General Comment No. 19. 179

The obligation to **respect** requires that States parties refrain from interfering directly or indirectly with the enjoyment of the right to social security. The obligation includes, inter alia, that the State should refrain from engaging in any practice or activity that, for example, denies or limits equal access to adequate social security; arbitrarily or unreasonably interferes with self-help or customary or traditional arrangements for social security and with institutions that have been established by individuals or corporate bodies to provide social security. ¹⁸⁰

The obligation to **protect** requires that the State is obliged to prevent third parties from interfering in any way with the enjoyment of the right to social security. Third parties include individuals, groups, corporations and other entities, as well as agents acting under their authority The obligation includes, *inter alia*, adopting the necessary and effective legislative and other measures, for example, to restrain third parties from denying equal access to social security schemes operated by them or by others and imposing unreasonable eligibility conditions; arbitrarily or unreasonably interfering with self-help or customary or traditional arrangements for social security that are consistent with the right to social security; and failing to pay legally required contributions for employees or other beneficiaries into the social security system. ¹⁸¹

The obligation to **fulfil** requires States parties to adopt the necessary measures, including the implementation of a social security scheme, directed towards the full realization of the right to social security. The obligation to fulfil can be subdivided into the obligations to facilitate, promote and provide. ¹⁸²

The obligation to *fulfil* (*facilitate*) requires States parties to take positive measures to assist individuals and communities to enjoy the right to social security. The obligation includes, *inter alia*, according sufficient recognition of this right within the national political and legal systems, preferably by way of legislative implementation; adopting a national social security strategy and plan of action to realize this right; ensuring that the social security system will be adequate, accessible for everyone and will cover social risks and contingencies. The obligation to *fulfil* (*promote*) obliges the States parties to take steps to ensure that there is appropriate education and public awareness concerning access to social security schemes, particularly in rural and deprived urban areas, or amongst linguistic and other minorities. States parties are also obliged to provide the right to social security when individuals or a group are unable, on grounds beyond their control, to realize that right themselves, within the existing social security system with the means at their disposal. States parties will need to establish non-contributory schemes or other

¹⁸¹ Ibid., Paragraph 45.

¹⁷⁹ General Comment No. 19 The Right to Social Security (Article 9), E/C.12/GC/19.

¹⁸⁰ Ibid., Paragraph 44.

¹⁸² Ibid., Paragraph 47.

¹⁸³ Ibid., Paragraph 48.

¹⁸⁴ Ibid., Paragraph 49.

social assistance measures to provide support to those individuals and groups who are unable to make sufficient contributions for their own protection. Special attention should be given to ensuring that the social security system can respond in times of emergency, for example during and after natural disasters, armed conflict and crop failure. 185

It is important that social security schemes cover disadvantaged and marginalized groups, even where there is limited capacity to finance social security, either from tax revenues and/or contributions from beneficiaries. Low-cost and alternative schemes could be developed to cover immediately those without access to social security, although the aim should be to integrate them into regular social security schemes. Policies and a legislative framework could be adopted for the progressive inclusion of those excluded from access to social security. ¹⁸⁶

The right to work

In the Universal Declaration of Human Rights, this right is dealt with in two Articles, namely Article 24 and Article 25. The right to work is also enshrined in Article 6 of the International Covenant on Economic, Social and Cultural Rights The right to work specific for people with disabilities is enshrined in Article 27 of the Convention on the Rights of Persons with Disabilities. The obligations ensuing from the right to work were defined by the CESCR in its General Comment No. 18.

States parties are under the obligation to **respect** the right to work by, inter alia, prohibiting forced or compulsory labour and refraining from denying or limiting equal access to decent work for all persons, especially disadvantaged and marginalized individuals and groups, including prisoners or detainees, members of minorities and migrant workers. In particular, States parties are bound by the obligation to respect the right of women and young persons to have access to decent work and thus to take measures to combat discrimination and to promote equal access and opportunities.¹⁸⁸

With regard to the obligations of States parties relating to child labour as set out in Article 10 of the ICESCR, States parties must take effective measures, in particular legislative measures, to prohibit labour of children under the age of 16. Further, they have to prohibit all forms of economic exploitation and forced labour of children. States parties must adopt effective measures to ensure that the prohibition of child labour will be fully respected. 189

Violations of the obligation to respect the right to work include laws, policies and actions that contravene the standards laid down in Article 6 of the Covenant. In particular, any discrimination in access to the labour market or to means and entitlements for obtaining employment constitutes a violation of the Covenant. The principle of non-discrimination is immediately applicable and is neither subject to

186 Ibid., Paragraph 51.

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¹⁸⁵ Ibid., Paragraph 50.

¹⁸⁷ The Right to Work. General Comment No. 18, E/C.12/GC/18.

¹⁸⁸ Ibid., Paragraph 23.

¹⁸⁹ Ibid., Paragraph 24.

progressive implementation nor dependent on available resources. It is directly applicable to all aspects of the right to work. The failure of States parties to take into account their legal obligations regarding the right to work when entering into bilateral or multilateral agreements with other States, international organizations and other entities constitutes a violation of their obligation to respect the right to work. ¹⁹⁰

As for all other rights in the Covenant, there is a strong presumption that retrogressive measures taken in relation to the right to work are not permissible. Such retrogressive measures include, *inter alia*, denial of access to employment to particular individuals or groups, whether such discrimination is based on legislation or practice, abrogation or suspension of the legislation necessary for the exercise of the right to work or the adoption of laws or policies that are manifestly incompatible with international legal obligations relating to the right to work. An example would be the institution of forced labour or the abrogation of legislation protecting the employee against unlawful dismissal. Such measures would constitute a violation of States parties' obligation to respect the right to work.

The obligation to **protect** includes, *inter alia*, the duties of States parties to adopt legislation or to take other measures ensuring equal access to work and training and to ensure that privatization measures do not undermine workers' rights. Specific measures to increase the flexibility of labour markets must not render work less stable or reduce the social protection of the worker. The obligation to protect the right to work includes the responsibility of States parties to prohibit forced or compulsory labour by non-State actors. ¹⁹¹

Violation of the above obligation follows from the failure of States parties to take all necessary measures to safeguard persons within their jurisdiction from infringements of the right to work by third parties. This includes omissions such as the failure to regulate the activities of individuals, groups or corporations so as to prevent them from violating the right to work of others; or the failure to protect workers against unlawful dismissal. 192

And, last but not least, the obligation to **fulfil**. States parties are obliged to *fulfil* (*provide*) the right to work when individuals or groups are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal. This obligation includes, *inter alia*, the obligation to recognize the right to work in national legal systems and to adopt a national policy on the right to work as well as a detailed plan for its realization. The right to work requires formulation and implementation by States parties of an employment policy with a view to "stimulating economic growth and development, raising levels of living, meeting manpower requirements and overcoming unemployment and underemployment". It is in this context that effective measures to increase the resources allocated to reducing the unemployment rate, in particular among women, the disadvantaged and marginalized, should be taken by States parties. The Committee emphasizes the need to establish a compensation mechanism in the event of loss of employment, as well as the obligation to take appropriate measures for the establishment of employment services (public or private) at the national and local levels. Further, the obligation to *fulfil* (*provide*) the

191 Ibid., Paragraph 25.

¹⁹⁰ Ibid., Paragraph 33.

¹⁹² Ibid., Paragraph 35.

right to work includes the implementation by States parties of plans to counter unemployment. The obligation to *fulfil (facilitate)* the right to work requires States parties, *inter alia*, to take positive measures to enable and assist individuals to enjoy the right to work and to implement technical and vocational education plans to facilitate access to employment. The obligation to *fulfil (promote)* the right to work requires States parties to undertake, for example, educational and informational programmes to instil public awareness on the right to work.

Violations of the obligation to fulfil occur through the failure of States parties to take all necessary steps to ensure the realization of the right to work. Examples include the failure to adopt or implement a national employment policy designed to ensure the right to work for everyone; insufficient expenditure or misallocation of public funds which results in the non-enjoyment of the right to work by individuals or groups, particularly the disadvantaged and marginalized; the failure to monitor the realization of the right to work at the national level, for example, by identifying right-to-work indicators and benchmarks; and the failure to implement technical and vocational training programmes.¹⁹⁶

The right to education

The right to education is enshrined in Article 26 of the Universal Declaration of Human Rights and in Article 13 of the International Covenant on Economic, Social and Cultural Rights. The right to education specific for people with disabilities is enshrined in Article 24 of the Convention on the Rights of Persons with Disabilities. The CESCR is dealing with the right to education in its General Comment No 13. 197

As early as in this Comment, the CESCR emphasized that all human rights impose three types or levels of obligations on States parties: the obligation to respect, the obligation to protect and the obligation to fulfil. According to the CESCR, the obligation to fulfil incorporates both an obligation to facilitate and an obligation to provide. The obligation to promote does not appear in the Comments of the Committee until later.

The obligation to **respect** requires States parties to avoid measures that hinder or prevent the enjoyment of the right to education. The obligation to **protect** requires States parties to take measures that prevent third parties from interfering with the enjoyment of the right to education. The obligation to **fulfil** requires the following: the obligation to **fulfil** (**facilitate**) requires States to take positive measures that enable and assist individuals and communities to enjoy the right to education. Finally, States parties have an obligation to **fulfil** (**provide**) the right to education. As a general rule, States parties are obliged to fulfil (**provide**) a specific right in the Covenant when an individual or group is unable, for reasons beyond their control, to realize the right

194 Ibid., Paragraph 27.

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¹⁹³ Ibid., Paragraph 26.

¹⁹⁵ Ibid., Paragraph 28.

¹⁹⁶ Ibid., Paragraph 36.

¹⁹⁷ General Comment No. 13. The Right to Education (Article 13), E/C.12/1999/10.

¹⁹⁸ Ibid., Paragraph 46.

themselves by the means at their disposal. However, the extent of this obligation is always subject to the text of the ICESCR. 199

In this respect, two features of Article 13 require emphasis. First, it is clear that Article 13 regards States as having principal responsibility in most circumstances. For example, in Article 13 (2) (e), States parties recognize that the "development of a system of schools at all levels shall be actively pursued". Secondly, given the differential wording in relation to primary, secondary, higher and fundamental education, the parameters of a State party's obligation to fulfil (provide) are not the same for all levels of education.²⁰⁰

States have obligations to respect, protect and fulfil each of the "essential features" (availability, accessibility, acceptability, adaptability - see the author's comment above) of the right to education. By way of illustration, a State must respect the availability of education by not closing private schools; protect the accessibility of education by ensuring that third parties, including parents and employers, do not stop girls from going to school; fulfil (facilitate) the acceptability of education by taking positive measures to ensure that education is culturally appropriate for minorities and indigenous peoples, and of good quality for all; fulfil (provide) the adaptability of education by designing and providing resources for curricula which reflect the contemporary needs of students in a changing world; and fulfil (provide) the availability of education by actively developing a system of schools. including building classrooms, delivering programmes, providing teaching materials, training teachers and paying them domestically competitive salaries. ²⁰¹

By way of illustration, violations of the right to education include the introduction or failure to repeal legislation which discriminates against individuals or groups, on any of the prohibited grounds, in the field of education; the failure to take measures which address de facto educational discrimination; the use of curricula inconsistent with the educational objectives set out in Article 13 (1) of the ICESCR; the failure to maintain a transparent and effective system to monitor conformity with Article 13 (1) of the ICESCR; the failure to introduce, as a matter of priority, primary education which is compulsory and available free to all; the failure to take "deliberate, concrete and targeted" measures towards the progressive realization of secondary, higher and fundamental education in accordance with Article 13 (2) (b)-(d) of the ICESCR; the prohibition of private educational institutions; the failure to ensure private educational institutions conform to the "minimum educational standards" required by Article 13 (3) and (4); the denial of academic freedom of staff and students: the closure of educational institutions in times of political tension in non-conformity with Article 4. 202

¹⁹⁹ Ibid., Paragraph 47.

lbid., Paragraph 48.

²⁰¹ Ibid., Paragraph 50.

²⁰² Ibid., Paragraph 59.

RIGHT TO LIVE IN THE COMMUNITY

The right to live in the community is a subset of the right to live independently as opposed to institutionalization and institutional care. The Convention on the Rights of Persons with Disabilities was adopted a short time ago (in 2006) and it is still not entirely clear how to interpret the obligations of States parties ensuing from the right to be included in the community under Article 19 of the CRPD. For this reason, the following section is going to focus on the analysis of Article 4 of the CRPD which sets out the obligations of the States; we will also try to formulate specific elements of the right to live in the community and, finally, the specific obligations of the State arising from this provision. This final analysis, which can be considered to represent the output of our work, is based on the conceptualization of the right to independent living carried out in the previous Chapter.

Obligations arising from the UN Convention on the Rights of Persons with Disabilities

In the sections above we have paid closer attention to the theory of law and to the general conclusions on the nature of state obligations made by the CESCR. I believe that these conclusions are so general and theoretically substantiated that they can be used also to define the obligations ensuing from the Convention on the Rights of Persons with Disabilities, specifically the right to be included in the community under Article 19 of the CRPD. Now let us look at Article 4 of the CRPD which defines the obligations arising from this Convention. Under Article 4 (1) and (2) of the CRPD:

"States Parties undertake to **ensure and promote the full realization** of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

[...]

With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law."

The original draft Article 4 of the CRPD did not expressly refer to economic, social and cultural rights. This fact became the subject of discussions within the United Nations, namely during the third ²⁰³ and fourth session ²⁰⁴ of the Working Group. During its fourth session, the Working Group agreed that Article 4 of the CRPD should include the concept of progressive realization of economic, social and cultural rights, balanced by the need to implement immediately those obligations that are capable of immediate implementation. At the same time, it was emphasized that non-discrimination is not subject to the doctrine of progressive realization. ²⁰⁵

Article 4 of the CRPD emphasizes that states are obliged to ensure and promote the "full realization" of all human rights. The full realization is emphasized also in Article 2 of the Convention on the Rights of the Child (Article 2); the earlier international conventions on human rights do not use such a strong vocabulary. As to the definition of the specific obligations to "ensure" and "promote", the original text of the draft Article 4 defined only the obligation to "ensure" the obligation to "promote" was added during the 7th session of the Group on the initiative of the African Group. 207

The obligation to *ensure* is expressly provided for in Article 2 of the ICCPR. It is a positive obligation which is interpreted by Nowak as incorporating the above mentioned obligations to *protect* and to *fulfil*. He argues that this can be inferred both from the provisions of the ICCPR itself and of the Human Rights Committee's jurisprudence. This obligation is explicitly defined by the Bill of Rights in the Constitution of the Republic of South Africa, Article 7 (2). According to this provision, "the state must respect, protect, promote and fulfil the rights in the Bill of Rights". This categorization was, referring

²⁰⁶ Cf. the original draft of the wording of Article 4:

"States Parties undertake to *ensure* the full realisation of all human rights and fundamental freedoms for all individuals within their jurisdiction without discrimination of any kind on the basis of disability." The original version is available at: http://www.un.org/esa/socdev/enable/rights/ahcwgreporta4.htm

²⁰⁷ Cf. the proposals relating to Article 4 submitted at the 7th session. The proposals are available at: http://www.un.org/esa/socdev/enable/rights/ahcstata4sevscomments.htm

Nowak, M. U.N. Covenant on Civil and Political Rights. CCPR Commentary, 2th edition. N.P.Engel:Kehl, 2005, p. 39.

²⁰³ Cf. the discussion available at: http://www.un.org/esa/socdev/enable/rights/ahc3sum4.htm

²⁰⁴ Cf. the discussion available at: http://www.un.org/esa/socdev/enable/rights/ahc4sumart04.htm
²⁰⁵ Cf. the Report of the Ad Hoc Committee available at: http://www.un.org/esa/socdev/enable/rights/ahc4reporte.htm

The original wording of Article 7 (2): "The state must respect, protect, promote and fulfil the rights in the Bill of Rights".

to Asbjørn Eide's work ²¹⁰, taken over by the African Commission on Human and Peoples' Rights. ²¹¹

Article 4 of the CRPD does not provide a clear definition of the obligation to respect, i. e. to refrain from interfering with the enjoyment of the rights of people with disabilities. This obligation can be inferred from the basic principle of the Convention as defined in Article 3 (1)(a), under which the state has the obligation to foster "respect ... for dignity ..." of people with disabilities, as well as from the individual rights guaranteed in the CRPD; for example, from the right to life under Article 10 of the CRPD, or the absolute prohibition of torture under Article 15 of the CRPD.

We can therefore conclude that four specific obligations of the State can be inferred from the Convention on the Rights of Persons with Disabilities, namely: i) the obligation to respect, ii) the obligation to protect, iii) the obligation to fulfil and iv) the obligation to promote rights of people with disabilities.

Formulation of the elements of the right to live in the community

In the section above we have analysed the elements of the rights which, in our opinion, constitute a general right to independent living. We also stated that we build on the assumption that the right to independent living incorporates the right to live in the community. We have seen that the elements of the rights defined in the CESCR are similar, and that four basic elements can be identified, namely: i) availability, ii) acceptability and iv) adjustment and quality. Let us now define the contents of the elements of the right to live in the community based on the above division.

Availability of the right to live in the community means that functioning community services are available in sufficient quantity. The nature of the services will vary depending on numerous factors, including the State party's developmental level. They will include, however, the underlying determinants of health, such as i) potable drinking water; ii) sanitation facilities, iii) trained professional personnel receiving domestically competitive salaries, and iv) essential methods and procedures of social work and therapeutic care. Availability is emphasized in Article 19 (a) of the CRPD.

²¹⁰ However, Eide did not formulate the obligation to "promote" The Commission directly referred to Asbjørn Eide's work "Economic, Social and Cultural Rights As Human Rights" in Asbjørn Eide, Catarina Krause and Allan Rosas (Eds.) *Committee on Economic, Social and Cultural Rights: A Textbook* (1995). pp. 21-40. The obligation to promote was formulated by van Hoof (see above).

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In the decision regarding the *Ogoni People* (Communication 155/96, Report of the Commission) the African Commission on Human and Peoples' Rights linked the obligation to "promote" with the obligation to "protect". The Commission observed that the States should in relation to the duty to protect make sure that individuals are able to fully exercise their rights and freedoms, for example by promoting tolerance, raising awareness and building infrastructures.

Life in the community must also be **accessible** to persons with disabilities, regardless of their disability. Accessibility is emphasized in Article 19 (b) and (c) of the CRPD. Accessibility has four overlapping dimensions:

Non-discrimination constitutes prohibition of differential treatment on the grounds of disability. Both direct and indirect forms of discrimination are prohibited, and states are required to eliminate discrimination both formally and substantively. However, we must bear in mind that the prohibition of discrimination is not absolute and differential treatment based on objective and reasonable grounds is justifiable. Discrimination involves any practice excluding a group of people with disabilities from the enjoyment of the right to life in the community – for example institutionalization of people with psychosocial disabilities, mainly in psychiatric hospitals which do not provide community services for this group. Non-discrimination also requires states to adopt positive measures to make community services available to all without distinction.

Community services must be *physically accessible*, i.e. within safe physical reach of all people with disabilities in all areas, both urban and rural. This dimension of the right to community life is very closely related to Article 9 of the CRPD, which guarantees accessibility. For people with disabilities, physical accessibility is very important, because physical barriers largely contribute to their social exclusion. This problem is related also to the network of services within a specific area. Services must be not only available, i.e. they have to exist and be functional, but they must also be accessible, i.e. they must be located within the reach of their actual and potential users.

Community services must be *affordable* to all people with disabilities. Any potential payments have to be based on the principle of equality. Equality requires that low-income people with disabilities do not have to bear a disproportionate burden in comparison with people with higher income. It is also necessary to realize that people with disabilities are at significant at risk of poverty; the affordability of the right to live in the community therefore overlaps with the obligations ensuing from the right to social security.

Accessibility of information includes the right to seek, receive and impart information and thoughts related to life in the community. The right to seek information goes beyond the passive right to seek certain information, especially that concerning the availability of services, but includes also an obligation to convey that information to people with disabilities, for example through assistance in the decision-making process as to the selection of the most appropriate service meeting the needs of the person with disabilities. Assistance, or support, is emphasized in Article 12 of the CRPD, which defines the concept of supported decision-making.

All services provided in the community must be **acceptable**, i.e. sensitive to the culture of the service users from different cultural environments, as well as to gender and age-based aspects of care. Services must respect confidentiality and aim to strengthen the independence and autonomy of their users. Acceptability of the right

²¹³ Ibid., Paragraph 13.

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²¹² General Comment No. 20, Paragraphs 8, 10.

to live in the community can be inferred from the provisions of Article 19 (b) and (c) of the CRPD.

And, finally, the right to live in the community implies **adjustment** and **quality** of community care which must be technically appropriate and be of good quality. This dimension requires *inter alia* that services are provided by trained professionals using professionally accepted methods, in particular social, psychological, educational and, in necessary cases, medical ones, and also that service providers use appropriate equipment. Adjustment and quality are emphasized in particular in Article 19 (a) and (c) of the CRPD.

State obligations arising from the right to live in the community

On the basis of Article 4 of the CRPD, we have arrived at the conclusion that four specific obligations of the State can be inferred from the Convention on the Rights of Persons with Disabilities, namely: i) the obligation to respect, ii) the obligation to protect, iii) the obligation to fulfil and iv) the obligation to promote the rights of people with disabilities. Let us now look at the content of these State obligations arising from the right to live in the community.

To respect, protect, fulfil and promote the right to live in the community

The obligation to **respect** the right to live in the community means that States must not institutionalize people with disabilities. This obligation at the national and regional level means that States and local authorities must abandon the systematic policy of providing institutional care to people with disabilities and/or refrain from introducing such a policy. The States are obliged to respect the freedom of persons with disabilities to choose their place of residence and where and with whom they live on an equal basis with others, and not to oblige them to live in a particular living arrangement as provided for in Article 19 (a) of the CRPD. In the Czech Republic, social services are at present provided on a contractual basis; however, if the choice of community service providers is not sufficient, there is often no alternative to institutionalization, which can be classified as lack of choice.

At the individual level, the government and the municipalities or regions have a duty not to institutionalize individuals. Institutionalization can be either forced, i. e. involuntary, or voluntary. It is necessary to prevent "forced" institutionalization, which can be overt or covert. Covert forced institutionalization means that a State, a municipality or a region have failed to develop community services, and therefore the only remaining choice is institutional care. Voluntariness in such a case is pure fiction.

The obligation to **protect** implies the obligation of the State to protect persons with disabilities from third parties; in the case of social care, this means in particular protection from non-government service providers. This obligation includes adopting legislation or other measures ensuring equal access to community services provided by third parties. The provision of the services must be subject to reviews in order to ensure that these services are provided by professionals meeting the appropriate

standards for education, skills and ethical behaviour. The state should prevent third parties from restricting the access of people with disabilities to information.

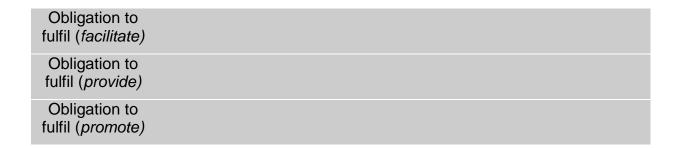
The obligation to **fulfil** means that the state transforms the care provided in institutions. This obligation is expressed *inter alia* in Article 19 (b) of the CRPD, which guarantees that "persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." The obligation to fulfil assumes deinstitutionalization, namely the shift of care from institutions to community settings. The preferred option is to adopt appropriate legislation and national policy governing the transformation of institutional care with a detailed plan of implementation of the right to live in the community. The state has an obligation to ensure the right to live in the community for all people with disabilities; no group of people with disabilities can be excluded from the obligation to transform the institutional care. The state is also obliged to ensure sufficient, quality and adequate community services.

The obligation to *fulfil* (*facilitate*) requires the States to adopt specific positive measures that enable and assist people with disabilities to enjoy the right to live in the community. States are obliged to *fulfil* (*provide*) the right to live in the community when an individual or group is unable, for reasons beyond their control, to realize the right themselves by the means at their disposal.

And finally, the obligation to **promote** means that States are obliged to ensure that people with disabilities are able to enjoy the rights and freedoms guaranteed in the CRPD, for example by promoting tolerance towards people with disabilities, raising of awareness and building of a new adequate infrastructure and the much needed reasonable modifications of the existing infrastructure. The State is obliged to take action to foster the education and awareness of the public, in particular of persons with disabilities, of those around them and of the NGOs, on the accessibility and availability of community services. This obligation is emphasized in particular in rural and deprived urban areas and in areas inhabited by ethnic or linguistic minorities. Combating prejudices against people with disabilities requires also awareness-raising of general public on the rights of people with disabilities, in particular on their right to live in the community, on the specificities of different types of disabilities and methods of coping with unexpected situations.

Table No 3: Overview of the State obligations ensuing from Article 19 of the CRPD

	Availability of	Accessibility of	Acceptability	Quality
	community	community	of community	of community
	services	services	services	services
	(Article 19 (a)	(Article 19 (b)	(Article 19 (b)	(Article 19 (a)
	of the CRPD)	and (c) of the	and (c) of the	and (c) of the
		CRPD)	CRPD)	CRPD)
Obligation to respect				
Obligation to protect				



Time perspective of the States' obligations arising from the right to live in the community

The State has certain obligations which have to be realized immediately, and also obligations of progressive realization. The obligations of immediate nature include i) non-discrimination in the access to the right to live in the community, ii) the obligation to take steps iii) the minimum core obligation of the right to live in the community, and iv) to monitor the realization of the right to life in the community.

Non-discrimination is related to the accessibility of the right to live in the community. Community services must be accessible to all without distinction immediately after the adoption of the Convention on the Rights of Persons with Disabilities. However, there is a question whether unjustified institutionalization of people with disabilities can be classified as discrimination. An affirmative answer (as suggested by the decision of the U.S. Supreme Court judgment in the *Olmstead* case (see below) would mean that de-institutionalization is an obligation of immediate nature. In such a case, the State would have an obligation to immediately offer to people living in institutions who would be able to live in the community the possibility to move from institutional to community care. At present, this is definitely not the case in the Czech Republic and it can therefore be argued that the State is violating its obligations under international law.

Another obligation of immediate nature is the obligation to take steps. As outlined above, this obligation assumes taking deliberate, concrete and targeted steps towards achieving the right to live in the community. To "take steps" primarily means to adopt legislative measures with a view to achieving the realization of the right to live in the community. Among the measures which might be considered appropriate, in addition to legislation, is the provision of judicial remedies and administrative, financial, educational and social measures. However, a change of legislation in certain areas is indispensable and we believe that this is also the case of transformation of social care. The main reason is the fact that social care providers in the Czech Republic are controlled by local governments which may be influenced only indirectly with certain social policy measures. Only legislation would have a direct and universal impact. While the current wording of Article 2 (2) of the Czech Social Services Act No. 108/2006 Coll. emphasizes the "autonomy" principle and Article 38 emphasizes the aim of the services which is to enable integration in the common social life to the maximum possible extent, there is no definition of the rights of the service users to be provided care in a natural environment. It is therefore appropriate to amend the provisions of the Social Services Act No. 108/2006 Coll., in particular its Article 38, by amending the first sentence to read as follows: "Everyone has the right to be provided social care services in the least restrictive environment."

The State has the obligation to progressively realize the right to live in the community; the obligation to deinstitutionalize social care is subject to progressive realization. The state is obliged to transform the institutional care "to the maximum of its available resources." The Czech Republic has approved the concept of transformation of residential social services in Article 127 of the Government Resolution of 21 February 2007. This serves as the basis of the project of transformation of pilot institutions, which is the responsibility of the newly created National Centre for Support of the Transformation of Social Services. This project allocates funds to transformation of several institutions across the regions. The state has to use these funds to achieve the above target; a violation would occur if the State reallocated these resources or failed to spend them, for example due to corruption.

THE RIGHT TO LIVE IN THE COMMUNITY IN THE CASE LAW

It could seem that judicial enforcement of the fulfilment of the right to live in the community is difficult because the enforceability of the so-called social rights has always been an issue. However, in this chapter we will show that it is possible. We

²¹⁴ The list of the institutions is available at:

http://www.trass.cz/TrassDefault.aspx?rid=27652&app=Article&grp=Content&mod=ContentPortal&sta=ArticleDetail&pst=ArticleDetail&p1=OID INT 73&p2=RoundPanel BOOL True&p3=VPath STRING &acode=44575396

will even see that most of the progressive judgments were adopted in the U.S., which is definitely somewhat ironic because the legal professionals in the U.S. have traditionally shown a rather reserved attitude towards social rights. The cases and judgments mentioned below can be viewed also through the prism of the obligations defined above in Chapter 2. In our opinion, a very practical aspect is the interdependence of these judgments with the elements of the right to live in the community, i.e. availability, accessibility, acceptability and adaptability. Most of the judgments we were able to find and process proceed from the U.S., which has a fairly extensive case law relating to institutionalization of people with disabilities. In addition to the U.S. court decisions, our survey includes judgments of the Supreme Court of Israel and of the Inter-American Commission on Human Rights. Unfortunately, we were unable to find more decisions but it is possible that there are not many more such decisions around the world.

Institutionalization as discrimination against people with disabilities: The U. S. Supreme Court decision in *Olmstead v. L.C.*

The landmark decision in the area of de-institutionalization is considered to be the U.S. Supreme Court decision in *Olmstead v. L.C*, 527 U.S. 581 (1999). In this decision the Supreme Court confirmed that unjustified isolation of persons with intellectual disabilities in institutional settings is a form of discrimination based on disability. The Olmstead decision emphasized the principle of inclusion and the need for the development of community care. President Obama's administration marked the tenth anniversary of the Supreme Court Olmstead decision by designating this year as "The Year of Community Living". According to President Obama, "the Olmstead ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently". ²¹⁵ Let us now focus on the Olmstead decision itself.

As to the background of the case, the plaintiffs were two women - L.C. and E.W. - with both mental retardation and psychiatric conditions (schizophrenia and personality disorder, respectively). Both women had a history of treatment in institutional settings. In May 1992, L. C. was voluntarily admitted to Georgia Regional Hospital at Atlanta, where she was confined for treatment in a psychiatric unit. By May 1993, her psychiatric condition had stabilized, and her treatment team agreed that her needs could be met appropriately in one of the community-based programs the State supported. Despite this evaluation, L. C. remained institutionalized for 3 more years until February 1996, when she was placed in a community-based treatment program.

E.W., the second plaintiff, was voluntarily admitted to the same hospital in February 1995 where she was also confined for treatment in a psychiatric unit. In March 1995, the hospital sought to discharge E. W. to a homeless shelter, but abandoned that plan after E.W's attorney filed an administrative complaint. By 1996,

http://www.whitehouse.gov/the_press office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities/

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²¹⁵ Press release by President Barack Obama on the tenth anniversary of the Olmstead decision as of 22 June 2009. The report is available at:

E. W.'s treating psychiatrists concluded that she could be treated appropriately in a community-based setting. She nonetheless remained institutionalized until 1997. At the time when L.C. was still institutionalized at the hospital, she filed suit challenging her continued confinement in a segregated environment. L.C. invoked violation of Title II of the Americans with Disabilities Act (hereinafter referred to as the "ADA"), which guarantees social inclusion of people with disabilities into society. Under the basic provisions of Title II of the ADA:

"Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

Public entities are defined in the ADA to mean any State or local government or any authority. The term "qualified individual with a disability" is defined in the ADA as an individual who "meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity. L.C. sought placement in community care with the ultimate goal of integrating her into the mainstream of society. E. W. intervened, stating an identical claim. The District Court granted partial summary judgment in favour of L.C. and E.W. The court held that the State's failure to place L. C. and E. W. in an appropriate community-based treatment program violated Title II of the ADA. In so ruling, the court rejected the State's argument that inadequate funding did not lead to discrimination against L. C. and E. W. by reason of their disabilities. The court concluded that "unnecessary institutional segregation of the disabled constitutes discrimination *per se*, which cannot be justified by a lack of funding."

The Court of Appeals for the Eleventh Circuit affirmed the judgment of the District Court, but argued differently as to the availability of community-based services and the related costs. According to the Court, the ADA imposes a duty to provide treatment in a community setting--the most integrated setting appropriate to that patient's needs; however, where there is no such finding by the treating professionals, the Court of Appeals held that nothing in the ADA requires the deinstitutionalization of the patient. The Court of Appeals also recognized that the State's duty to provide integrated services is not absolute. The state's argument based on the lack of funding would be relevant if the funds expended in order to provide L.C. and E.W. with community services "would be so unreasonable given the demands of the state's mental health budget that it would fundamentally alter the services [the State] provides."

The Supreme Court focused on two major questions arising during the proceedings. The first one was whether unnecessary institutionalization amounts to discrimination on the grounds of disability, and the second one was the issue of reasonableness of costs against the state's entire mental health budget, dealt with mainly by the Court of Appeals.

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²¹⁶ Sec. 12132

²¹⁷ Cf. Sec 1231(1)(A)(B)

²¹⁸ Cf. Sec 12131(2)

When considering the discrimination issue, the Supreme Court relied on the intent of the federal legislature and did not develop any theories on the concept of discrimination. The Supreme Court emphasized that Congress explicitly identified unjustified segregation as a form of discrimination. The Congress determined that historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.²²⁰ The Supreme Court recognized that unjustified isolation of persons with disabilities is a form of discrimination which reflects two evident judgments:

Institutional placements of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.²²¹ Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. ²²²

The Supreme Court thus accepted a very important argument that unjustified isolation is properly regarded as discrimination based on disability. The issue of discrimination against people with disabilities is part of the accessibility of the right of this group to live in the community. The Supreme Court therefore stated that this right was not accessible to the plaintiffs as they were discriminated against by reason of their disabilities.

The Supreme Court further defined two conditions for the provision of services in the community. A person with disability is eligible only if he/she meets the "essential eligibility requirements" for habilitation in a community-based program. The assessment of these essential requirements is to be provided by professionals; however the assessment must be reasonable. According to the Supreme Court, absent such qualification, it would be inappropriate to remove a patient from the more restrictive setting. And, second, according to the Supreme Court, there is no federal requirement that community-based treatment be imposed on patients who do not desire it. 224

Community v. institutional care in the U.S.: Availability of resources according to *Olmstead v. L.C.* and the relevant case law

In Olmstead, the Supreme Court upheld the concept of the "most integrated setting", according to which a public entity shall administer services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" and stated

²²² Ibid., p. 16.

²¹⁹ Cf. the dissenting opinion of Judge Thomas who engaged in more theoretical aspects of discrimination in the context of this case; however, see the clear and quite strong rejection of such conclusions in the Olmstead decision, Footnote No. 10

²²⁰ Olmstead, p. 15.

²²¹ Ibid., p. 15.

²²³ Olmstead, p. 17.

²²⁴ Ibid., p. 17.

that the disabled persons are entitled to receive such treatment.²²⁵ The Supreme Court also stated that this right is not absolute. Apart from the question whether institutionalization qualifies as discrimination by reason of disability, the Supreme Court had to deal also with the issue of possible changes in government policy with a potential impact on other services provided by the Government. This is essential because de-institutionalization and community services assume the availability of specific expenditure and resource allocation within the state budget. Therefore, a very important issue for the Supreme Court was whether the expenditure will affect the nature of the services, programs or activities administered by public entities. The Court referred to the Code of Federal Rules (CFR), 28 CFR § 35.130 (b)(7)(1998). According to this provision, a public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity. This would constitute a "Fundamental alteration defense". In respect to this, the Court observed that:

"In evaluating a State's fundamental-alteration defense the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably. 226

According to the Supreme Court, the States may take into account the economic impact of deinstitutionalization and of the creation of further adequate community care services provided by the State, and the courts have a duty to take this into account. The States should consider three following factors: a) the cost of providing community services, b) the resources available to fund community services, and c) the needs of others with mental disabilities and the range of the necessary services. However, according to Silvers and Stein, this conclusion leads to the inevitable fact that courts have been faced with the dilemma of what to do when allocating resources to accommodate some disabled people while adversely impacting similarly disabled people, or even people who are not disabled. In the post-*Olmstead* world, courts are forced to consider the impact on a state's budget created by competing demands on available resources. This aspect is fully reflected in other decisions of U.S. courts.

In the **Townsend v. Quasim²²⁸** case of 2003, the United States Court of Appeals, Ninth Circuit, was dealing with a summary complaint where the lead plaintiff was Mr Levi Townsend. By the time of the proceedings, Mr Townsend was in his eighties, had diabetes and was a bilateral amputee. In 1999, the Plaintiff was entitled to choose between state assistance services and moving to a nursing home; he chose to receive community-based assistance services which enabled him to remain

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²²⁵ The Court cited the Code of Federal Rules (28 CFR § 35.130(d) (1998).

Olmstead, p. 12. The State can also successfully use this defense if it: "...were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated... "

Silvers, A., Stein, M., A. Disability and Social Contract. The University of Chicago Law Review, Vol. 74, 2007, p. 1638.

²²⁸ Townsend v. Quasim, 328 F3d 511 (9th Cir 2003).

near his friends and family. However, in 2000, Mr Townsend's income increased to approximately forty-six dollars above the legal threshold limit entitling him to receive assistance service, and he was informed by the Washington State Department of Social and Health Services that he would have to move to a nursing home within 30 days. Mr Townsend filed an appeal against this decision at the District Court which granted summary judgment in favour of the DSHS. The Court of Appeals reversed the District Court's decision applying the Supreme Court's reasoning in the Olmstead case. The Court of Appeals confirmed that unjustified institutionalization constitutes discrimination based on disability, which applies also to persons with disabilities. At the same time, it focused on the costs of providing community-based long term care services. The Court of Appeals said that:

"Plaintiffs have asserted that it is cheaper on a per capita basis to provide long-term care services to individuals in a community-based setting rather than a nursing home. This assertion, however, does not account for the cost of serving additional persons who are eligible to receive long-term care services but would not have previously availed themselves of this care when the services were offered only in a nursing home environment. At the same time, even if extension of community-based long term care services to the medically needy were to generate greater expenses for the state's Medicaid program, it is unclear whether these extra costs would, in fact, compel cutbacks in services to other Medicaid recipients."

The Court thus rejected both the arguments of the State and the conclusions of the court of first instance as to the impact of community-based long term care on the state budget. However, at the same time, it refused to make a simplistic comparison of the cost of community care v. the cost of institutional care, adding to this equation an assessment of the cost of care provided to people who would use community services, but do not use services in institutions. This is quite a complex issue which requires the availability of relevant information. However, it is not impossible for the court to find answers to such complex questions and to sufficiently justify the conclusions in its decision. This is demonstrated on the very detailed and comprehensive decision in DAI v. Paterson as discussed below.

In **Fisher v. Oklahoma Health Care Auth.**²²⁹, the United States Court of Appeals, Tenth Circuit (2003) was dealing with a case in which three women with physical disabilities challenged Oklahoma's decision to reduce the number of prescription drugs available under a community-based waiver program. In their complaint, the Plaintiffs alleged that they would face the potential of institutionalization in nursing facilities (where residents are entitled to an unlimited number of prescriptions). The District Court confirmed Oklahoma's decision concluding that the Plaintiffs could not maintain a claim under the ADA because they are not presently institutionalized and face no risk of institutionalization, and stating that the State's decision was reasonable given the state's fiscal crisis. The Court of Appeals reversed this decision holding that, given the economic impacts, the mere fact that the decision to cap the prescription benefit was reasonable due to the state's fiscal crisis does not constitute a defense. The fact that Oklahoma has a fiscal problem, by itself, does not lead to an automatic conclusion that preservation of

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²²⁹ Fisher v. Oklahoma Health Care Auth., 335 F.3d 1175 (10th Cir. 2003)...

unlimited medically-necessary prescription benefits for participants would result in a fundamental alteration in the nature of the services, programs, or activities ²³⁰

Let us now look at the court decisions in which States successfully used the argument of additional costs of de-institutionalization and change in the structure of the services provided. In one of the very first decisions relating to this issue, **Williams v. Wasserman**²³¹, the District Court of Maryland adopted the State's arguments. The State of Maryland pointed out the need to expend funds from the state budget to cover the provision of community services to the Plaintiffs and the lack of savings that would cover immediate expenses. The Court accepted this defense and on the basis of expert opinions, it concluded that it will last between three to five years before the State is able to fund the costs of community care, considering the development of community care for other persons in need and the necessity to maintain a minimum number of hospital beds. ²³²

In another case, Pennsylvania Protection & Advocacy, Inc. v. Department of Public Welfare of Pennsylvania²³³ of 2003., the Court rejected Plaintiff's claim requiring the state's entire budget to be considered when determining if additional funding would fundamentally alter the provision of other services, in this case of the state's mental health program. The Court held that it did not have to look beyond the resources allocated within the state's mental health budget.

Let us quote the last example - the decision in Frederick v. Department of Public Welfare of the Commonwealth of Pennsylvania²³⁴ (2004). In this case, the United States Court of Appeals was hearing a summary complaint of approximately 300 Plaintiffs with serious and persistent mental disabilities. Approximately 32 % of the Plaintiffs were classified as short-stay patients (approximately 10 months) and 68 % were classified as long-stay patients (approximately 12 and more months). Appellants filed this class action lawsuit in September 2000, claiming that, because they were qualified and prepared for community-based services, their continued institutionalization violated the anti-discrimination and integration mandates of the Americans with Disabilities Act ("ADA"). They claimed that the state authority has failed to provide services to them in the most integrated setting appropriate to their needs and has developed no plan to assure that this be done. The District Court decided in favour of the State and accepted the defense based on deinstitutionalization costs. The Court of Appeals first rejected to merely compare the cost of institutionalization against the cost of community-based health services, then it rejected the proposal of the Plaintiffs to order the state authority to request additional funds to finance community-based services and, finally, it rejected also the argument suggesting the shuffling of the budget. The Court of Appeals thus upheld the decision of the District Court.

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²³⁰ Ibid., pp. 1182-83.

²³¹ Williams v. Wasserman, 164F.Supp.2d 591 (D.Md. 2001).

²³² Ibid., 637-638.

²³³ Pennsylvania Protection and Advocacy, Inc. v. Department of Public Welfare, 243 F. Supp. 2d 184 (M.D. Pa 2003).

Frederick v. Department of Public Welfare of the Commonwealth of Pennsylvania, 364 F3d 487, 494-95 (3d Cir 2004).

People who do not live in institutions have also the right to live in the community

The U.S. courts were facing a question whether persons who do not live in institutions still have the right to live in the community and whether the principles defined in the Olmstead decision cover also this area. Basically the question was whether Olmstead should be understood in the narrow sense as comprising only persons already living in institutions, or in a broader sense in which the right to live in the community as set forth by the U.S. Supreme Court includes also a preventative element, i.e. avoidance of institutionalization of people with disabilities who have not yet been institutionalized. Fortunately, the courts did infer this preventative element and case law now interprets the Olmstead decision to cover also persons at risk of institutionalization. Let's now look at three decisions in which the courts have clearly confirmed this fact.

The first case is **Makin v. Hawaii**²³⁵ (1999). This class action litigation was filed on behalf of approximately 700 individuals with mental retardation on waiting lists for community-based services in Hawaii. The Court stated that the right to live in the community according to the ADA applies also to persons living in the community, not just to persons already institutionalized if the State fails to provide them appropriate services. This case was resolved through a settlement. In **Bruggeman ex rel. Bruggeman v. Blagojevich**²³⁷, the United States Court of Appeals, Seventh Circuit, confirmed that adults with developmental disabilities who are living with their parents are covered by the Olmstead decision. The complaint was filed by a group of parents who became unable to care for their adult children and required their placement in a specific institution. A clearly preventative element was confirmed by the United States Court of Appeals, Tenth Circuit, in its decision in **Fisher v. Oklahoma Health Care Auth**. Auth. In Court stated that the right to receive community services is not limited to people who are currently institutionalized.

Obligation of the State of New York to ensure community services: *Disability Advocates, Inc. (DAI) vs. Paterson*

An important decision is the recent judgment of the United States District Court Eastern District of New York in **Disability Advocates**, **Inc.** (**DAI**) **v. Paterson**. ²³⁹ In 2003, the NGO Disability Advocates, Inc. ("DAI") brought this action against the placement of individuals released from psychiatric facilities to 100 Adult Homes. According to DAI, these people (approximately 4,300 persons) were not receiving services in the most integrated settings appropriate to their needs. More integrated settings would constitute apartments scattered throughout the community where they could receive flexible services as needed. The District Court accepted this argument

²³⁵ Makin v. Hawaii, 114 F. Supp. 2d 1017 (D. Hawaii 1999).

For details see Mathis, J. Where are we five years after Olmstead. Clearinghouse REVIEW Journal of Poverty Law and Policy, January-February 2005, pp. 575-576.

²³⁷ Bruggeman ex rel. Bruggeman v. Blagojevich, 324 F.3d 906 (7th Cir. 2003).

Fisher v. Oklahoma Health Care Auth., 335 F.3d 1175 (10th Cir. 2003).

²³⁹ Disability Advocates, Inc. v. Paterson ("DAI I"), 598 F. Supp. 2d 289 (É.D.N.Y. 2009).

in its decision of August 2009. Later, in March 2010, the Court decided that the state has to adopt the Plaintiffs' proposal for the development of community care, which consisted inter alia in the development of approximately 1,500 supported housing beds per year until such time as there are sufficient supported housing beds available for all who desire such an arrangement.

In its comprehensive decision from August (210 pages), the Court was dealing in detail with the legal aspects of the case using very extensive evidence. Leibowitz notes that since the constituents in this case were not coerced into their current living arrangement of adult homes, the traditional argumentation of choice and noncoercion would not have been of help. Allegations of torture, abuse or freedom of movement were not applicable. Rather, the subtler form of coercion was at play: eligibility for support in everyday life made conditional upon receiving it within adult homes. The case thus hinged on proving to the Court that adult homes were in fact institutions, [...] and that as such, offering support only within these frameworks constituted discrimination.²⁴⁰

The solution to the first question the Court faced, i. e. whether Adult Homes are "institutions", is very interesting and, in our opinion, it is to some extent transferable to the Czech Republic. The Court basically identified certain factors supporting the conclusion that Adult Homes are "institutions", namely:

- Much of residents' daily lives takes place inside the Adult Homes;
- ii) Residents' visits to neighbourhood amenities such as parks, restaurants. libraries. religious entertainment facilities are rare;
- Opportunities to interact with people who do not have disabilities iii) are very limited:
- Mental health programs and case management contribute little to iv) residents' integration into the community;
- Adult homes discourage residents from engaging in activities of v) daily living and foster "learned helplessness".

The Court also compared supported housing to Adult Homes to find out which of these services represents a more integrated setting. It arrived to a clear conclusion that it is supported housing, and it concluded that residents of supported housing "have far greater opportunities to interact with nondisabled persons and be integrated into the larger community". 241 The Court therefore very strongly accented the participatory aspect of life in the community.

In the second part of its Decision, the Court was dealing with the costs of the requested relief. The reasoning of the Court is too extensive to set forth herein, and we will therefore mention only the general conclusions.. The Court concluded that the requested relief would not increase costs to the State²⁴², it would not adversely impact other individuals with mental illness,²⁴³ and that the New York State is capable

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²⁴⁰ Leibowitz, T. Living in the Community – Disentangling the Core Right. Paper presented at the Colloquium on Disability Law and Policy, April 2010, University of Galway, p. 11.

Ibid., p. 56.

²⁴² Ibid., pp. 152-180.

²⁴³ Ibid., pp. 180-181.

of expanding its existing housing program²⁴⁴. As to the obligation to develop 1,500 supported housing beds, the Plaintiffs submitted to the Court guidelines governing the proposed relief plan. These proposed guidelines include a four-year transition period, by the end of which Defendants would achieve the following goals:

- 1) all current Adult Home residents who desire placement in supported housing have been afforded such a placement if qualified;;
- 2) all future Adult Home residents including individuals admitted to the Adult Homes both during and after the four-year transition period who desire placement in supported housing are afforded such a placement if qualified; and
- 3) no individual who is qualified for supported housing will be offered placement in an Adult Home at public expense unless, after being fully informed, he or she declines the opportunity to receive services in supported housing.²⁴⁵

The adoption of these guidelines would require the development of at least 1,500 supported housing beds per year. However, in its decision itself, the Court neither approved the plan nor did it order its implementation but rather gave the State the opportunity to develop its own plan. Later, when the District Court was informed about the plan proposed by the State, it released an order in March 2010 rejecting the State's proposal and fully adopting Plaintiff's proposed remedial order.²⁴⁶ The State of New York appealed, and the appeal is currently pending.

Community services must be affordable: Israeli Supreme Court in Bizchut et al. v. the State of Israel

In **Bizchut et al. v. Israel**, the Supreme Court considered the case of six individuals with physical and intellectual disabilities who were in need for a high level of support, represented by a non-governmental organization The Israel Human Rights Center for People with Disabilities. The petitioners had lived all their lives with their parents, within the community. When the time came to consider leaving the nest, they all met with the same barrier. Though they are entitled by law to state support for living outside of their families' homes, the Ministry of Social Affairs denied their request to receive support within the framework of an apartment in the community. The basis for denial was a ministerial policy establishing the ability to independently administer self-care and "be integrated into most aspects of societal activity" as threshold criteria for receiving support within a community-based arrangement. Accordingly, the petitioners were offered institutional arrangements only.

Similarly as in certain U.S. cases described above, forced institutionalization was not at stake here – rather qualifications on the right to live in the community, prompting Bizchut to argue that living in the community is an inalienable right, not subject to proving one's "ability." It further argued that institutional life segregates one from the community and does not enable the exercise of choice. The Supreme Court concluded that the right to live in the community cannot be qualified by requiring independence as a condition for state support to live in the community.

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²⁴⁴_{-.-} Ibid., pp. 181-183.

²⁴⁵ Ibid., p. 206.

The order is available at:

The state subsequently revoked its original policy and established new criteria that render living in the community the rule for those in need of high level of support as well. However, the blessing turned out to be mixed. Alongside the change in policy, the state introduced a new criterion according to which living arrangements for individuals in need of a high level of support would be provided only within group homes for 16 to 24 residents. The state defined the setting of group homes as a setting that is included within the meaning of "living and being included in the community." Bizchut found this clarification unacceptable but was not successful in persuading the court that such a policy was incorrect. ²⁴⁷

Degrading and inhuman treatment and the obligation of the State to close an institution due to unsatisfactory conditions

Deinstitutionalization can be related also to dismal conditions in institutions leading to the closure of such an institution. Below we give two examples in which the Courts decided to close facilities due to degrading and inhumane conditions. The first one is the decision of the Supreme Court of India in *Vikram Deo Singh Tomar v. State Of Bihar* (1988)²⁴⁸, the second one is the **recommendation of the Inter-American Commission on Human Rights (**2003)²⁴⁹.

In August 1988, the Supreme Court of India was dealing with a writ petition relating to the conditions in a Care Home in the state of Bihar. The writ petition arose upon a letter alleging that the female inmates of the Care Home were compelled to live in inhuman conditions. During its investigation, the Supreme Court found out that the building in which the inmates were housed was a century old dilapidated house rented for the purpose which was absolutely uninhabitable and unsafe. During the rainy season the roof leaked almost at every point. Five small damp and dirty rooms with no windows were used to accommodate twenty five inmates, while the remaining women had to sleep in an open verandah. Only a few of the women have been provided with blankets and cots. Whereas the capacity of the "Care Home" was over one hundred, only twenty five thin blankets were available. There was no woollen clothing at all, nor were they provided with soap or oil. The diet provided to them was hardly adequate to sustain them. As regards toilet facilities, there was only one water tap on the premises which also was not in proper working order. There was acute scarcity of water. There was no bathroom or toilet inside the apartment. The inmates stated that they were often beaten up in case they complained before the authorities, and most of them expressed a desire to be set free to earn their livelihood or to return to their families. The Supreme Court of India found a violation of Article 21 of the Constitution of India which guarantees the right to live with human dignity. ?The Court used a very sharp tone, stating:

> "What we see before us in the instant case is a crowded hovel, in which a large number of human beings have been thrown together, compelled to subsist in conditions of animal survival, conditions which blatantly deny their basic humanity. It is clear that the Welfare Department of the

²⁴⁸ Vikram Deo Singh Tomar v. State Of Bihar, 1988 AIR 1782, 1988 SCR Supl. (1) 755.

Leibowitz, T. Living in the Community – Disentangling the Core Right. Paper presented at the Colloquium on Disability Law and Policy, April 2010, University of Galway, pp.13-14

Annual Report of the Inter-American Commission on Human Rights 2003 (OEA/Ser.L/V/II.118, Doc. 5 rev. 2), Chap. III.C.1.

State Government of Bihar views its responsibilities in regard to these women with a lightness which ill befits its existence and the public funds appropriated to it. The name of "Care Home" given to these establishments is an ironic misnomer. The primitive conditions in which the inmates are compelled to live shock the conscience."

The Supreme Court also ordered that the State should provide suitable alternative accommodation and invest money in the existing equipment. The Court expressly stated that:

"The State Government should provide suitable accommodation expeditiously for housing the inmates of the present "Care Home". It is necessary meanwhile to put the existing building, in which the inmates are presently housed, into proper order immediately, and for that purpose to renovate the building and provide sufficient amenities by way of living room, bathrooms and toilets within the building, and also to provide adequate water and electricity. A suitable range of furniture, including Cots must be provided at once, and an adequate number of blankets and sheets, besides clothing, must be supplied to the inmates. The Welfare Department of the State Government will take immediate steps to comply with these directions."

In 2003, the international non-profit organization Mental Disability Rights International (MDRI) together with the Center for Justice and International Law (CEJIL) petitioned the Inter-American Commission on Human Rights to grant precautionary measures to protect the physical and mental integrity of the individuals hospitalized in Paraguay's Neuro-Psychiatric Hospital. Life threatening human rights abuses in the hospital were enumerated: detention in locked cells, severe overcrowding, atrocious hygienic conditions, and severe neglect in medical and non-medical (e.g. nutritional) care. Also cited were the absence of rehabilitation services, discharge plans and community based services. The Commission issued a decision requesting the government to take all necessary measures to ensure the physical, mental and moral integrity of the persons hospitalized in the institution, stating that:

"In December 2003, the Commission granted precautionary measures on behalf of the patients of the *Hospital Neurosiquiátrico* (Neuropsychiatric Hospital). The information available describes the sanitary and security conditions there as inhuman and degrading, and as posing a threat to the physical, mental, and moral integrity of the patients. The information received calls attention to the instances in which female patients hospitalized there have been raped, resulting in pregnancy. It is also indicated that boys and girls were held together with adults. In this context, the Commission notes that youths Jorge Bernal and Julio César Rotela, 18 and 17 years old respectively, were kept in solitary confinement in small cells, naked, and without access to the bathrooms. In view of the risk to the beneficiaries, the Commission asked the Paraguayan State to adopt measures to protect the life and physical, mental, and moral integrity of Jorge Bernal, Julio César Rotela, and the 458 patients at the Hospital Neurosiquiátrico of Paraguay, including

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²⁵⁰ Leibowitz, T. Living in the Community – Disentangling the Core Right. Paper presented at the Colloquium on Disability Law and Policy, April 2010, University of Galway, pp.12-13.

making a medical diagnosis of their health conditions, with special emphasis on the situation of women and children. The Commission also asked that the use of solitary confinement be restricted and, when used, respect the conditions established in the relevant international standards.²⁵¹

According to Leibowitz, from the start, the challenge to abuse in the institution was coupled with a demand for the development of alternatives for the institution's residents, comprising of community based health care, rehabilitation, housing, and vocational opportunities, and a transition plan from the hospital to the community. Indeed, what had begun as a demand to halt the human rights abuses rampant in the psychiatric institution evolved into negotiations over progressive deinstitutionalization and an expansion process of community-based mental health services in Paraguay. ²⁵²

FINAL RECOMMENDATIONS

- 1) The Czech Republic is obliged to respect, protect, fulfil and promote the right of people with disabilities to live in the community.
- 2) The obligation to respect the right to live in the community means that States must not institutionalize people with disabilities. This obligation at the national and regional level means that States and local authorities must abandon the systematic policy of providing institutional care to people with disabilities and/or refrain from introducing such a policy.

 251 Annual Report of the Inter-American Commission on Human Rights 2003 (OEA/Ser.L/V/II.118, Doc. 5 rev. 2), Chap. III.C.1, Para 60.

Leibowitz, T. Living in the Community – Disentangling the Core Right. Paper presented at the Colloquium on Disability Law and Policy, April 2010, University of Galway, p.13.

- 3) The obligation to protect implies the obligation of the State to protect persons with disabilities from third parties; in the case of social care, this means in particular protection from non-government service providers, but also ensuring of equal access to community services provided by third parties.
- 4) The obligation to fulfil means that the state transforms the care provided in institutions. The obligation to fulfil assumes de-institutionalization, namely the shift of care from institutions to community settings. The preferred option is to adopt appropriate legislation and national policy governing the transformation of institutional care with a detailed plan of implementation of the right to live in the community.
- 5) The obligation to promote means that the State is obliged to ensure that people with disabilities are able to enjoy the rights and freedoms guaranteed in the CRPD, for example by promoting tolerance towards people with disabilities, raising of awareness and building of a new adequate infrastructure and the much needed reasonable modifications of the existing infrastructure.
- 6) The State is obliged to avoid discrimination against people with disabilities. Unjustified institutionalization of people with disabilities can be classified as discrimination. To eliminate discrimination, legislation must be adopted (see below) and the existing social policy of transformation of institutional care must be consistently applied and extended.
- 7) It is desirable to adopt legislation measures governing the right of the users to be provided community services (in the Czech Social Services Act No. 108/2006 Coll.). We propose to amend the provision of Article 38 and insert the following sentence: "Everyone has the right to be provided social care services in the least restrictive environment."
- 8) The control mechanism for providing care should focus on the activities of the providers resulting in transformation of residential care. It is also desirable to create a control network covering all future community-based services and available and accessible to service users.
- 9) The State is obliged to transform the institutional care progressively "to the maximum of its available resources". This obligation is related to the non-discrimination and to the legislation governing the right to be provided social care services in the least restrictive environment.

10) The Czech Republic has the obligation to use the funds allocated to the transformation of social care institutions to achieve the given target; a violation of international law would occur if the State reallocated these resources or failed to spend them.

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