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Over the centuries, in all communities, people with disabilities were stigmatised and excluded from the possibility of equal participation in social life or autonomy– erased from history, sometimes even in a physical way, or deprived of independence as the object of charity. In recent years, there has been a revolutionary global change in approach to close the protection gap and ensure that persons with disabilities enjoy the same standards of equality, rights and dignity as everyone else. The Convention on the Rights of Persons with Disabilities, which entered into force in 2008, signalled a "paradigm shift" from traditional care-oriented, medical-based approaches to disability to one based on human rights.

The aim of the thematic volume of Bialystok Legal Studies entitled "Disability and Law" was to identify the current barriers and solutions on the way to full-fledged active functioning of people with disabilities in society and to analyse actual implementation of the rights of people with disabilities in the context of international, regional and national law, as well as in a comparative perspective.

The wide thematic spectrum encouraged scientists to submit interdisciplinary papers based on findings from various fields of science and cultural, geographical and temporal realities, as well as from their personal experience. The authors from numerous universities and academic units worldwide prepared a fascinating and diverse set of papers on the legal, socio-economic and educational conditions of disability – including examination of attempts to define the value of human life and the phenomenon of disability in philosophy and law, implementation of fundamental and constitutional rights of people with disabilities – also regarding specific impairments, rights of groups with special needs in education, employment policies and access to culture for people with disabilities, lessons from the past for protection against violence.

The editors would like to express their deep gratitude to all of the authors for their invaluable contributions to this volume of the journal and to the general debate on the issues connected with disability – and of course, to invite them as well as the readers to continue and inspire the dialogue in future.

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The Question of the Value of Human Life in Theoretical Discussions and in Practice. A Legal Philosophical and Theory of Law Perspective

Abstract: The value of human life has a basis in cultural norms, both moral and religious. In democratic states it is reflected in the right to life, which has become a foundation for all other human rights and freedoms. Nonetheless, in contemporary legal philosophical thought, the treatment of life as an absolute value and as absolutely inviolable is not the only perspective. Alongside the traditional principle of the sanctity of life, there are those who propose to give precedence to its quality. That quality is gradable and depends on biological and genetic factors. Such a view brings to light new aspects of legal interference in the domain of the life of individuals. It justifies, for example, the permissibility of abortion in the case of a foetus suffering lethal defects. It raises the possibility of allowing claims for redress for harm done by bringing about *wrongful life* ("life that is not worth living") or *wrongful birth*. These issues are highly controversial from an axiological standpoint, while also becoming a source of moral dilemmas. At the same time, given the progress currently being made in biotechnology, they demand legal regulation.

Key words: quality of life, sanctity of life, wrongful life, wrongful birth, prenatal injuries

1. Introduction

The concept of quality was originally applied to the domain of consumption and material objects. In recent decades it has come to be transferred from the level of "thing" to the level of "person". In the wealthy democracies, material comfort has become something universal. "Quality", which was previously a function in the struggle for universal welfare and stabilisation, has become a criterion for the classification of life (*quality of life*). Beginning from the 1960s, as a result of globalisation, the pluralisation of moral attitudes and world views, and rapid progress in science (especially biomedicine and biotechnology), intervention in the domain of human life started to become ever more bold, aiming to promote those forms of life that would fulfil "high quality standards". At the same time a "new quality" appeared in ethical discussions, previously dominated by the traditional *sanctity of life* ethics[1]. This has led to controversies and debates concerning the limits of medical interference in human life, and its legal regulation.

The confrontation between the principles of sanctity of life and quality of life characterises contemporary bioethical discourse. It should be noted that the primary subject of bioethical debates is life as such (*bios*). Bioethics is currently becoming primarily a form of moral management of human life. It seeks solutions that will respect the dignity of a person, favour the integral development of human beings in accordance with their nature, and also ensure stable development for both present and future generations. The chief goal of bioethics, then, may be described most generally as improved quality of life[2].

Doctors, bioethicists and lawyers are today faced with the question of whether every human life (as an overriding, inviolable and ultimate value) is deserving of legal protection, or whether such protection should apply to life of adequate quality[3]. It is becoming necessary to choose the values and principles on which civilisation in the 21st century is to be founded. Making such a choice may prove to be extremely difficult, assuming that it is even possible. Let us note that sanctity of life ethics and quality of life ethics are two entirely divergent visions of reality, born out of quite different philosophical traditions. Nonetheless, the working out of a common "moral grammar" would appear to be essential for a globalised world, particularly in view of the practical possibilities being offered by medicine.

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[1] See more: L. Nordenfelt, Quality of Life. Health and Happiness, Avebury, Aldershot 1993, M. Nussbaum, A. Sed (eds.), The Quality of Life, Clarendon Press, Oxford 1993, W. Chańska, *Nieszczęsny dar życia. Filozofia i etyka jakości życia w medycynie współczesnej*, Wrocław 2009, D. Ślęczek-Czakon, *Problem wartości i jakości życia w sporach bioetycznych*, Katowice 2004, D. Szawarski, Wartość życia, *Etyka* 1984, no 21, pp. 41-69.

[2] M. Bazela, Życie wysokiej jakości, czyli po co nam bioetyka?, *Archeus. Studia z bioetyki i antropologii filozoficznej* 2004, no. 5, pp. 5-13.

[3] J. Umiastowski, Wokół kodeksu etyki lekarskiej, *Ethos* 1994, nos. 1-2, p. 244.

2. Sanctity of life ethics versus quality of life ethics

Sanctity of life ethics is rooted in Christian anthropology and personalism[4]. It has been the foundation of traditional Western ethics. It is based on the principle of the sanctity of human life, and it assumes a natural moral order and the integral nature of a human being as a unity of body and soul. It considers human life to have inalienable value, regardless of its character and quality. Life is held to be inviolable from the moment of conception up to the moment of death. The basic goal of this ethic is the protection of the human person; such as it is, and not such as it might become through technical intervention. The concept of sanctity is not to be understood here in a strictly theological sense. It denotes a certain perfection, fullness, inviolability. And it is this sense that attaches to the phenomenon of human life, which is a value in itself, and at the same time a fundamental value. The realisation of other values proves to be possible only where there is life. In medicine, the principle of the sanctity of life is associated with a prohibition on subjecting decisions about a patient's life to an assessment of the quality of that life.

Quality of life ethics, on the other hand, has its roots in the Enlightenment tradition, which was based on rationalism, scientism, agnosticism, mechanistic materialism and utilitarianism. Quality of life ethics takes account of the aforementioned assumptions. It attempts to respect the pluralism of world views and the autonomy of individuals. At its foundation lies the principle of quality of life, which is gradable and may be dependent on various properties which condition its desired status. The way of understanding this "quality" is not set in stone, but is subject to evolution depending on cultural, economic and political factors, as well as scientific findings. Modification and revision of the principle is possible through democratic social dialogue. It is society that is to decide, through consensus, whether particular behaviours are to be accepted or rejected. The goal of quality of life ethics is to obtain results that might satisfy the greatest number of people, while minimising social harm. The making of choices may be assisted by the principles of *utility* and *benevolence*.

The term "quality of life" is multidimensional and polysemous. Its meaning may be considered from a strictly medical point of view, but also from a broader perspective, encompassing for example the social (linked with economic) and ethical (axiological) planes.

In medicine the term is used in the context of health care and health protection. We may note that a description of the emotional, physical and social welfare of a human individual confirms his or her capacity to function normally (that is, to perform life tasks). Health-related quality of life may thus be significantly impaired by

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[4] See John Paul II, Encyclical: *Evangelium Vitae. On the value and inviolability of human life*, Vatican 1995, no. 2.

illness. The medical sense of quality of life also takes on a social meaning. Economic decisions concerning principles of access to preventive and therapeutic medicine may lead to improved quality of life and increased longevity – or the reverse.

In its ethical meaning, the term refers to the moral principles that are used to evaluate the quality of life. Such an evaluation becomes a basis for the taking of decisions on the continuation or curtailment of life. The axiological dimension of quality of life is usually considered in opposition to sanctity of life ethics. Roman Tokarczyk writes that an insurmountable antinomy is drawn between sanctity of life ethics and quality of life ethics. The first is characteristic of religious systems (particularly Catholicism). It demands moral and legal protection for the whole of a human life (from conception to natural death) and is characterised by rigorism. The second – the secular quality of life ethics – is less rigoristic. While upholding the principle of protection of human life, it admits many exceptions[5]. For example, it provides for the possibility of aborting a foetus with untreatable lethal defects that will lead to miscarriage or the inevitable death of the child soon after birth[6].

3. The value of life according to quality of life ethics and its opponents

Adherents of quality of life ethics share the conviction that the value of life may be different depending on its quality. This conviction is founded on an inclination to make an ontological separation between biological life and personal life. They believe that, for a life to be the life of a person, it must fulfil certain conditions, such as self-awareness, understanding of future and past, emotional balance, capacity for self-control, ability to care for others, and curiosity.[7] They also refer to the potential ability to establish interpersonal relations[8], and the requirement of a minimal independence from the surroundings[9]. They accept that a poorly functioning human body may be equal in value to a well-functioning animal body[10].

From the standpoint of the quality of life principle, attempts are made to evaluate whose life is worth living, and whose is not (in the latter case the term *wrongful life* is applied). By this principle, effort is made to determine a lower bound for the minimum level below which human life ought not to be sustained and rescued[11].

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[5] R. Tokarczyk, Jakość życia jako prewartość, http://romantokarczyk.pl/juris/bio8.html (access 6.4.2018); D. Ślęczek-Czakon, *Problem wartości…, op. cit.*, p. 238.

[6] Furthersee: W. Chańska, *Nieszczęsny dar…, op. cit.*

[7] J. Fletcher, Indicators of Humanhood: A Tentative Profile of Man, *The Hastings Center Report* 1972, vol. 2, p. 14.

[8] R.A. McCormick, The Quality of Life, the Sanctity of Life, *The Hastings Center Report* 1978, vol. 8, pp. 30-36.

[9] Further see: E.E. Shelp, *Born to die? Deciding the fate of critically ill newborns*, New York 1986.

[10] Further see: P. Singer, *O życiu i śmierci. Upadek etyki tradycyjnej*, Warsaw 1994.

[11] P. Singer, *O życiu…, op. cit.*, p. 80.

The assumptions of quality of life ethics are criticised by supporters of the traditional viewpoint. Attention is drawn to the imprecision of the boundary between "rightful" and "wrongful" life (that which is worth living and that which is not)[12]. It is noted that increasing technical possibilities of controlling the biological processes of nature are enabling increasingly dangerous interference with the biological life processes of a human being. There is consequently a fear that technocratic power will lead to the degradation of the individual and commercialisation of the human body[13]. In the view of opponents of quality of life ethics, medicine ought not to determine the value of a person's life, that person being primary and independent. It should simply assume the existence of that value and bring about improvement of the patient's quality of life through medical treatment. What they view as the main problem, however, is that the quality of life principle is a morally dangerous idea, linked to possibilities of eugenic selection, being based on the logic of discrimination and exclusion. It carries with it the temptation to make a distinction between those lives that are deserving of continuation, and those which, in view of their "low quality", ought to be terminated (lives that are not worth living). The opponents of quality of life ethics find such a philosophy to be unsympathetic to the chronically ill, disabled and dying. It becomes a manifestation of the "culture of death" or anti-life logic. It is fundamentally discriminatory since it takes away the right to life in the name of an imprecisely defined quality of life[14].

Incidentally, doubts of an ethical nature apply also to the taking of decisions by doctors and geneticists as to whether they should provide parents with full information on their child's genetic state, and to the delineation of the rights of parents to take decisions in genetic matters – not only those relating to pregnancy or abortion, but also those which concern the genetic selection of embryos, gamete tests, and the like[15].

4. Some remarks on the legal consequences of the creation of a "life not worth living"

In the context of considerations concerning quality of life ethics, some questions that have already gained classical status relate to claims made on the grounds of *wrongful conception*. Freedom in the sphere of procreation is associated with the

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[12] See e.g. T. Biesaga, Wartość życia w ujęciu etyki personalistycznej, *Seminare. Poszukiwania naukowe* 2003 no. 19, pp. 169-175; http://cejsh.icm.edu.pl/cejsh/element/bwmeta1.element.desklight-7d98499b-ee08-4bee-9fff-d2dc0cdb4a5f?q=bwmeta1.element.cejsh-a89a8c34-9490-41f6-a9f9-d8755c9f0723;9&qt=CHILDREN-STATELESS (access 6.4.2018).

[13] T. Biesaga, Wartość życia…, *op. cit.*, p. 173.

[14] B. Chyrowicz, *Zamiar i skutki,* Lublin 1997, p. 193ff.

[15] R.M. Green, Parental autonomy and the obligation not to harm one's child genetically, *Journal of Law, Medicine & Ethics* 1995, vol. 25, p. 2ff.

granting of the right to abortion in situations where there may be justified grounds for such claims. This is inextricably linked to questions about the consequences of culpable prevention of the exercise of that right. From the standpoint of the topic of this article, the most significant considerations would appear to concern the inability to obtain a legal termination of pregnancy when a child is expected to be born with a lethal defect.

Such situations give rise to court cases concerning wrongful conception: where the parents have made efforts to prevent the birth of a defective child, but due to the doctor's disregard of that fact, birth nonetheless takes place. The result is the birth of a child that is incurably ill (with lethal defects, for example), whose life may be evaluated as "not worth living"[16]. In such cases, charges may be laid against doctors on the ground that they failed to prevent, and indeed declined to eliminate, an impaired life subject to the risk of serious burdens, contrary to the contractual obligation to which they were subject – namely that they did not perform an abortion (or performed it improperly). The doctors thus brought about an unwanted maintenance burden, causing what are known as prenatal injuries. It should be noted that claims on this ground are also made in instances of the birth of healthy children, which in their parents' view for some reason ought not to have been born. Irrespective of the precise reason for a claim of wrongful conception, a key question is whether the creation of a "life not worth living" (or, simply, an unwanted life) may even be considered in terms of harm or injury. This problem has frequently been analysed with reference to court judgments[17]. An affirmative answer to the question has been confirmed in

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[16] Furthersee: T. Justyński, *Poczęcie i urodzenie się dziecka jako źródło odpowiedzialności cywilnej*, Kraków 2003; L. Garlicki, Sąd Najwyższy USA a „prawo do życia", *Państwo i Prawo* 1992, no. 8; T. Justyński, Urodzenie się dziecka jako źródło szkody. Uwagi na marginesie orzeczenia Sądu Najwyższego RFN z 27.06.1995 r., *Prawo i Medycyna* 2000, no. 8; T. Justyński, Odpowiedzialność cywilna lekarza w związku z nieudanym zabiegiem sterylizacji (w świetle prawa niemieckiego), (in:) A. Sokala, E. Gajda (eds.), *Honestevivere. Księga pamiątkowa ku czci Profesora Władysława Bojarskiego*, Toruń 2001; M. Kowalski, Odpowiedzialność odszkodowawcza lekarza z tytułu*wrongfulbirth*w prawie niemieckim, *Prawo i Medycyna* 2002, no. 11; W. Lang, W sprawie statusu prawnego*nasciturusa*, *Państwo i Prawo* 1983/6; W. Lang, M. Safjan, Odpowiedzialność prawna za szkody prenatalne i prekoncepcyjne, (in:) W. Lang (ed.), *Prawne problemy ludzkiej prokreacji*, Toruń 2000; M. Nestorowicz, Odpowiedzialność cywilna lekarza wobec narodzonego dziecka z tytułu *wrongful life* w prawie francuskim, (in:) A. Łopatka, B. Kunicka-Michalska, S. Kiewlicz (eds.), *Prawo. Społeczeństwo. Jednostka. Księga jubileuszowa dedykowana Profesorowi Leszkowi Kubickiemu*, Warsaw 2003; M. Safjan, Rozwój współczesnej medycyny i biologii a prawna ochrona dziecka poczętego, *Studia Prawnicze* 1988, no. 3; T. Smyczyński, Pojęcie i status prawny dziecka poczętego, *Studia Prawnicze* 1989, no. 4; T. Smyczyński (ed.), *Wspomagana prokreacja ludzka*, Poznań 1996.

[17] For example, the cases: *Christensen v. Thornby*; *Sciuriaga v. Powell*; *Emeh v. Kensington and Chelsea and Westminster Area Health Authority*; for an analysis of judgments in this area see: T. Justyński, *Poczęcieiurodzenie…*, *op. cit.*, pp. 35-41.

numerous judgments (including those of courts in Poland)[18]. The positions adopted by judges would appear to reflect the growing popularity of quality of life ethics[19].

Another consequence of the popularisation of the principle of quality of life is the ever more frequent pursuit of claims on the grounds of *wrongful life* and *wrongful birth*. These apply in particular to life which ought not to have come into existence since it does not meet an appropriate standard of quality and is evaluated as "not worth living"[20]. In considering such cases, judges have to decide what is meant by this term, as well as related terms such as "wrongful life", "wrongful conception" and "wrongful birth". They are required to answer the questions of whether, in allowing somebody's birth, one can be doing harm (injury); whether life as such can constitute injury; and how to estimate the size of such injury. The concept of injury is key to such considerations. There are two types that may arise: *prenatal injuries*[21] and *preconception injuries*[22].

The term *wrongful life* may be considered as primary with respect to *wrongful birth*. This concept has its roots in American case law and is associated with various ideas of quality of life. Although claims on this ground do not concern children with lethal defects, it is appropriate to refer to them, since such claims are evidence of the popularisation of quality of life ethics. Most generally, they relate to complaints by disabled children (the plaintiffs in the cases) who in their own opinion are living in a "grievous state"[23]. They feel compelled to live a life that is not worth living due to

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[18] T. Justyński, *op. cit*., pp. 34-35.

[19] Furthersee: A. Breczko, *Podmiotowość prawna człowieka warunkach postępu biotechnomedycznego*, Białystok 2011, p. 199ff.

[20] M. Soniewicka, Regulacje prawne wobec rozwoju nowoczesnych technik kontroli prokreacji. Analiza roszczenia *wrongful life*, *Diametros* 2009, no. 19, pp. 137-159.

[21] Prenatal injury is associated, in the case of wrongful life claims, with liability in civil law for harm done to a child after conception but before birth. The term is a broad one and covers all kinds of injury done to a *nasciturus*. It is used in practice in relation to "material damage" done to the foetus by medical personnel. It concerns the causing of health defects as a result of improper actions occurring after the child's conception. The existence of such liability has long been accepted in many legal systems. Typical situations in which it arises include the infection of a pregnant woman with a venereal disease during blood transfusion, transfusion of blood of the wrong group, administration of harmful medication, etc.; see e.g. M. Nestorowicz, Odpowiedzialność cywilna według *common law* za szkody wyrządzone *nasciturusowi* przed i po jego poczęciu, *Państwoi Prawo*1983, no. 8.

[22] This class of injury covers circumstances occurring before a child's conception that cause damage to its body or health, if they were the fault of medical personnel. See e.g. M. Nestorowicz, *Prawo medyczne*, Toruń 2001, p. 175; M. Safjan, *Prawo wobec ingerencji w naturę ludzkiej prokreacji*, Warsaw 1990, p. 174ff. From the large number of writings on preconception injuries, it may be concluded that there is an increasing trend towards the granting of legal protection to a person even before his or her conception. See T. Justyński, *Poczęcieiurodzenie…*, op. cit., p. 17.

[23] There is a wealth of American literature on preconception injuries; see e.g. J.A. Midlock, Prenatal Injuries Caused by Negligence Prior to Conception: An Expansion of Liability, *Chicago-Kent Law*

their mothers' being refused the right to abortion[24]. These plaintiffs argue that it would have been better had they not been born at all. They declare that they would prefer not to live, since their existence does not have a sufficiently "satisfying quality"[25].

The right of every person to be born as a whole, functional being was formulated in a judgment of the New York court of appeal in the case *Park v. Chessin*[26]. This was the first time that an American court had awarded damages to a child on this ground. Full damages were also awarded in the 1980 case *Curlender v. Bio-Science Laboratories*[27]. It should be noted that, in spite of the verdicts mentioned here, American courts tend to be unwilling to consider wrongful life claims. Only in exceptional cases do they award damages to disabled children for the "fact of their birth". By the mid-1980s only three US states had granted (partial) legal protection to children born with genetic or developmental defects due to errors made by medical personnel providing preconception and prenatal advice and diagnosis. Until the end of the 1990s such claims were prohibited, either by legislation or by the courts, in the great majority of states. One of the fundamental legal arguments against the recognition of claims for damages for wrongful life referred to the problem of "nonexistence" and the impossibility of deciding whether any kind of existence is better than no existence[28]. In Europe, such damages have so far been awarded only in France and the Netherlands[29]. European courts are therefore highly sceptical as regards the justifiability of such claims. Weronika Chańska claims that the reasons for this may include both the "troublesome" legal issues and – perhaps primarily – the ethical judgments involved in the concept of a "life not worth living"[30].

Claims on the ground of wrongful birth are made by the parents of disabled children against doctors who culpably failed to diagnose the defect during pregnancy (or even prior to conception) and thus prevented the pregnancy from being terminated (or caused conception to take place). The doctor is not treated here as the party causing the defects – after all, the "life not worth living" is brought about by nature. The charges against the doctor are solely that, through incorrect diagnosis, he or she deprived the parents (the plaintiffs) of the right to decide whether they wish to accept the "burden" of a defective child. In such cases, redress is not sought for the

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Review 1977, vol. 54(2), p. 583; M. Capron, Tort Liability in Genetic Counseling, *Columbia Law Review* 1979, vol. 79(4), p. 683.

[24] W. Chańska, *Nieszczęsny dar…*, *op. cit.,* p. 69ff.

[25] M. Soniewicka, Regulacje prawne…, *op. cit*., p. 137.

[26] 387, N.Y.S. Zd. 204 (1976).

[27] 106 Cal App 3 d 811, 165 CalRptr 477 (1980).

[28] A thorough analysis of judgments in this area was made by J. Różyńska, „Wolałbym nie istnieć, niż żyć w takim stanie". O koncepcji krzywdy opartej na racjonalnej preferencji Joela Feinberga, *Etyka* 2014, no. 49, pp. 59-82.

[29] W. Chańska, *Nieszczęsny dar…*, *op.cit*., p. 70.

[30] *Ibidem*, p. 71.

serious defects suffered by the child; the plaintiff seeks damages for the very fact of the "wrongful birth".

It is indeed difficult to decide whether the right to autonomy in matters of procreation ought to include the right to decide in the matter of a possible abortion, or whether the right of every being to life implies the impossibility of deciding – without that being's expressed will – to take away that life. Nonetheless, claims for wrongful conception, wrongful life and wrongful birth have become a "signal" of modern times. They provide an example of the ever clearer contradiction in moral and legal evaluations[31]. The traditional concepts and legal constructs are confronted with an entirely new social reality. Analysis of theory and practice leads to the conclusion that such cases cannot be downplayed. The arguments advanced on the basis of quality of life ethics might indicate that a person's right to dignity and autonomy ought to imply the need to create appropriate legal regulations to enable such claims.

5. Can someone be injured by being brought to life?

A fundamental question inherently connected with claims for wrongful life is whether nonexistence can be better than existence. Can a person be injured by being brought to life, in a situation where at the prenatal stage it was known that the person would be born with a congenital untreatable disease or disability? This problem has been the subject of debate in the ethical and legal literature[32]. The controversies relate to whether it is even justified for courts to award compensation for the "harm of existence". Such harm relates to the fact of the creation of a life branded with pain and suffering, and moreover associated with particular needs and costs. Without examining in detail the various ways of understanding the very concept of "harm of existence", let us consider an interesting proposal of Joel Feinberg. That author, aware of the impossibility of comparing existence with nonexistence, views such harm through the lens of a "rationalisation of preference". He states that, if potential parents have good reason to suppose that their child's life will be one of poor quality, they ought not to allow such a life to come into being. In his view, by consciously calling the child into existence, they are doing it harm. Their decision is therefore *prima facie* morally wrong. When precisely may we speak of the "harm of existence"? Feinberg proposes attempting to imagine a situation in which a person might rationally prefer immediate death to continued life. Let us thus imagine that, after death, a person is received by a deity who makes the following proposition: either you are to be born

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[31] P. Jaworek, Narodziny dziecka jako źródło szkody w prawie cywilnym, (in:) M. Warciński, K. Zaradkiewicz (eds.), *Wybrane zagadnienia prawa cywilnego*, Warsaw 2006, p. 57ff.

[32] J. Różyńska, „Wolałbym nie istnieć…, *op. cit.*, p. 59ff.

again as a child with a fatal disease (such as Tay-Sachs disease)[33], or you are to be instantly annihilated. By choosing the first option, they will gain up to four years of life full of pain and suffering, ending once again in death. Feinberg claims that one would have to be mad to choose the first option, just as a rational person would not hesitate to choose immediate nonexistence if the deity required them to choose between the same alternatives on behalf of a person they loved and truly cared for, such as a spouse or child[34]. In his view, every rational thinking person would choose the option of "not-existing" in such a situation. The thought experiment thus demonstrates that it is possible to have a rational preference for nonexistence[35]. Naturally, this applies only to exceptional, extreme cases[36]. One may assert that parental autonomy in deciding whether a child with serious genetic defects should come into the world does not always justify in an obvious way a decision as to the child's birth. What is morally controversial may be the fact that, having a choice between a healthy child and one with severe genetic defects, a parent might consciously choose the latter[37].

6. On the legitimacy of the right to abortion in the case of a foetus with lethal defects

Under current Polish law, abortion is permitted in case of severe and irreversible impairment of the foetus (in accordance with the so-called "criteria model"). In the bioethical debate concerning this issue – which in Poland proves still to be controversial – arguments of substance are relegated to a secondary role. In the ongoing discussions concerning the *Stop Abortion* proposal, there is some visible manipulation. The "anti-choice" campaigners use images of smiling children with Down's syndrome as an argument for a ban on what they call "eugenic abortion". The aforementioned proposal would remove from Polish law the "embryopathological criterion" (one of only three exceptions allowing legal termination in what is already the most restrictive anti-abortion legislation in Europe)[38]. The references made

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[33] This is an onerous and incurable disease, detectable in prenatal diagnosis. Its effects include neurological damage, intellectual disability, deafness, blindness and other serious developmental defects, leading to death at an age of around 2-3 years. http://neuropsychologia.org/choroba-tay-sachsa (6 April 2018).

[34] J. Feinberg, Wrongful Life and the Counterfactual Element in Harming, *Social Philosophy and Policy* 1986, vol. 4, p. 22.

[35] J. Feinberg, Harm to Others, *The Moral Limits of Criminal Law* 1987, vol. 4.

[36] B. Steinbock, *Life Before Birth: The Moral and Legal Status of Embryos and Fetuses*, Second Edition, Oxford 2011, p. 124.

[37] D. Szawarska, Preimplantacyjna diagnoza genetyczna (PGD) i zasada odpowiedzialności rodzicielskiej, (in:) A. Krawczak, E. Maciejewska-Mroczek, M. Radkowska-Walkowicz, *Dziecko. In vitro. Społeczeństwo. Ujęcie interdyscyplinarne*, Warsaw 2018, p. 229.

[38] Polish Act of 7 January 1993 on family planning, protection of human foetuses and conditions for the admissibility of termination of pregnancy (Dz.U. 1993 No. 17 item 78).

– in the debate over planned changes to abortion law – to "eugenic abortion" are, we believe, an oversimplification. The category of "eugenic considerations" is indeed used in the philosophy of law and in bioethics, these being listed among the conditions that justify abortion. However, these are cases where there has been found to be a risk to the life or health of the mother, or else serious developmental defects or damage to the foetus[39]. They should not be identified with a treatment of abortion as a means of controlling births, as would be implied by the pejorative connotations of "eugenics". Eugenics, in the version proposed by Francis Galton, was to be a method of improving the genetic material of a race, nation, species or whole society, controlled by a central authority. To ascribe similar intentions to parents taking a decision to terminate a pregnancy because of a fatal defect of the foetus would appear unjustified and even unethical. Great caution should be exercised in attempting to juxtapose, or even identify, the concept of abortion with that of eugenics. Such a view would appear not to take account of the fact that decisions in such a complex matter are accompanied by moral dilemmas experienced by the person deciding about a possible abortion. It is also difficult to regard the concept of procreative freedom as equal to the treatment of abortion as a procedure available "on demand". In such a significant discussion, arguments on either side should not be devoid of sensitivity to ethical values, and all the more so should not be formulated under the influence of popular opinions, ideology or manipulation.

The definition of a developmental defect in medicine is a very broad one. Not every such defect is considered in law as a ground for abortion. Certainly, "lethal defects" are currently regarded as such a ground (and should continue to be). These are the most serious developmental anomalies, for which the medical prognosis is poor – in terms of not only the possibility of treatment, but in particular the possibility of mere survival. They usually result in miscarriage or the birth of a dead child. Only in rare cases is there a chance of a live birth, but even then, the child usually dies while still a baby: 95% die before the age of one year. Even if the child survives, it is not possible to establish any contact with him or her. This occurs, for example, in the case of newborns with Edwards syndrome or with anencephaly (lacking a cerebral cortex). The existence of such beings is associated with incredible burdens, being accompanied by intellectual disability, serious heart defects, convulsive fits, bone and skeletal defects, obstruction of the oesophagus, respiratory disturbances, defects in the formation of the face, eye defects (from anophthalmia to cyclopia), microcephaly, polydactyly, cleft palate, and many other conditions. Only in isolated cases do children with "lethal defects" survive to adulthood, and even then, they are subject to numerous limitations and the need for constant care[40].

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[39] T. Pietrzykowski, *Spór o aborcję*, Katowice 2007, pp. 26-27.

[40] https://oko.press/bezoczne-mozg-poza-czaszka-zarosniecie-przelyku-brzydkie-dzieci-wadami-wrodzonymi (access 6.4.2018).

The question therefore arises: do we have the right to condemn these seriously handicapped human beings to several months (sometimes several years) of existence under such enormous burdens, in the name of the principle of sanctity of life? Can a life that is limited solely to the experiencing of an untreatable disease, suffering (accompanied by the absence of any awareness) and waiting for death be regarded as a value in itself? It should be considered that the creation of such a life will undoubtedly lead to suffering not only on the part of the parents (particularly the woman required to carry her pregnancy to term knowing that the child will die soon after birth), but also on the part of the child, who – before death arrives – will be forced to undergo a number of onerous medical procedures such as mechanical ventilation, continuous painkilling treatment, and possibly – in the case of more favourable prognoses – dozens of surgical operations. It is unquestioned that every human being has the constitutional right to life and a legal guarantee of the protection of his or her dignity; but in such cases the question arises whether the value of life is in every instance an exceptionless premise for the maintenance of biological existence[41].

It seems that one must agree with Joanna Różyńska's observation that the right to abortion in such cases protects the right of parents to take an informed decision on whether they wish to and are able to take on the responsibility of caring for a child that requires such special attention. It also protects the welfare of the incurably sick child. As she rightly states, to perceive the suffering of others and assume moral responsibility for the quality of the life that we give to a child, we do not have to undertake the formidable task of comparing "existence" with "nonexistence"[42].

The question of the legal regulation of abortion should not be treated as an attack directed against the principle of the protection of human life. It should rather be understood as a legal guarantee of freedom of choice in a morally controversial situation. The granting of such a choice "does not compel anyone to regard abortion as a justified exception from the protection of human life if they do not share that view, whereas a legal ban on abortion forces those of the opposite view to act as if they regarded abortion as a morally unacceptable attack on the 'sanctity' of life"[43]. It seems that the law cannot force people into heroism, even if this takes place in the name of the dogmas of the country's dominant religion. The authorities should nonetheless support children born into a "state of harm" and their "heroic parents". Is it a good solution that such support be provided in the form of compensation

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[41] We should add that, although the treatment of life as an absolutely overriding and autotelic value is a fundamental assumption, exceptions from it may be admitted in certain extreme situations. Cases are known where the value of life and the need to protect it come into conflict with other values, such as honour or obligations to one's country. Exceptions on grounds of self-defence and "higher necessity" might also be mentioned.

[42] https://polityka.pl/tygodnikpolityka/spoleczenstwo/156127,1/za-kulisami-legalnej-aborcji.read (access 6.4.2018).

[43] T. Pietrzykowski, *Etyczne problemy prawa*, Warsaw 2011, p. 136.

awarded for a “life not worth living”? Certainly this should not be the sole solution; particularly since it often leads to the stigmatisation of the people making such claims – as wishing to profit from their misfortune – which may undoubtedly strike at their sense of dignity.

7. Conclusions

Traditionally oriented ethics has addressed the description and classification of protection of human life using the concept of value, understood as autotelic value. The determinant of the protection of this value is the idea of the sanctity of life. This view has been influenced by religious concepts related to the sanctity of life, viewed as an objective value, constituting a “gift”. On this basis, human life is assigned *per se* a special value that distinguishes people from other species. Modern bioethical thinking takes account also of another perspective, that of quality of life. This attitude results from a redefinition of the assumption that the granting of a particular value to the lives of representatives of the human species arises from mere biological membership of that species[44]. It is pointed out that the valuing of human life may depend on a human’s possession of certain properties, such as consciousness, the ability to feel, and so on. The treatment of the value of life as an attribute having an absolute nature, though morally and axiologically justified, is not the only perspective for understanding the protection of life and the relation of that value to other important and legally protected values.

The challenges brought about by technological and medical progress force legislators to make significant axiological choices. It is not easy to decide whether legal regulations may be a sufficiently effective and refined tool for the positivisation of the problem of quality of life. Certainly, though, the regulation of such subtle questions should not be a source of irreducible divisions and conflicts but should rather be a tool of consensus. In a situation where traditional legal categories come up against changes in science and in social reality, it is important and desirable for a set of moral values to be developed which might serve as a universal point of reference in deciding these cases, which are difficult both morally and legally.

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[44] Such an extreme anthropocentric perspective is seen by some bioethicists as a manifestation of speciesism; see P. Singer, *Etyka praktyczna*, Warsaw 2003, p. 65, *passim*.

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People with Disabilities as a Vulnerable Group. The Concept of Protection of the Rights of Vulnerable Groups[1]

Abstract: The social model of disability, which focuses on determining the reasons for disabilities not connected with the individual as such, but pointing at the social barriers that limit the individual in the environment where he/she lives, is consistent with the assumptions of the UN Convention on the Rights of Persons with Disabilities and is a coherent and complementary element of the concept of individual vulnerability attributed to people who are marginalised in a given society. Since the EU is a party to the aforementioned Convention, while the provisions of the ECHR should introduce the minimum standard of protection of fundamental rights in the EU, it should be determined whether the legislative standard set by the Convention has been implemented in a binding manner at the level of EU law and ECHR.

Keywords: vulnerable groups, social model of disability, discrimination, marginalisation

In line with the opinion expressed in the Communication from the European Commission dated 15 November 2010, one in six people in the EU is disabled[2], the degree of disability ranging from mild to severe, which means that around 80 million Europeans are often prevented from taking part fully in society and the economy because of environmental and attitudinal barriers. The rate of poverty of people with disabilities is 70% higher than the average, one of the reasons being limited access to employment. Over a third of people aged over 75 have disabilities that restrict them to some extent, and over 20% are considerably restricted. Furthermore, these

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[2] For reasons of clarity it should be stated that the terms 'disabled people' and 'people with disabilities' will be used interchangeably. All persons characterised by physical or psychological disability are – for the purposes of analyses carried out in this article – treated as members of a single social group: that of people with disabilities.

numbers are set to rise as the EU's population ages[3]. Just these facts alone can be considered sufficient to draw the conclusion that disability is a feature of many people living in the EU, which at the same time causes their social marginalisation. The marginalisation of disabled people is also caused by prejudices, which are deeply rooted in each society and which are based on common stereotypes[4]. Stereotypes, in turn, convey a negative message, because they comprise unjustified simplifications or generalisations, while the image they create is incomplete, because they ascribe certain (usually negative) features regardless of whether all the elements of the image form a coherent whole[5]. A stereotypical approach has far-reaching negative consequences for those who want to exercise their rights despite the prejudices in their environments. The issue is important inasmuch as it may lead to a structural problem if the stereotype is used by state authorities. Beyond any doubt, if state authorities – including the administration of justice[6] – follow stereotypes, this may lead to substantive and factual errors. This manifests as practices that work to the disadvantage of certain people. These practices can be overt or covert actions or omissions to act and create structural or institutional discrimination[7]. Discrimination is a deeper manifestation of status loss on the continuum of stereotyping. The key component of this process is the use of dichotomous categories: male/female, white/black; healthy/disabled. Because of the fact that individuals do not live in isolation, but in a society filled with a network of various kinds of relationships, links, and dependencies, no individual is separate from systems of difference which serve to position people in various, often inequitable ways[8]. It is imaginable that some will be more regularly at the former and others most frequently at the latter end of the spectrum. By virtue of their position in a social hierarchy, members of marginalized groups are unlikely to be viewed as contributors to important collective social goals.

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[3] 1. Introduction, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. COM(2010) 636 final. Brussels, 15.11.2010.

[4] I. Solanke, Discrimination as Stigma. A Theory of Anti-discrimination Law, Hart Publishing 2017, p. 9.

[5] S. Buchowska, Stereotypy oparte na płci a dyskryminacja kobiet – aspekty prawno-międzynarodowe [in:] Z. Niedbała [ed.] Prawo wobec dyskryminacji w życiu społecznym, gospodarczym i politycznym, Warsaw 2011, p. 26; broadly about the formation of stereotypes M. Dębicki, Wokół stereotypów narodowych i niektórych zjawisk pokrewnych. Nowe formy starych dylematów [in:] R. Dopierała, K. Kaźmierska [eds.] Tożsamość, nowoczesność, stereotypy, Krakow 2012, pp. 327-338.

[6] Równe traktowanie uczestników postępowań. Przewodnik dla sędziów i prokuratorów [eds.] D. Pudzianowska, J. Jaruga, Warsaw 2016.

[7] I. Solanke, Discrimination as Stigma. A Theory of Anti-discrimination Law, Hart Publishing 2017, p. 33.

[8] B. Gough, M. McFadden, Critical Social Psychology – An Introduction, Basingstoke, Palgrave 2001, p. 13.

On the other hand, less privileged groups feel an obvious pressure to conform to norms which they do not fully accept. This is the process resulting in the formation of the so-called vulnerable groups, whose rights are – as a rule – limited and stratified by the social majority controlling the decision-making processes in the society.

The concept of individual 'vulnerability' as a social feature was defined as 'universal, inevitable, enduring aspect of the human condition'[9]. From this point of view, vulnerability should be perceived as a feature forming part of the human nature (as a part of human identity), as a result of which feature individuals are constantly exposed to potential (intended or unintended) harm connected with the risk of the changing circumstances (due to the constantly evolving character of societies), or with the adopted assumption that such individuals have to be subordinated to other individuals. From this perspective, also the vulnerability of a certain group should be seen as a dynamic concept, ascribed to – but also permeating into – the notion of minority groups[10]. When we attempt to capture the essence of the definition of a 'vulnerable group' in the language of human rights, we should consider that such a group is made up of individuals who particularly frequently experience unequal treatment or need to introduce special instruments for their protection in society. Nevertheless, it has to be emphasised that even though social vulnerability concerns, first and foremost, an individual as such, the notion should not be reserved for the outcome of an assessment of the individual's situation only. It seems possible that a different thesis can be adopted, namely that individuals with a common feature or established identity can be classified, within a single group, as vulnerable individuals. By the same token, vulnerability is an inherent part of a given social situation and consequently can be ascribed to a whole group of people distinguished by it[11].

Disability is an issue that is associated mainly with medical problems, rather than legal ones[12]. For a relatively long time, international law did not attempt to protect disabled people, in contrast to the protection accorded to other vulnerable groups,

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[9] M.A. Fineman, The vulnerable subject: Anchoring equality in the human condition, 'Yale Journal of Law & Feminism' 2008, no. 20, p. 8.

[10] L. Peroni, A. Timmer, Vulnerable groups: The promise of an emerging concept in European Human Rights Convention Law, 'International Journal of Constitutional Law' 2013, no. 4, p. 1060.

[11] *Ibidem*, p. 1068.

[12] M. Rioux, Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality, Can. J.L. & Juris. 1994, no 7, p. 127; K. Kurowski, Niepełnosprawność i osoba niepełnosprawna – od medycznego do społecznego modelu niepełnosprawności (w:) Najważniejsze wyzwania po ratyfikacji przez Polskę Konwencji ONZ o Prawach Osób Niepełnosprawnych. Biuletyn Rzecznika Praw Obywatelskich 2012, no 10, p. 8.

such as children[13] or women[14]. There is no doubt that it was only the last decade that saw a development of disabled people' rights protection, including a unified approach to the social definition of disability at both international and national level. It is the UN Convention on the Rights of Persons with Disabilities (which the EU has ratified[15]) which is the most important measure of the fight against segregation and exclusion of disabled people, while at the same time promoting the social, not the medical, model of disability. This model assumes that it is the social space where barriers preventing disabled people from participating efficiently exist[16]. The causes of disability are not linked with the individual as such, but rather with the environment where the individual lives, which restrains him/her and where social, economic, and architectonic barriers are identified.

The Convention affects directly the way EU law is applied and interpreted. As a rule, if the Convention includes a guarantee which is not regulated in EU legislation, it assumes the function of an instrument filling a legal lacuna. In the process of interpreting EU law, the Convention becomes an interpretative benchmark[17]. The study of legal instruments at the level of EU law and the European Convention on Human Rights[18] does not lead to an unequivocal conclusion that these two

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[13] UN Convention on the Rights of the Child was adopted by the United Nations General Assembly on 20 November 1989 and ratified by Poland on 30 April 1991 (Polish official journal Dz. U. 1991, No. 120, item 526).

[14] UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), was adopted by the United Nations General Assembly on 18 December 1979 and ratified by Poland on 30 July 1980 (Polish official journal Dz. U. 1982, No. 10, item 71).

[15] The Convention was done in New York and adopted by the United Nations General Assembly on 13 December 2006. It entered into force on 3 May 2008 (the 'Convention'). On behalf of the EC, the Convention was signed on 30 March 2007, subject to its possible conclusion at a later date. The European Union ratified the Convention, whose text was included in Annex I to Council Decision 2010/48/EC of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities (OJ UE L 23, 27.1.2010, p. 35). The ratification instrument was deposited on 23 December 2010. It should be stressed that this is the first case when the EU became a party to an international human rights treaty.

[16] The social model of disability is the opposite to the medical (individualised) model. The latter assumes a medical approach to the problem of disability, linking an individual's diseases with his/her problems with functioning in the society. This model functions in the US legal system. Cf.: M. Rioux, Towards a concept of equality of well-being: Overcoming the social and legal construction of inequality, 'Canadian Journal Law & Jurisprudence' 1994, no. 7, p. 127.

[17] More broadly, L. Waddington, The European Union and the United Nations Convention on the Rights of Persons with Disabilities: A story of exclusive and shared competences, 'Maastricht Journal of European and Comparative Law' 2011, vol. 18, no. 4, p. 431 ff.

[18] Convention for the Protection of Human Rights and Fundamental Freedoms, done in Rome on 4 November 1950, as amended by Protocols Nos. 3, 5 and 8 and supplemented by Protocol no. 2 (Polish official journal Dz. U. 1993, No. 61, item 284 as amended), the 'ECHR'. The body adjudicating on the basis of ECHR provisions is the European Court of Human Rights, the 'ECtHR'.

legal regimes have adopted and efficiently promote the social model of disability. Even though the European Convention on Human Rights plays an important role in strengthening the rights of people with disabilities, Articles 3, 5, 8 or 14 ECHR being among the ones of key importance, the concept of vulnerable groups as ones that require special protection due to the system of distribution of goods in a given society, resulting in a privileged position of a selected part of the population and an unfavourable situation of other members of the population, is a concept which is only beginning to gain importance[19]. Nevertheless, classification of people with disabilities as a particularly vulnerable group shows a certain evolution in ECtHR case law. Determining the existing vulnerability of such people enables the Court not only to strengthen the idea of equality as such, but also to broaden their rights through application of the doctrine of positive obligations of the state[20]. In this context, the Court attaches great weight to detainees with mental health conditions. Such people are considered as 'particularly vulnerable detainees'[21], or as 'more vulnerable than the average detainee'[22], or as detainees 'in a particularly vulnerable situation'[23]. Similar attention is given to other persons with mental conditions, the Court finding that 'persons of unsound mind' within the meaning of Article 5(1) ECHR are vulnerable persons. In the judgment in *Alajos Kiss v. Hungary* the Court held that individuals suffering from mental health conditions are a 'particularly vulnerable group' due to the discrimination they suffer from other members of the society[24]. In this judgment the Court emphasised clearly that if restriction of fundamental rights applies to a particularly vulnerable social group, which had in the past suffered considerable discrimination, such as mentally disabled people, then the state's margin of appreciation is substantially narrower and there must be very weighty reasons for

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[19] A publication which merits approval in the context of problems of vulnerable groups in ECtHR case law is Y.A. Tamimi, The protection of vulnerable groups and individuals by the European Court of Human Rights, http://njb.nl/Uploads/2015/9/Thesis-The-protection-of-vulnerable-groups-and-individuals-by-the-European-Court-of-Human-Rights.pdf (access 11.10.2017). The author analyses 557 cases examined by the ECtHR, in all of which the word 'vulnerability' or related words (the analysis covers case law until 2013, inclusive of that year). The conclusion is that the concept of vulnerability of individuals and social groups appears with increasing frequency in ECtHR case law and in 2013 it applied already to 8% of all cases examined by the Court, compared to 2% in 2007.

[20] A. Timmer, A Quiet Revolution: Vulnerability in the European Court of Human Rights' [in:] M. Fineman, A. Grear [eds.] Vulnerability: Reflections on a New Ethical Foundation for Law and Politics, Ashgate 2013, p. 147 ff.

[21] For instance, ECtHR judgment of 17 June 2012, case *Munjaz v. the United Kingdom*, application no. 2913/06; of 24 November 2009, case *Halilovic v. Bosnia and Herzegovina*, application no. 23968/05.

[22] For instance, ECtHR judgment of 10 January 2013, case *Claes v. Belgium*, application no. 43418/09; of 18 December 2007, case *Dybeku v. Albania*, application no. 41153/06.

[23] For instance, ECtHR judgment of 22 January 2013, case *Lashin v. Russia*, application no. 33117/02.

[24] ECtHR judgment of 20 May 2010, case *Alajos Kiss v. Hungary*, application no. 38832/06.

introducing such restrictions. The reason for such an approach is that, such groups were historically subject to prejudice with lasting consequences, resulting in their social exclusion. The prejudices may also result from legislative stereotyping which prohibits the individualised evaluation of such persons' capacities and needs[25].

Yet on the other hand, the concept of vulnerable groups distinguished in ECtHR case law has also come under criticism[26]. Importantly, the criticism comes from dissenting judgments of ECtHR judges. As an example, we can mention the opinion expressed by judge B. Borre, who clearly disagreed with the role assumed by the ECtHR in case *D.H. and Others v. the Czech Republic*, stressing that evaluating the whole social context in the case was at variance with the Court's duty to analyse the case in the individual context[27]. He considered that an assessment of the historical background and social evolution could not lead to generalising conclusions for all members of a so-called vulnerable group. A similar criticism of generalising assessments in respect of members of a vulnerable group was delivered by judge A. Sajó in his dissenting opinion in case *M.S.S. v Belgium and Greece*[28].

The focus on the social model of disability in EU law was impossible for a long time due to lack of EU competences in the sphere of social policy, which prevented active influence on the situation of disabled people. Currently, it is the Charter of Fundamental Rights[29] and Directive 2000/78/EC[30] that provide for the basic obligations of Member States in the context of prohibition of discrimination of disabled people and equalising their chances in the society. However, it should be stressed that EU legislation – both primary and secondary (even the instruments of soft law) – does not contain a definition of 'disability'. Who is a person whose health limitations result in a disability has been decided by the Court of Justice in its judgments.

In case C-13/05 *Chacón Navas*,[31] the CJ held that the concept of 'disability' should be understood as 'a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life'. What was particularly important for the CJ was the distinction between disability and sickness, which is another hindrance in

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[25] ECtHR judgment of 20 May 2010, case *Alajos Kiss v. Hungary*, application no. 38832/06, para. 42.

[26] I. Truscan, Considerations of vulnerability: from principles to action in the case law of the European Court of Human Rights, RETFORD 2013, no. 3, p. 75.

[27] Dissenting opinion of judge B. Borre on ECtHR judgment of 13 November 2007, in case *D.H. and Others v. the Czech Republic*, application no. 57325.

[28] Dissenting opinion of judge A. Sajó on ECtHR judgment of 21 January 2011, in case *M.S.S. v. Belgium and Greece,* application no. 30696/09.

[29] Charter of Fundamental Rights of the European Union (OJ C 326, 26.10.2012, p. 391).

[30] Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation (OJ EC L 303, 2.12.2000, p. 16).

[31] CJEU judgment of 11 July 2006, in case *Sonia Chacón Navas v. Eurest Colectividades SA*, C-13/05.

employment. This was done by adopting the assumption that a disability by definition has a long-term nature, while the notion of sickness (in EU law) assumes that it is a short-term indisposition of an employee.

The definition of disability given in the *Chacón Navas* judgment was criticised by both legal scholars[32] and advocates-general. It was stressed that making the assumption that in case of disability there usually is a permanent impairment of the body's facilities (whether physical, mental or psychological) that prevents or considerably limits the participation in social life, including in particular taking up and remaining in employment, is inconsistent with the current paradigm whereby disability is considered an element of social diversity and not a restriction experienced by a certain person. CJ judgment in cases *Jette Ring and Skouboe Wenge*[33] is yet another attempt to engage in reflections about the definition of disability. This judgment is also important because it contains a definition formulated on the basis of a Framework Directive, but after the EU became a party to the Convention. As soon as in the introduction to the reflections, the CJ stressed that 'the primacy of international agreements concluded by the European Union over instruments of secondary law means that those instruments must as far as possible be interpreted in a manner that is consistent with those agreements'. Consequently, the notion of 'disability' determined for the purposes of applying the Framework Directive, was modified so as to reflect Article 1 of the Convention, which includes among people with disabilities 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. What the CJ also considered important was that recital (e) of the preamble to the Convention provides that 'is an evolving concept and that disability results from the interaction between people with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'. In the end, the Court held that the concept of disability as used in Directive 2000/78/EC must be interpreted as including a condition caused by an illness medically diagnosed as curable or incurable where that illness entails a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers, and

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[32] 'By embracing the medical model of disability, and focusing on the limitation caused by impairment and the need to prove such limitation, the Court's decision flies in the face of values underlying the Directive an Community disability policy', L. Waddington, Case C-13/05, Chacón Navas v. Eurest Colectividades SA, 'Common Market Law Review'. 2007, vol. 44, no. 2, pp. 487-499.

[33] CJEU judgment of 11 April 2013 in joined cases *Jette Ring v. Dansk almennyttigt Boligselskab, Lone Skouboe Werge v. Dansk Arbejdsgiverforening*, acting on behalf of *Pro Display A/S, in liquidation*, C-335/11 and C-337/11.

the limitation is a long-term one. The CJ confirmed the view that a disability should be understood as a result of an interaction between individuals with disabilities and the barriers created by the society was also confirmed in another judgment, in case C-363/12[34].

The final confirmation of the social character of the European model of disability made it possible to determine whether EU law assumed the functioning of the concept of a vulnerable group made up of persons with disabilities. A question asked in this way should be answered in the affirmative, while the reflections should move in the direction of consumer law. In this context, a reference should be made to the contents of Directive 2005/29/EC[35] on unfair commercial practices, which lists examples of such commercial practices, clarifying that they are contrary to the requirements of professional diligence and distort the economic behaviours of an average customer or an average member of a consumer group, if a commercial practice is addressed to a specific group of consumers (Article 5(2)). Article 5(3) of the Directive provides that 'commercial practices which are likely to materially distort the economic behaviour only of a clearly identifiable group of consumers who are particularly vulnerable to the practice or the underlying product because of their mental or physical infirmity, age or credulity in a way which the trader could reasonably be expected to foresee, shall be assessed from the perspective of the average member of that group. In turn, two other directives, i.e. Directive 2001/95/EC[36] and Directive 2011/83/EU[37], make references to the concept of vulnerable groups in their preambles. Even though these legal instruments do not expressly mention disabled people as a vulnerable group, the clear differentiation – resulting from their contents – between average consumers and particularly vulnerable consumers, including an emphasis on those with physical or mental disability, allows us to conclude that this is a group that requires adopting a higher standard of protection. In line with the guidelines from the European Commission[38] consumers' susceptibility to risks has a multi-dimensional character and such is also the infuence of the personal characteristics on the likelihood of being a consumer susceptible to risks. For this reason, the EC recommends referring

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[34] CJEU judgment of 18 March 2014, in case *Z v A Government Department and The Board of management of a community school*, C-363/12.

[35] Directive 2005/29/EC of the European Parliament and of the Council of 11 May 2005 concerning unfair business-to-consumer commercial practices in the internal market, OJ UE L 149, 11.6.2005, p. 22), e.g. Article 5; recital 19 of the preamble.

[36] Directive 2001/95/EC of the European Parliament and of the Council of 3 December 2001 on general product safety (OJ UE L 11, 15.1.2002, p. 4).

[37] Directive 2011/83/EU of the European Parliament and of the Council of 25 October 2011 on consumer rights (OJ UE L 304, 22.11.2011, p. 64), e.g. recital 34 of the preamble.

[38] European Commission, Staff Working Document, Guidance on the Implementation of Directive 2005/29/EC on unfair commercial practices, SEC (2009) 1666, p. 53-54.

disability (psychological or physical) to both sensory impairments and limited mobility and other forms of infirmity.

The EU instruments mentioned above treat 'vulnerable consumers' as a static group, which is inconsistent not only with the assumption that all consumers may prove to be vulnerable and in need of special protection when they are parties to transactions with experts[39]. Thus, lack of identification of such special situations (vulnerable situations) makes it impossible to develop – also in the context of disabled people – the right standard of protection. Moreover, the static and medical concept of disability adopted in the directives, which is applied to disabled vulnerable consumers, cannot be changed by applying the relevant provisions of the Convention on the Rights of Persons with Disabilities, as individuals cannot invoke the direct effects of its provisions[40]. Therefore, one should conclude that disabled consumers may experience a lack of adequate protection of their legal status due to the gap that exists between the state of their identity, which differs from that of the rest of the society, and the external legal environment, which gap cannot – as the law stands now – be bridged by the concept of individual vulnerability, developed by (typical of) EU law. The formation of a desired standard might help in the coexistence of the purpose of protection of particularly vulnerable consumer groups and the purposes guaranteeing an efficient functioning of the internal market in the EU.

Concluding the above reflections, one should state that neither EU law nor ECtHR case law meets the requirements necessary to accord protection to disabled persons as a vulnerable group. Even though the issues relating to the situation of disabled people are an important area of human rights law and ECtHR case law does distinguish the needs of this group of people, stressing the importance of 'inherent difficulties' in everyday life, rather than indicating positive solutions having the nature of positive obligations of the state, may only intensify the group's maginalisation. At the level of EU law, the concept of a vulnerable group whose members are disabled people remains linked with the role played by these people on the internal market. Nevertheless, lack of binding definitions of both 'vulnerable group' and 'disabled people' does not help in determining – at the level of case law – to what extent the enhanced standard of protection for these people should be introduced.

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[39] I. Barral-Vinals, Freedom of contract, unequal bargaining power and consumer law on unconscionability [in:] M. Kenny, J. Devenney, L. O'Mahony [eds.] Unconscionability in European Private Financial Transactions, Cambridge 2010, pp. 46-61.

[40] CJEU judgment of 18 March 2014, in case *Z v. A Government Department and The Board of management of a community school*, C-363/12, para. 90.

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Providing Effective Communication Access for Deaf People: An Insider's Perspective

Abstract: By way of narrative, the Author outlines decades of discrimination based on his deafness by providing his insider's perspective as a member of the Deaf community who experienced the lack of effective communication access in various settings. He proposes a number of concrete steps to combat disability-based discrimination, including the provision of funding for auxiliary aids and services.

Keywords: deafness, accessibility, effective communication access, disability-based discrimination, funding

Night fell at Kennedy Airport in New York. A full moon shone on the dark waters of the Atlantic Ocean, shimmering on the sea like a line of diamonds extending far into the darkness. An Eastern Airlines Whisperjet rolled onto the runway, turned, and stopped. "Eastern 233, cleared for takeoff," crackled a voice in the pilot's headset, and as the pilot eased the throttle forward, the engines growled to life. Lurching forward and picking up speed, the Whisperjet raced past the twinkling blue lights outlining the three-mile long runway at Kennedy. Engines humming at full power, the jet reached "V" speed – the takeoff speed – and gently coaxed by the pilot, the nose of the plane rose up. With a whispery sigh, the jet soared into the air, tucked in its wheels, and banked left over the moonlit sea.

This passage is a distillation of a story that played a critical role in my development as a deaf child in a "mainstream" environment.[1] Born profoundly deaf to two educated

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[1] This essay acknowledges my debt to African American women scholars who have asserted the primacy of narrative as a tool of analysis worthy of respect on an equal basis with more mainstream scholarly articles. CITE. By telling stories that underscore the points I wish to make about growing up deaf prior to the enactment of the Americans with Disabilities Act, 42 U.S.C. § 12.180 et seq., and the Individuals with Disabilities Education Act, CITE, I continue in that vein

white-collar professionals with typical hearing,[2] I graduated college in 1975, the year Congress passed the Education of All Handicapped Children's Act.[3] Despite growing up without a law that mandated my inclusion, I was mainstreamed in public schools, and did not know sign language. The only deaf child in a classroom full of hearing children and adults with no access to visual language,[4] communication in school from kindergarten to college was a challenge. I was forced to fend for myself. Around the fifth or sixth grade in an elementary school in New Rochelle, New York, I started to write a story of a plane taking off from an airport at night.[5] Sitting in the back of the classroom, I rewrote draft after draft of the story. In this process, I embellished the details, indulging in a sweet fantasy that helped me cope with being deaf in an all-aural environment.[6]

I derived two benefits from this work. First, I imagine the teacher thought, "What a sweet student that little Mikey Schwartz is, he's taking notes." Writing kept her at bay.[7] In fact, during my entire academic career, no teacher except one ever

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of literary production. CITE. "Mainstream" was an old term for "inclusion" where the child with a disability was included in the classroom. Eastern Air Lines was a prominent air carrier during my childhood (https://en.wikipedia.org/wiki/Eastern_Air_Lines), and one of my first flights was on an Eastern Whisperjet Boeing 727 from New York's La Guardia Airport to Montreal, Canada. These early flights spurred my fascination with aviation.

[2] 90% of deaf children are born to parents with typical hearing who do not know sign language and are unfamiliar with deaf culture. CITE. I was in this cohort with 105 dB loss in one ear and 95 dB loss in the other ear. My father was a professor of group work at Columbia University School of Social Work, and my mother was a school social worker in the White Plains, NY, school district. Although they did not sign, they understood the importance of creating a sense of belonging, not just inclusion. This essay is dedicated to their memory.

[3] Education of All Handicapped Children Act, CITE. Ultimately renamed Individuals with Disabilities in Education Act (IDEA), the mainstreaming law required school districts to educate children with disabilities along with children who were not disabled. CITE.

[4] Today visual language is possible through CART, an acronym for computer-aided real-time transcription. CITE. A court reporter or stenographer uses shorthand software to convert spoken dialogue into real-time captioning projected on a laptop or wall screen. CITE. The latter is an example of universal design, a product available to all viewers, not just deaf ones. CITE. CART was non-existent during my youth, and as I did not sign, a sign language interpreter – a rarity in mid-20th century America – would have been useless.

[5] My father traveled often as a consultant, and his departure airport was Idlewild, precursor of Kennedy International Airport. The sweet smell of jet fuel suffusing the air and the graceful four-engine Boeing 707s swooping in and out wove a magical world for me. It was the stuff of fantasy indulged in long class hours where I had no idea what the teacher and the children were saying.

[6] This writing took place in pre-computer America where the pen and the pad ruled supreme. While communication access at school was problematic, I had access at home with my parents and my older brother completely accessible to me. We communicated through speech and lip-reading.

[7] In a sense, the act of writing cloaked me like a Romulan Bird of Prey. *See* http://www.startrek.com/database_article/cloaking-device.

called on me.[8] Even my law school professors did not call on me. They were as afraid of me, as I of them.

Second, the constant rewriting and editing of my story honed my English writing skills.[9] The story offered many angles to explore: pilots engaged in radio chatter with the control tower; the dark cockpit illuminated by the glow of the instrument panel's colored lights; flight attendants battening down the hatches for take off; passengers in quiet anticipation of flight; ground crews, waving orange swizzle sticks and bustling around the planes like ants on the march; planes on the tarmac, red and blue strobe lights flashing rhythmically in the night. I learned to describe action, using active verbs, create images and dialogue, and add color, all in an effort to move the story forward.

Writing was my self-assigned reasonable accommodation.[10] Since I had no effective access to communication in class, my writing created the conditions that rationalized my presence in the classroom. It enabled me to "pass" as a hearing member of the class – I knew where privilege lay.[11]

The aural environment of my youth was not accessible. American television programs like *The Andy Griffith Show, The Many Loves of Dobie Gillis, Leave it to Beaver, Gilligan's Island, I Dream of Jeannie, Bewitched, The Beverly Hillbillies, The Ed Sullivan Show,* and my favorite, *Combat* – none of them were captioned for deaf and hard of hearing viewers.[12] Hollywood movies were no better – *Deliverance, Psycho, 2001: A Space Odyssey, Bonnie and Clyde, A Clockwork Orange, The Graduate, Midnight Cowboy* – none were captioned.[13] Access to live theater dialogue was non-existent. The telephone was of no use.[14]

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[8] Mr. Pahle, my "special education" teacher in second grade, was an exception.

[9] Certainly, the story prefacing this essay reflects a maturity and sophistication I did not possess in sixth grade, but oddly enough, the process in creating this story as an adult replicated exactly the same process I used to create the story in my youth: slaving over every word, rewriting over and over until I was satisfied with the piece. Flaubert of *Madam Bovary* fame who would spend an entire day on one sentence would chuckle knowingly. CITE

[10] CITE to the ADA.

[11] *See* A.S. Wilensky, *Passing for Normal: A Memoir of Compulsion,* Broadway Books, NY (2000).

[12] The American publication, *TV Guide,* provided network program listings where the brief description of the show's plot helped me follow the action. *See* https://www.tvguide.com.

[13] It helped to read reviews of movies before deciding what to see. For instance, I read Anthony Burgess's 1962 novel, *A Clockwork Orange*, which helped me follow the movie without captions.

[14] Ironically, Alexander Graham Bell obtained the first U.S. patent on a telephone in an effort to provide his deaf wife with a means of communication. http://www.elon.edu/e-web/predictions/150/1870.xhtml. It was not until the invention of the teletypewriter (TTY) in YEAR using old Western Union machines enabling deaf people to communicate with each other over the telephone lines. CITE. A national telephone relay system did not come into existence until the passage of Title IV of the Americans with Disabilities Act of 1990, mandating the establishment of a 24/7/365 system enabling deaf and hearing people to communicate with each other at any time during the week. CITE.

The lack of a communication accessible landscape in the Fifties and Sixties was not only physical. It was attitudinal. It was the era of 'no thought' given to disability, and when disability asserted itself in the form of a demand or request for accommodation, the response was one of shocked disdain at the effrontery of the disabled person to even politely ask for equality and inclusion.[15] I recall applying for undergraduate admission to Harvard University in the early 1970s and being asked by an incredulous admissions interviewer, "Why do you think as a deaf person that you'll do well at Harvard?" I can still see him looking at me quizzically, seemingly under the impression that a deaf person could not handle the rigors of a Harvard education.

The struggle against racial discrimination in America and the war in Vietnam during the Sixties and Seventies spurred the rise of the disability rights movement in the United States.[16] Agitation for disability rights led to Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.[17] These laws promised radical change in the lives of people with disabilities in the United States, and undoubtedly Section 504 and the ADA have facilitated some progress toward a fairer and more inclusive America.[18]

However, when it comes to effective communication access in the various contexts of American life (*e.g.*, employment, justice, education, health care, market relations), significant gaps in stakeholder compliance with the law remain.[19] From my perch as supervising attorney and director of the Disability Rights Clinic at Syracuse University College of Law and identifying as a full-fledged member of the Deaf community in the United States, I have seen widespread non-compliance with the ADA's legal mandate to provide effective communication access.[20] Of particular

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[15] For greater insight into the struggles by people with disabilities to counter bigotry based on disability discrimination, see the work of Bill Peace. CITE.

[16] CITE.

[17] CITE.

[18] CITE.

[19] CITE to numerous DOJ settlements regarding interpreters. DOJ enforcement doesn't appear to be making a dent in America's non-compliance with the law. An area for qualitative research. By social relations, I mean interpersonal interactions, and by market relations, I mean access to private businesses selling goods and services to the general public.

[20] CITE Title III of the ADA. For more information about my work at the Disability Rights Clinic, *see* http://law.syr.edu/academics/clinical-experiential/clinical-legal-education/disability-rights-clinic/. As a Deaf director and supervising attorney of a disability law clinic, I grapple with the application of the law of effective communication access in these contexts. My clinic handles disability-based discrimination in employment (ADA Title I), access to government services like the courts and penal institutions (ADA Title II), and access to private businesses selling goods and services to the public (ADA Title III). The clinic also works with families whose children require special education services in the public schools under the Individuals with Disabilities Education Act (CITE). This work has enlightened me to the extent and depth of the lack of

note are law firms and courts whose compliance with the ADA leaves something to be desired.

Four stories illuminate the problem of non-compliance in the legal profession. In 1992, two years after the enactment of the ADA when the statute became effective, I applied to 135 law firms in New York City.[21] My resume included my 1981 graduation from New York University School of Law and stints as a law clerk for District Judge Vincent L. Broderick of the United States District Court for the Southern District of New York; an Assistant District Attorney in the New York County District Attorney's Office; and a Trial Attorney in the Civil Rights Division of the United States Department of Justice in Washington, D.C.

One would think that record would have generated an interview. I did not get a single invitation, let alone an interview. Why? In the interest of transparency and honesty, I inserted in my cover letter the fact I was deaf.

My suspicion of disability-based discrimination by these firms was confirmed two years later when I applied to a private law firm in Greenwich Village, New York. This time I added to my resume a stint as an Assistant Attorney General in the Civil Rights Bureau of the New York State Department of Law and an LL.M. degree from Columbia University Law School. This time I did not mention my being deaf. I immediately received an invitation to interview for an opening in the firm.

I showed up at the firm's office, and when the senior partner came out to greet me, I told him I was deaf and read lips. He was clearly shocked, mouth agape. Without a word, he led me into his office, sat down at his desk, picked up the telephone, and turned around in his chair with his back to me. Whether he was receiving a telephone call or making one, I do not know. After twenty minutes of twiddling my fingers, I saw the partner hang up the phone and turn to me. What happened next was a punch to the gut: "I'm sorry, we have no openings." He got up, walked me to his door, and bid me goodbye.

Fast forward to the early 2000s. Now a law professor at Syracuse University, I had the opportunity to participate in the annual meetings of the Association of American Law Schools ("AALS").[22] In order to participate in these meetings, I requested the provision of CART (computer-aided real-time transcription) and a team of two sign language interpreters.[23] CART enables me to read the dialogue

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effective communication access for deaf people – despite the legal requirement to provide this access at no charge to the deaf person, compliance remains low.

[21] Although President George H.W. Bush signed the ADA in 1990, key provisions of the law did not go into effect until 1992. CITE to the ADA. Of the 135 firms, one third were large firms, one third medium-sized, and one third smaller firms. I picked them for their work in areas of law that were of interest to me.

[22] *See* https://www.aals.org.

[23] When an interpreting assignment goes over one hour, custom requires two interpreters because one person's effectiveness decreases after one hour without relief from a second interpreter. *See*

on either a laptop screen or a wall mounted screen; the interpreters enable me to ask questions and make comments. However, when I arrived at the conference in San Diego, I ran into difficulties in obtaining effective communication access at the conference. One incident crystallized the AALS's attitude toward accessibility: it denied my interpreter's entry at a luncheon because her name was not on the list of invited guests. I pointed out that I could not participate in the conversation at my table if I didn't have an interpreter with me. After a few minutes of embarrassing argument with other law professors looking on, the AALS reluctantly agreed to let my interpreter sit at my table. My request for full coverage – not only official events but also non-official events like networking and meals – was rejected.[24]

Even today the AALS maintains it will not cover networking and meals.[25] I told the AALS that the conference started when the attendees came downstairs at the start of the day for breakfast and ended when they went upstairs to their rooms in the evenings. In between "AALS-sponsored events" are the many interactions between law professors – an opportunity to network and develop professional relationships, which is a raison d'etre of the AALS conferences. But the AALS will provide interpreters only at its sponsored events. This reading of the law is a restricted interpretation of the ADA. Do only what is minimally required.

Finally, but not least, was my treatment in the Civil Court of the City of New York. While living in Rochester, New York, I attended a performance of *Stomp* in the East Village, Manhattan, where a performer swept debris and dust from the stage in my face. I filed suit for assault in the New York City Civil Court since that court had jurisdiction over the theater company that staged the show. But every time I traveled from Rochester to Manhattan for the legal proceedings, the judge failed to arrange sign language interpreters, necessitating another postponement. The court's non-compliance with the ADA constituted a drain on my financial resources, and I was forced to drop the lawsuit.

I am not alone. The deaf clients of the Disability Rights Clinic tell stories of being denied effective communication access in the workplace, the courtroom, the stationhouse, the classroom, lawyers' offices, physicians' practices, and financial institutions like banks and insurance companies. A common refrain is, "We don't provide sign language interpreters. Bring your own."[26]

The problem of denial is compounded by the strenuous effort a Deaf plaintiff must invest in seeking justice. Even if a Deaf person understood their legal right

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www.rid.org.

[24] Clearly the AALS was worried about the cost of providing disability-related accommodation. Instead of seeing me as an opportunity to develop a progressive, pro-active system for accommodation, they pinched pennies in a cost-benefit analysis.

[25] *See* https://www.aals.org/clinical2018/accessibility/. Here, the AALS states that sign language interpreters are available for "AALS-sponsored events only."

[26] CITE the ADA Titles I through III. Explain what each title stands for.

to a remedy for an ADA violation, obtaining counsel to pursue the grievance is a challenge in of itself because many lawyers are reluctant to provide interpreters in their private offices.[27]

The collective experience of the Deaf community of which I am a part suggests a pattern of non-compliance that violates the spirit and the letter of the ADA. The problem of access to justice in the United States merits closer examination.

What should we do?

First is to recognize the motivation behind the reluctance to pay for sign language interpreters and CART is financial. It belies an attitude that devalues disability. "But for the grace of God go I." "Better dead than disabled." When something is devalued, people don't want to spend money on it.

Second is to conceptualize and execute a qualitative research project designed to develop a nuanced and complex picture of the problem of effective communication access for the Deaf community. The narratives of Deaf people who have been denied a sign language interpreter or CART justify taking the problem seriously and enacting significant law reform to address it.

Third is to think about Congressional legislation that would address the problem. One approach might mimic the Internal Revenue Service's requirement that we all file an income tax return. Likewise every entity covered by the ADA – from employers to local/state government services to private businesses – would be required to file a statement certifying effective compliance with the law, including an outline of specific steps the entity has taken, or will be taking, to ensure compliance. If a person with disability files a grievance alleging non-compliance, the entity would need to demonstrate compliance and failing that, to adopt policies and practices that promote inclusion and pay a fine commensurate with the degree of the offense. The advantage of this scheme is two-fold. One, it shifts the burden of proving non-compliance from the person with a disability to the entity. Given the rate of poverty in the community of people with disabilities, the burden is best placed on those who can afford to contest the allegation of noncompliance.[28] Two, the fines can be used to provide effective communication access, including sign language interpreters and CART.

Congress could also create a funding model akin to Title IV of the ADA where the federal government through the Federal Communications Commission collects a tiny fee from every person's telephone bill for the purpose of establishing a national telephone relay system enabling deaf and hard of hearing callers to communicate with people with typical hearing.[29] A dollar from everyone's tax return could establish

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[27] *See* https://www.ada.gov/tirone.htm.

[28] CITE to statistics showing the poverty rate for people with disabilities.

[29] CITE to Title IV of the ADA.

a fund supporting compliance with the law. Entities that need to provide appropriate auxiliary aids and services can apply for some financial relief.

While law cannot guarantee what a culture is not willing to give,[30] law can regulate human behavior by removing the financial incentive to deny Deaf people access to sign language interpreters and CART because of the cost of the accommodations. A counter-incentive is an ironclad funding stream to reduce or eliminate the desire to avoid spending money on accommodating Deaf people. Thus, Congress needs to pass legislation based on one of the above models or a hybrid where the burden of compliance is shifted from the Deaf person to the provider of communication access and simultaneously provides funding.

America's track record in providing effective communication access for the Deaf community needs improvement. Congress clearly needs to act.

By the way, today I no longer rewrite and edit a story about a plane taking off from an airport at night. I don't need to do so. I have my pilot's license earned in the cockpit of a Cessna 172 where I "have slipped the surly bonds of earth and danced the skies on laughter-silvered wings."[31]

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[30] CITE to the intro quote to Mary Johnson's book, Make Them Go Away.

[31] CITE to John Magee's poem, "High Flight" Magee was a pilot for the Royal Air Force of the United Kingdom who was killed in an accident during World War II. CITE.

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Autism as a Disability (from the Lawyer's Perspective)

Abstract: Autism is a complex neurological disorder, one of the most important developmental disorders. The life and functioning of a person with the autism spectrum is very complex and difficult, and the psychological burden of the whole family is very high. The clinical picture is very complicated and its origins are unknown. People with autism differ from each other in both the level of intelligence and the extent of the disorder. Scientific research has proven that despite the similarities among people with autism spectrum there are huge differences between these people. Autism as a pervasive development disorder was introduced in Polish law on 01/01/2010 – marked with the symbol 12-C. Disability in Polish law does not have one universally applicable definition. The large number and variety of legal acts concerning people with disabilities causes information chaos, making it difficult to identify instruments for the effective enforcement of such rights. Autism as a pervasive developmental disorder disturbing the functioning of the whole organism to a large extent, is a severe disability. Specialists diagnosing the disease in most cases include it in the deepest, i.e. significant degree of disability.
Keywords: autism, autism spectrum disorder, discrimination, disability, holistic development disorder, statute, charter of disabled people rights, EU, WHO, developmental disorders.

The term "autism" is derived from the Greek word *"autos"* meaning "alone". It was used for the first time by a Swiss psychiatrist Eugen Bleuler, who in 1911 described schizophrenia as a disease entity including the closure in their own world and relaxing the discipline of logical thinking among its axial symptoms. However, this was not the first case of describing children closeted in "their own world". In old fairy tales, myths and legends, information about children developing properly, but later being changed or taken away by a fairy can be found. In folk predictions, there have been examples of children not interacting with people and not afraid of any dangers[1].

Despite the 75-year history of scientific struggles, autism is a disorder that implies a number of doubts and questions, prompting to continually search for undisclosed answers. The complexity of issues experienced by people with autism spectrum disorder and their family members motivate many specialists: researchers and practitioners to help improve the quality of life of these people and their families. Currently, science provides knowledge on the causes of the disorder and its mechanisms, as well as on the treatment methods, whereas care and hope allow us to change the reality of people with autism spectrum disorder, creating conditions for a life with dignity.

For many years, the understanding and social approach to the disabled person and their place in society have changed – from exclusion, stigma, through tolerance, acceptance and inclusion. Broadly understood equality, emancipation is the pursuit of social equality according to the needs and abilities of each person. It should be emphasized that it is also an idea of recognizing the rights of people who are excluded due to their otherness, differences in behavior, possibilities of functioning and performing various social roles.

1. What is autism?

In 1994, autism was classified as pervasive developmental disorders category (12-C). Every person with this disorder differs individually; therefore the location of autism among other diseases was subject to constant change. By contrast, in 2010, the 12-C code was introduced in Polish jurisprudence. Until now, people with autism have been obtaining the code indicating a disability e.g. due to neurological defects or mental illness. The introduction of the code will help to estimate the number of births of people with autism in Poland, but it can only happen in a few years[2]. The continuous lack of computerization of the disability certification system is another obstacle, which prevents the creation of nationwide databases allowing for realistic measuring of the number of certificates mentioning autism and for creating lists, for example, for individual regions[3].

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[1] L. Bobkowicz-Lewartowska, Autyzm dziecięcy-zagadnienia diagnozy i terapii, Kraków 2011, p. 11.

[2] It applies to the earliest possible diagnosis of a child. It is now possible to diagnose a child at the age of 16-30 months, which accelerates the effective rehabilitation of those with autism spectrum disorders.

[3] Data on autism, the Fundacja Synapsis website: http://www.synapsis.org.pl/autyzm/skala (access 4.10.2018).

It should be remembered that comorbidities occur in more than 75% of people with ASD (Autism Spectrum Disorder) and are one of the most important aspects of the diagnosis. However, the diagnosis of ASD is not a complete picture. Autism spectrum often occurs with intellectual disability, ADHD, oppositional defiant disorder (ODD), anxiety disorders, depression, tics, etc. and other disorders such as gastrointestinal ones or sleep related. In contrast, in adults bipolar disorder and schizophrenia coexist[4].

It should be emphasized that early diagnosis of a child with autism should be the first step in therapy, rehabilitation, education and in adult life. The Synapsis Foundation has launched a nationwide screening program for autism. The Polish version of the diagnosis tool for children between the ages of 16 and 30 months[5]. The duration of the "Badabada" Early Autism Detection Program was planned for a period of 5 years. Its aim is to introduce and disseminate procedures, standards and tools that allow to monitor the child's development in the first years of life, to capture symptoms from the autism spectrum (ASD) or ASD risk at the stage of their manifestation. The Synapsis Foundation expects the Program to reduce the degree of disability caused by ASD disorders through rapid intervention in the early stages of disorders, and therefore wants to aim for a possibly large group of children (at least half the population above 1 year of age) to be screened as part of routine care activities (nurseries, pediatric clinics, POZ). After performing both diagnostic activities, parents will receive written information about the degree of ASD risk or determine the child's atypical behavior and the further steps they should take. The program is to be piloted in selected institutions, and ultimately all over in Poland.

The diagnosis of autism in a child affects each family in a different way. Parents must focus on helping the child with autism spectrum, and devote less attention to the issues of marriage, other children, work, finances or personal relationships and responsibilities. These families may face many challenges and stress factors that affect their children's development, cohesion and quality of life. Important factors that affect families are the availability of an appropriate support and advisory system, as well as cooperation with professionals focused on developing common goals. It should be noted that people professionally involved in this issue participate in the training of

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[4] M. Fitzgerald (Department of Psychiatry, Holy Trinity College in Dublin, at the International Scientific Conference, Focus on Autism, Kraków 2018, p. 41) emphasizes that people with ASD: are commonly prescribed with drugs such as: Ritalin, Risperidone, Melatonin and antidepressants - especially in connection with the progressive age of the patient. Sometimes, instead of the diagnosis of ASD, there is a diagnosis of a coexisting disorder, which has serious consequences for treatment and quality of life. The range of these comorbidities may vary depending on the problem: with ADHD 25-50%; epilepsy 7-30%; sleep disorder 80%; intellectual disability 54%; obsessive-compulsive disorder 8-37%; anxiety disorder 10-60%; tics 11-22%; depression 1-50%; oppositional and rebellious disorders 27-40%.

[5] Early detection of autism can be found on the website http://www.badabada.pl (access 21.11.2018).

people with autism spectrum, while parents generally do not use training or get little support in this regard[6]. It should be emphasized that non-governmental organizations operating throughout the country attempt to help parents by implementing all types of projects related to people with autism spectrum, *de facto* these are only consultancy measures and not long-term activities.

The dominant feature in the behavior of children with autism spectrum is the impaired ability to perceive, understand and respond appropriately to desires and intentions of others. These difficulties in social interactions or in communication help to see the issue of autism spectrum. Currently, the most attention is devoted to eye contact and face-to-face interaction, imitation skills, pretend playing, sharing attention or intentional communication. *De facto*, the earliest diagnosis of autism contributes to the start of therapy, which significantly alleviates its effects.

Autism is noise and chaos. A disorder that cannot be arranged. This is how one patient describes his condition in a book authored by Katarzyna Markiewicz[7], that results from many years of research, therapeutic and diagnostic practice. It should be emphasized that there are many more valuable publications available which concern the feelings, experiences and attempts to understand people with autism spectrum[8].

Autism is characterized by significant quantitative and qualitative disorders in communication, in the social sphere and in behavior. There is a group of autistic people who do not communicate verbally. Due to the depth of their autistic disorder, verbal language has not developed. Most often, such people are assessed as low-functioning, often they are relieved of school duty. This group of autistic people included Maciej Oksztulski – the co-author of this paper[9].

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[6] Facing a son's autism. The mother of the co-author has been working in non-governmental organizations in the city of Białystok for over twenty years, first with the National Autism Society Department [Oddział Krajowego Towarzystwa Autyzmu] and then with the "Oswoić Świat" Foundation, of which she is a co-founder and board member.

[7] K. Markiewicz, Charakterystyka zmian w rozwoju umysłowym dzieci autystycznych, Lublin 2007, p. 69. The author reviews theories and views on the issues of autism and presents the effects of her own research on changes in mental development with autistic children. A valuable part of the work is the description of individual case studies. The book also indicates guidelines for improving the development of autistic children or the characteristics of changes in their mental development.

[8] E.g. . Shore, Za ścianą. Osobiste doświadczenia z autyzmem i zespołem Aspergera. Warszawa 2008.; J. Copeland, Z miłości do Ani, Warszawa 1995; D. Zoller, Gdybym mógł z wami rozmawiać… . Warszawa 1994.; R. Kawa, Wypalenie zawodowe a jakość życia terapeutów pracujących indywidualnie z osobami z autyzmem. Dziecko Autystyczne, Warszawa 2010, vol. XVIII no. ½, pp. 119 – 125.

[9] He is the only autistic not speaking person in Poland, who (in 2015) obtained a master's degree in law at the Faculty of Law at the University of Bialystok, full-time studies. In 2017 he completed a research internship in the United States at Syracuse University College of Law, during which he obtained the necessary data to analyze the American legal standard in the education of people with autism.

Autism is more and more often referred to as a civilization disease, as the number of people affected by it increases from year to year. The national data are still changing, but it is estimated that the number of autistic people is in its tens of thousands, although there is no data on the distinction between the number of children and the number of adults. In the near future, autism, along with cancer, AIDS and diabetes will be one of the most serious problems affecting human health. The clinical picture of autism spectrum is very complex and the reasons for its formation are essentially unknown. On the one hand, people with autism differ with respect to the level of intelligence, on the other hand – to the extent and depth of the disorder. Scientific research has proven that, despite the presence of similarities in autistic people, there are huge differences between them[10].

Currently, people affected by autism can benefit from learning in special, integrational and public schools. They are attended not only by higher-functioning children, but also by people causing more educational problems. Pursuant to the Act of 7 September 1991 on the education system: *A child with autism or pervasive developmental disorders may fulfill the school obligation in a public school, an integration school, an integration ward, a special school in a special ward and other alternative forms permitted by Polish law*. It all depends on how soon after the diagnosis the decision about early treatment and education will be made. On the one hand – thanks to this in the future, the child will find a place in the school world faster, but on the other hand – intensive work with them should be introduced from the moment he/she is diagnosed to the time he/she goes to school. Naturally, everything is based on the opinion on need for early support of the child's development or on the basis of the decision on need for special education, if the child starts learning in a pre-school group[11]. According to the above-mentioned act, people with autism find their place in pre-school and school education as due to the high cost of education they benefit from the conversion factor of 9.5, which is the highest in the disability scale, due to the special nature of the disability. Thus, there is a significant improvement in the education of children with autism. It should be noted that the autistic child of pre-school age is not able to make contact with their peers, they isolate themselves. They are hyperactive, they follow their own patterns, and any reaction of the environment can trigger aggression. The autistic child has great difficulty communicating, cannot play with their peers, they are not attractive to them. They are also unattractive to their peers. They often get angry, aggression and auto-aggression occur. During the school period there are still communication disorders, behavioral difficulties and other behaviors "stereotypical" for individual units[12]. Many autistic children of this age reveal their talent in some field, for example: mathematics, art, music, or learning

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[10] J. Bluestone, Materia autyzmu. Łączenie wątków w spójną teorię, Warszawa 2012, p. 1.

[11] Rozporządzenie z dnia 4 kwietnia 2005 r., „Monitor Polski", No. 68, item 587.

[12] L. Bobkowicz-Lenartowska, Autyzm dziecięcy… *op. cit.*, pp. 18 - 19, 23, 51 - 57, 64 - 67.

foreign languages. Unfortunately, the ability to think abstractly, understand the context of conversation, or intonation is disturbed. The big problem is the lack of contact with peers. They are often misunderstood, ridiculed, unable to communicate with them[13]. They go "in their own ways", often trying to get close contact with teachers. They do not perceive their differences. They are disturbed by the noise at school, constant changes. Much depends on the conditions that the school can provide. According to Gałka and Pęczkowska[14], emphasis should be placed on: getting a wide knowledge on autism, organizing the school environment, elimination of excess sensory stimuli, cooperation with institutions, conducting a child's therapy, creating an individual education program, revalidation classes and constant contact and cooperation with parents. It is from them that teachers get the most information about the child. If the autistic student graduates high school and passes the matriculation exam – there is a chance for them to take up studies.

Students from the autism spectrum may experience certain difficulties. Most often here are: difficulties in contact with other students and teachers, poor understanding of social code contained in body language and social symbolism (hence frequent maladjustment to the situation, perceived by the surrounding "otherness" in dealing with others, such as excessive seriousness, eccentricity, social naivety, childishness, ineptitude in performing typical social roles, etc.), feeling fear in social situations, especially during a conversation, inability to conduct dialogue and cooperation, one-sidedness of social behavior, e.g. a tendency to monologue, not to let others speak or, on the contrary, only to listen in silence, as well as the need to maintain a certain routine in their behavior, or resistance to change and dramatic experience of sudden unexpected changes, poor organizational skills, easy distractions, the need for a concrete and logical consequence in everything, literal understanding of phrases and texts, non-differentiation between relevant issues and non-essentials, or meticulousness, excessive focusing on details, excessive perfectionism, as well as low resistance to stress and triggering regressive behaviors in difficult situations[15].

The counterweight to these difficulties are individual features that can help at studying, and sometimes even allow to gain an advantage over other students. In fact, these include the excellent memory capacities often found in this group, including the capacity and durability of memorized facts and structural elements. If they are motivated, they can quickly master new areas of knowledge, from different often

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[13] J. Błeszyński, Rodzina jako środowisko osób z autyzmem, Toruń 2005, pp. 100, 129 - 133.

[14] U. Gałka, E. Pęczkowska, Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu, Centrum Metodyczne Pomocy Psychologiczno – Pedagogicznej, Warszawa 2009.

[15] See more: R. Stefańska - Klark, Zespól Aspergera – nienormalność, wysoce oryginalna odmienność czy po prostu ekstremalny wyraz w zakresie pewnych różnic indywidualnych?, [in:] Żyć wspólnie: odkrywać Innego, przeciwdziałać zniewoleniu, realizować wspólne cele, Kraków 2005.

thematically distant areas, and attach them to that already possessed, which makes them "walking encyclopedias". Although, at least at the beginning, this knowledge may not be easily analyzed or reflected, giving the impression of a mere ballast, the gradual mastering of mental methodologies makes these students admirable experts, sometimes interdisciplinary[16]. Their legal status is determined by legal standards of disability. The Ministry of Science and Higher Education emphasizes that "(...) the recipients of legislative actions are all people with autism spectrum disorders with a certified disability, who are not distinguished from the group of disabled people. Therefore, in the current legal state, the adjustment of the assistance to the needs of certain students with autism spectrum disorders remains within the autonomy of the university"[17].

The Act on Vocational and Social Rehabilitation and Employment of People with Disabilities[18] aims to compensate for the differences in chances on the labor market arising from disability. However, the employment rate of persons with autism remains at a very low level, and their income from work, even if supported by retirement or care benefits, often places these people in marginalized positions.

The mental barrier of the Polish society does not allow people with autism spectrum disorders to find their place in the labor market, despite the huge amounts of EU funds (e.g. in the Regional Operational Program of the Podlaskie Voivodship for 2014-2020 [*Regionalny Program Operacyjny Województwa Podlaskiego na lata 2014-2020*] within Axis VII *Improving social cohesion, Measure 7.1. Active development integration* [*Oś VII Poprawa spójności społecznej, Działanie 7.1. Rozwój aktywnej integracji*] are directed at professional activation, including job creation in social enterprises for the excluded and supporting social entrepreneurship (under Measure 7.3 *Strengthening the role of the social economy in socio-economic development of the Podlaskie Voivodship* [*Działanie 7.3 Wzmocnienie roli ekonomii społecznej w rozwoju społeczno-gospodarczym województwa podlaskiego*])[19]. The measures of the operational programs implementing the EU funds are *ad hoc*, and meaningfully they can be implemented usually by non-governmental organizations[20].

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[16] Studenci z autyzmem i Zespołem Aspergera, available online on: https://www.researchgate.net/publication/322021685_Studenci_z_autyzmem_i_zespolem_Aspergera_Funkcjonowanie_przyczyny_sukcesow_i_porazek_warunki_skutecznego_wspierania (access 5.10.2018).

[17] Response to the interpellation no. 1768 regarding the students and PhD students with autism, dated 29 March 2016, of the Secretary of State in the Ministry of Science and Higher Education Aleksander Bobko.

[18] Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnieniu osób niepełnosprawnych (Dz. U. 2008, No. 123, item 776).

[19] See more: Oksztulski M., Prawo do pracy osób z niepełnosprawnością – autyzmem w prawie i praktyce (na przykładzie województwa podlaskiego), MA thesis supervised by prof. Maciej Perkowski, Wydział Prawa Uniwersytetu w Białymstoku, Białystok 2015, pp. 85 – 87.

[20] One such example is the Fundacja Wspólnota Nadziei, which in the period January 2010 - December 2011, implemented the European Social Fund project under the Human Capital

Counteracting social exclusion of people from marginalized groups is one of the important elements of our joint responsibility for social issues. The idea can be realized by employers' support in employing people with autism, it can bring tangible benefits (not only an image value) to the employer. The participation of a person with autism at work in any institution or company teaches all greater sensitivity and empathy, openness and attitude of kindness and acceptance for others; teaches how to draw experience, knowledge and ideas from diversity. It is a prerequisite for balanced social development, affects the personal development of colleagues and deepens understanding of interpersonal relationships, helps to get rid of many fears and frees people from thinking in terms of stereotypes about other people. Thanks to such experiences, social inclusion of people with disabilities, including the autism spectrum, has a chance to become a natural and real process.

2. Law and autism as a disability

People with reduced sensory or intellectual efficiency or reduced functional capacity are classified as people with disabilities. This category includes people with reduced communication, mobility, psychophysical skills or people with cerebral palsy. Autistic people are usually sensory, often intellectually disabled, with reduced social functionality and communication skills. Since 1996, the National Health Fund [*Narodowy Fundusz Zdrowia*] has used the classification of the World Health Organization (WHO), where autism, as a disease entity, has the symbols F84 (F84.0 to F84.9)[21]. It is worth pointing out that according to the WHO: *A disabled person is a person whose impairment and lowering in the body's functioning efficiency make social functioning impossible, difficult or limiting, taking into account such factors as gender, age and external factors*[22].

In the European Union, the rights of persons with disabilities are defined differently in the various Member States. It should be emphasized that highly developed countries have legal provisions directly concerning autistic people, while countries with weaker economic condition are based on provisions referring in general to disability. On the other hand, the countries in which the aid was not sufficiently comprehensive and effective have introduced legal regulations which

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Program - measure 7.2.1, project. Support for employment of adults with autism (the project covered 60 people from the autism spectrum from the Małopolska province).

[21] Zał. Nr 6 do zarządzenia Nr 65/2007/DSOZ, Prezesa NFZ z dnia 20 września 2007 r. w sprawie określania warunków zawierania umów (Dz. U. No. 210, item 2135, with amendments).

[22] The WHO definition of disability, available on: http//www.bon.edu.pl/budw/-menu_glowne (access 6.10.2018).

separately refer to the problems of people with autism – taking into account the specificity of disability caused by autism[23].

In European Union law: Council Directive 2000/78/EC of 27.11.2000 establishes a general framework for equal treatment in employment and occupation[24]. It is implemented by the judgment of the Court of 11.07.2006 in the case of Sonia Chacón Navas against Eurest Colectividades SA[25], defining disability as a limitation, resulting specifically from a physical, mental or psychological dysfunction, constituting an obstacle for a person to participate in professional life. The Court also emphasizes that to fall within the concept of disability, it must be likely to be long-term. As a result, a person with whom an employer terminates a contract of employment solely because of illness is not covered by the general framework established by Directive 2000/78 to combat discrimination based on disability.

For the identification of the legal status of autism in the European Union, Art. 5 of the Council Directive 2000/78 of 27.11.2000 is important in providing rational accommodations for people with disabilities: *In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.* It should be emphasized that the Charter of Fundamental Rights[26] in Art. 21, directly concerning people with disabilities, prohibits all kinds of discrimination. A similar provision, though more general, is in the Constitution of the Republic of Poland, in

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[23] For example: as part of the Think Autism Strategy in 2014, the UK government allocated £4.5m to the Innovation Fund for autism and the autistic-conscious community; http://www.autism.org.uk/about/strategy/2010-strategy.aspx (access on 14.10.2018), another example is Hungary, where the strategy on autism aims to improve the quality of life of people affected by autism at the stage of early selection, diagnosis, education, adult training, employment and family support (more on: F. Dell, R. Cera, Protecting the Rights of People with Autism in the Fields of Education and Employment, Springer Open). Denmark was one of the first countries in the world to open up the education system to people with disabilities, where people with autism spectrum have their place (A. Zawiślak, Organizacja kształcenia specjalnego w duńskiej szkole podstawowej, [in:] Z. Gajdzica (ed), Rozwój i funkcjonowanie osób niepełnosprawnych. Konteksty edukacyjne i prawne. Kraków 2007, p. 83.).

[24] Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation. Official Journal L 303, 02/12/2000 P. 0016 – 0022.

[25] Judgment regarding Directive 2000/78 / EC on equal treatment in the field of employment and work - Concept of disability, http://www.curia.europe.eu/juris/showPdf.jsf.jessionid=9ea7d2dc (access 14.10.2018).

[26] E., Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu, Warszawa 2009.

Art. 32, par. 2: *No one shall be discriminated against in public, social or economic life for any reason*[27]. However, Art. 26 of the Charter of Fundamental Rights states that: *The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community*. On the other hand, a very similar wording in Art. 69 of the Constitution of the Republic of Poland should be noted: *Public authorities shall provide, in accordance with statute, aid to disabled persons to ensure their subsistence, adaptation to work and social communication*. Also, Art. 32 para. 1 of the Constitution on equality of all citizens before the law should not be overlooked.

Determining the status of autism is not conducive due to the fact that there is no universally valid definition of disability in Polish law. In accordance with the Act on Vocational Rehabilitation and Employment of People with Disabilities: *Disabled persons are people whose physical, mental or mental condition permanently or periodically impedes, limits or prevents the performance of social roles, in particular resulting in inability to work*[28]. In turn, in the resolution of the Sejm of the Republic of Poland of 1.08.1997 regarding the Charter of the Rights of Disabled Persons, the notion of disability is defined as follows: *persons whose physical, psychic or mental abilities permanently or periodically obstruct, limit or prevent daily life, studying, working and performing social roles in accordance with legal norms and customs*[29].

In practice, there are two separate certifying systems confirming the disability: on the degree of disability and on incapacity to work (also there are judgments on disability to work on a farm and regulations regarding uniformed services). The disability certification is governed by the provisions of the Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities of 27 August 1997. They are based on the medical disability model, with many defects, internally contradictory, using vague, also pejorative terms; the classification of disabled person to the appropriate degree cannot be done on its basis. In the above Act, Art. 2 describes disability as: *the permanent or periodic inability to fulfil social roles due to permanent or long-term violation of the body's efficiency, in particular resulting in inability to work*. Art. 3 sets three levels of disability: significant, moderate and light. Their definitions are included in paragraph 1-3 art. 4 i.e.:

1) *the significant degree of disability applies to the person with disturbed efficiency of the body, unable to work or capable of working only in the conditions of employment and requiring, in order to perform social roles, permanent or*

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[27] Konstytucja RP z dnia 2 kwietnia 1997 r., art. 32, ust. 2 (Dz. U. 1997 No. 78, item 483).

[28] Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych (Dz. U. 2008 No. 123 item 776 with amendments).

[29] Karta praw osób niepełnosprawnych, uchwała Sejmu Rzeczpospolitej Polskiej z dnia 1 sierpnia 1997 r., art. 1 (M.P. of 1997, No. 50, item 475).

long-term care and help of other people in connection with the inability to independent existence.

2) *the moderate degree of disability applies to the person with disturbed efficiency of the body, unable to work or capable to work only in sheltered employment conditions or requiring temporary or partial assistance of other persons to perform social roles.*
3) *the light degree of disability applies to the person with disturbed body efficiency, resulting in a significantly reduced ability to perform a job compared to the capacity of a person with similar qualifications with full efficiency and physical ability, or with restrictions in the exercise of social roles that are offset with the help of orthopaedic equipment, auxiliaries or technical measures.*

In the definition of the significant degree of disability, the legislator used the term *inability to independent existence*, explaining it as *the impairment of the body to the extent not enabling to satisfy the basic needs of life without help of other people, considering primarily self-service, mobility and communication*.

According to the Act on retirement pensions and other pensions from the Social Security Fund of 17 December 1998[30], an individual who has totally or partially lost the ability to perform paid work for health reasons and is unlikely to regain the ability to work after he has been retrained shall be deemed to be an individual unable to work:

1) *An individual who has lost the ability to perform any kind of work shall be deemed to be an individual totally unable to work.*
2) *An individual who has to a significant extent lost his ability to perform work in keeping with his qualifications shall be deemed to be an individual partly unable to work.*

The judgment on complete incapacity to work *de facto* does not mean a work ban, and many of people who have obtained the judgment do work. Often, the definition of total incapacity to work misleads employers who do not want to employ persons with such a judgment. Changes in this area require the amendment of the Constitution so that art. 67 of the Constitution of the Republic of Poland guarantees persons with an appropriate degree of disability the right to social security, which should be structured in such a way as to support the maximum use of the work potential of a given person. People with profound disabilities should have the highest social security.

The nature of these wordings is pejorative and at the same time imprecise. It should be emphasized that the purpose of social and professional rehabilitation

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[30] Ustawa z dnia 17 grudnia1998 r. o emeryturach i rentach z Funduszu Ubezpieczeń Społecznych, (Dz. U. 1999, No. 162, item 1118).

is the ability of disabled people to fulfill social roles and being employed, so the legislator itself undermines the sense of the act. It should be noted that due to the development of new technologies, but also changes in the society's approach to the issue of disability, people with different types and degrees of disability now fulfill social roles that once seemed unachievable to them. According to the definition of the significant degree of disability, these people have impaired ability and are not able to function independently. The process of rehabilitation or the elimination of barriers in the environment also have an impact on the possibility of functioning in society.

It should be emphasized that the large number and diversity of legal acts concerning persons with disabilities increases public awareness in this respect, however, it causes a great deal of information chaos, in which it is difficult to identify instruments for the effective enforcement of such rights. For their real respect, it is essential to monitor the observance of these rights by both public entities and non-governmental organizations appointed for these purposes.

3. Conclusions

Pervasive developmental disorders are a group of neurodevelopmental dysfunctions significantly affecting the overall life of patients and their families. Recognized at an early age, in most cases they accompany patients suffering from them throughout their lives. They are also a significant burden for their relatives – one of the largest in psychiatry[31]. In fact, overall developmental disorders in one of the family members have a significant impact on the family life cycle and the course of its individual phases. It should be emphasized that each stage of measuring the diagnosis of overall developmental disorders confronts a clinician with different diagnostic and therapeutic challenges. Experts are expected to give advice related to specific decisions or life dilemmas. This applies to both the person with autism spectrum and the reactions of relatives to their illness; from the first suspicions of the presence of autism, through the process of reaching a diagnosis, intensive treatment, searching for miraculous therapies, reconciliation with the child's condition, their changing functioning during adolescence, adulthood challenges and finally fear of what will happen to a person with autism spectrum after the death of parents[32].

It should be strongly stated that autism as a pervasive development disorder (12-C), which disturbs the functioning of the whole organism to a large extent, is a disability. Specialists diagnosing the disease in most cases include it in the deepest,

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[31] M. Pilecki, Całościowe zaburzenia rozwoju w biegu życia, Międzynarodowa Konferencja Naukowa: Focus on Autism, Kraków, September 2018, p. 99.

[32] *Ibidem*.

i.e. significant, degree of disability[33]. Only dignity as a special value of a human being as a person remaining in interpersonal relationships justifies and gives sense to a personal life and makes the attitude towards oneself and the group from which a given person originates positive. While early diagnosis, therapy, rehabilitation and education as well as finding a place in the labor market relieve symptoms of autism.

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[33] Currently, the discussions are underway on whether autism is a disease because there are no means of treatment (medication or surgical procedures), the problem has been raised at the International Scientific Conference, Focus on Autism, Krakow 2018 – the opinions were very divided.

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Development of Law on Protection from Disability-Based Discrimination in Russia

Abstract: The article describes and analyses current law on protection from disability-based discrimination in Russia. Amendments in the national legislation were adopted in accordance with the Convention on the rights of persons with disabilities ratified in 2012. Prohibition of discrimination on the grounds of disability is included into the law. However, the development of the mechanisms of protection of the right not to be discriminated against has only just started. While a special anti-discrimination law is not yet devised, legal actors have to apply the existing legal provisions which do not cover all aspects of protection from disability-based discrimination.

Keywords: Russian law on protection of persons with disabilities, concept of disability, prohibition of disability-based discrimination, judicial practice concerning protection of rights of persons with disabilities

Introduction

Prohibition of discrimination on the grounds of disability is quite a new legal phenomenon in Russian law. Although the general principle of equality and non-discrimination[1] had been included into the national law years ago, disability as a prohibited ground of discrimination only appeared in the legislation after the ratification of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter – the Convention). The concept of disability-based

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[1] Article 19 (par. 2) of the Russian Constitution (1993) reads: *The State guarantees equality of human and civil rights and freedoms, regardless of sex, race, ethnicity, language, origin, property or official status, place of residence, religious beliefs, convictions, membership of civil society associations or other circumstances. All forms of restrictions on the citizens' rights on the ground of social, racial, national, language or religious affiliation are prohibited.*

discrimination and the corresponding field of law therefore have only recently begun taking shape within the national legal system.

Pursuant to Arts 4 and 5 of the Convention, States Parties ought to establish measures of implementation of the provisions on protection against discrimination. According to the UN Committee's interpretation,[2] such measures include the following:

- an explicit prohibition of discrimination on the basis of disability in national law;
- recognition in legislation that the denial of reasonable accommodation is a prohibited form of discrimination in all areas of law;
- an entitlement of persons with disabilities to protection under the law on an equal basis with others;
- measures to ensure effective, accessible and affordable access to remedies by persons with disabilities;
- independent mechanisms tasked with the investigation and sanction of discrimination against persons with disabilities.

Analysis of the national legislation shows the following.

1. Prohibition of discrimination on the basis of disability in law

The notion of disability-based discrimination became part of the national law after ratification of the Convention. Article 3.1 of the Federal Law *On social protection of persons with disabilities in the Russian Federation*[3] reads as follows:

In the Russian Federation, discrimination based on disability is not allowed. For the purposes of this Federal Law, discrimination on the basis of disability is understood as any distinction, exclusion or restriction due to the disability, the purpose or effect of which is to diminish or deny the recognition, realization or equal enjoyment of all human rights and freedoms guaranteed in the Russian Federation in political, economic, social, cultural, civil or any other field.

As follows from the provision, it is not allowed to discriminate (treat differently, exclude or restrict rights stipulated by the national law) on the mere ground that a person is disabled in any way. The national definition of disability actually reproduces the definition given in Art. 2 of the Convention. The wording of the provision implies that any distinction, exclusion or restriction the purpose or effect

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[2] UN Committee on the Rights of Persons with Disabilities. Guidelines on periodic reporting to the Committee on the Rights of Persons with Disabilities, including under the simplified reporting procedures, CRPD/C/3, pars 18 – 26. These guidelines are aimed at assisting States Parties to incorporate the human rights-based approach in their implementation policies.

[3] Federal Law *On social protection of persons with disabilities in the RF* (amended), dated November 24, 1995, No. 181-FZ.

of which is to diminish or deny equal recognition or exercise of human rights and freedoms stipulated both in the Constitution and the Russian legislation is not allowed. It does not leave any ground to misinterpret the prohibition to discriminate and therefore is explicit and unambiguous.

There are several points in the provision, however, that entail omission of some important ideas expressed in the Convention. Firstly, the scope of the disability notion as represented in the national law is limited compared to that in the Convention. Disability, in accordance with the above mentioned Federal Law, implies a result of an expert assessment of persistent disorders influencing a person's body functions due to illnesses, injuries or defects, and causing a limited everyday life for such person and their need for social protection measures. Actually, only a relatively serious disorder may result in the status of a disabled person (*invalid*) entailing respective social protection in accordance with the said law. Such conditions as e.g. temporary (yet serious) illnesses, mild mental or other disorders, and mild psychiatric or intellectual dysfunctions are generally outside the scope of disability. In accordance with various laws, persons in such circumstances may receive protection[4], which, however, does not match the level of protection the status of *an invalid* provides. The respective laws do not refer to the Federal Law *On social protection of persons with disabilities.* The clause '*For the purposes of this Federal Law*' deprives those persons who may have assumed (anticipated, prospective) disability of a right to claim that they were discriminated on the basis of their disability. The same concerns family members of persons with disabilities – they are not protected by this Federal Law. The scope of the prohibition of disability-based discrimination is therefore narrow and embraces only those who fall under provisions of the above mentioned Federal Law.

Secondly, a part of Art. 2 of the Convention is missing in the above said provision. The last sentence of Art. 2 '*It includes all forms of discrimination, including denial of reasonable accommodation*' was not included in the law. As all provisions of the Convention, including Art. 2, apply directly and immediately in Russia, the absence of the provision in the national law does not hinder the reference to it. However, the implementation of the Convention requires that the concept of reasonable accommodation and the relevant national legislation must be established.

2. Legislation on reasonable accommodation

While the concept of reasonable accommodation was not included in the law on social protection of persons with disabilities, practical issues are left to the discretion of executive authorities at federal, regional and municipal level (within their competence) as their general obligation to provide accessibility of services,

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[4] Federal Law *On psychiatric assistance and guarantees of its provision*; Federal Law *On social insurance in case of a temporary labor incapacity*, etc.

buildings, facilities and the whole infrastructure. Article 15 of the Act establishes the scope of this obligation including the duty to provide barrierless access, assistive facilities, and accompanying and personal assistance services. In case it is impossible to constructively adapt buildings or transport infrastructure to meet the needs of persons with disabilities, the owners of the respective objects in cooperation with organizations of persons with disabilities have to establish (devise) minimal measures of accessibility or provide services either at home or remotely, if possible.

One of the first government agencies to respond to the accessibility provisions of the Law was the Federal Ministry of Transport, which adopted a special Decree[5] with unified regulations concerning accessibility of railway transport and stations as well as services provided there. Notwithstanding a huge and old railway infrastructure, it is efficiently being transformed.

The same applies to airlines for which certain impetus was given by the judicial cases referred to below.

Provisions on accessibility have been included into the regulations of all executive agencies and instructions for public officials. However, the reference to the concept of reasonable accommodation in such regulations is scarce and not binding.

3. Access to court and remedies

While a special anti-discrimination law seems to be a distant future, Russian law does not prevent or hinder access to justice in cases of discrimination. Complaints about a person being discriminated against on grounds of their disability can be filed in accordance with the ordinary judicial civil or administrative procedure. Administrative procedure applies in cases where provisions of a normative act or a decision, action (or inaction) of a public agency (authority) or an official are adopted (made) against the principle of equality and non-discrimination as stipulated by the Constitution or specific legislation and interfere with certain individual rights. In cases where a private person or an organization exercised discriminatory actions, thus violating the respective right of a person, the civil judicial procedure applies. In both cases the applicant must prove the fact of unequal treatment and provide evidence that such treatment violated a certain individual right. In administrative cases the public agency or an official must prove that the disputed decision or action (inaction) conformed with legal requirements.

In the absence of a specific anti-discrimination legislation an applicant in most cases is left without such guarantee as the “shift of burden of proof”. Moreover, the absence of the provision that the denial of reasonable accommodation constitutes discrimination makes it complicated for the applicant to dispute the discriminatory

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[5] Decree of the Ministry of Transport. November 6, 2013, No. 329.

character of such denial and claim for remedies, even if the applicant can apply to the court pursuant to the regular civil procedure. The absence of anti-discrimination law leaves an applicant without a possibility to acquire a judgement "not to discriminate in future" and to receive a material redress. It is not therefore unusual for applicants (in cases of discrimination) to complain about a certain right violation and claim compensation for moral damages only.

Some examples from the judicial practice can illustrate the initial steps of forming the legislation on protection from disability-based discrimination.

3.1. The case of Natalya Prisetskaya (Moscow District Court, 2008)[6]

Circumstances of the case

The Applicant (a member of an NGO of persons with disabilities) was going to travel with the *S7 Sibir* airline. While buying a ticket, she duly informed the company that she used a wheelchair. On arrival at the airport she passed through check-in for the flight and underwent a security inspection in accordance with the regular procedure. She was then driven by airport assistance services to the aircraft she was to board with the help of airport assistants. While waiting for permission to go on board the aircraft at the foot of the boarding steps, she received notice from the aircraft's crew that she could not take the flight without a personal assistant accompanying her. Communication with the crew mediated by the airport assistants had no effect; the crew denied permission to board and refused to communicate with the applicant directly. Later that day, she had to buy a new ticket and flew the same route with another airline but from a different airport; Altogether she had to spend about 10 hours in the airports, travelling from one to the other and then the flight, without the possibility to take a rest. She said that the denial of boarding could not be predicted because as an NGO activist she had flown previously with other carriers without restriction. She felt discriminated against and the overall situation caused her physical suffering and emotional distress. She sought compensation for moral damages.

Applicable law

Article 15 of the Federal Law *On social protection of persons with disabilities in the RF* obliges all organizations (public and private alike) to provide access to all means of transport for persons with disabilities.

Article 310 of the Civil Code of the RF prohibits unilateral cancellation of the agreement between persons, which applies as a general rule to all types of agreements including an agreement between a customer and an airline. The Civil Code states that

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[6] Decision of the Cheryomushky district court of Moscow, 17 October 2008, case No. 2-5572/08. The case description and documents are available on the web-site of the Non-Governmental Organization "Perspektiva" (Moscow) https://perspektiva-inva.ru/protec-rights/trial/851-vw-851 (access 08.08.2018).

specific grounds for unilateral cancellation of agreement shall be stipulated only by a legislative act.

Article 107 of the Air Code of the RF stipulates that an air carrier has the right of unilateral cancellation of the air carrier agreement with a passenger only in cases when the state of health of the passenger requires specific conditions of transportation or threatens the passenger or other passengers on board providing that it is proved by medical documentation.

According to the Customers' Rights Protection Act, unlawful denial of services to a customer entails an administrative fine. A violation of the rights of customers according to this law gives the customer a right to claim compensation for moral damages.

According to Article 55 (3) of the Constitution of the RF, human rights and freedoms may be restricted only by a federal law and only to the extent necessary to protect the constitutional order, morality, health and interests of other persons, state defense and public safety.

Defendant's views

Representatives of the S7 Sibir airline stated that the crew acted in accordance with the company's regulations based on the Decree of the Ministry of Transport[7] according to which an air carrier has the right to reject carriage (boarding) to a passenger in a wheel-chair, or a passenger on a stretcher in case appropriate conditions are not available on board the aircraft. The decision to deny carriage to the passenger was made by the aircraft captain as the passenger in a wheel-chair had no personal assistant to help her move. According to the Ministry's General Regulations on air carriage as understood and applied by the Defendant, a passenger unable to move independently shall be accompanied by a personal assistant. The decision was made with the purpose of protecting the passenger from possible harm.

Decision of the court

The Court upheld the claim and ruled that the Defendant violated the rights of the passenger. The court noted that the Defendant had no reasonable grounds to assume that the state of health of the passenger could harm her or other passengers. Neither the law nor other regulations stipulated that the "absence of an accompanying person or assistant" was a specific reason to restrict the rights of passengers or deny boarding. Moreover, in case there exist specific restrictions, the passenger should be informed thereof beforehand in accordance with the law and the regulations, which was not done in this case.

The Defendant appealed the decision but the appeal was not supported, and the court of cassation upheld the decision.

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[7] General Regulations on the carriage of passengers, luggage and cargoes and the respective services. Decree of the Ministry of Transport dated June 28, 2007, No. 82.

3.2. Redress – possible and actual

As far as the complaint was based on the provisions of the Customers' Rights Protection Act, the applicant had certain rights to claim compensation for material and moral damage. According to this Act, a customer whose rights are violated has the right to claim refund of the sum paid to the perpetrator along with compensation of related material losses (in this case – the sum paid for another ticket and the expenses related to the delay in the airport and transport to another airport, time lost, etc.). Similarly, in other cases of violations of civil rights or agreements, a victim has the right to claim compensation for material damage.

In the above said case, the applicant preferred not to claim such compensation since the case was a judicial precedent and it was important to reach a judgment that in principle would serve for the future protection of other persons with disabilities. Such idea proved efficient. Several other cases were subsequently brought before courts and finally this induced the adoption of amendments to the General Regulations on air carriage.

"Moral damage" is a legal concept that gives a person the right to claim pecuniary compensation for physical and moral suffering in cases of violation of personal non-material rights (e.g. degrading treatment, disparagement, insult by words or actions, etc.). The Customers' Rights Protection Act endows a person the right to claim compensation for moral damages also in cases of violation of consumers' rights.

In the above said case the applicant sought for such compensation and the court partly upheld the claim. The court actually reduced the sum of the compensation from 1 million rubles (sought by the applicant) to 50 thousand rubles (a 95% reduction). Whether the compensation for moral damages was fair in this case is generally at the discretion of the court, which decides on the amount of compensation (within the sum claimed by the applicant) according to the circumstances of the case and the inner assumption of the judge on the degree of the applicant's suffering. The legal provisions on moral damage outline only the general framework for such decisions.

Art. 151 of the Civil Code envisages that in cases of moral damage caused by a violation of non-material rights or in other cases specifically stipulated in the legislation (as with the law on protection of customers' rights) the court has the right to decide on compensation for moral damage. While deciding on the amount of the compensation the court must take into account the degree of the perpetrator's guilt, the individual circumstances of the case and the applicant. The Decree of the Supreme Court Plenum[8] on compensation for moral damage was adopted long before the new developments in law and has no reference to discrimination cases.

Judicial practice of compensation for moral damage varies significantly and induces professional discussions on fairness and common criteria of such

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[8] Decree of the Supreme Court Plenum as of December 20, 1994 (last amended in 2007) on the issue of applying the legislation on compensation for moral damage.

compensation. One of the points of view is that the existing judicial practice diminishes the concept of moral damage (the objective reason for which is a difficulty to "calculate" a moral harm) while the society requires more clear and objective criteria of fair and reasonable compensation for its occurrence.[9]

Getting back to the prohibition of discrimination in law, there is a need to support the general provision by the correspondent reasonable and fair redress for victims of discrimination. Currently, there are no adequate legal instruments in the Russian law that would prevent discrimination in future and provide reasonable and fair redress for the victim. One of the ways to induce serious changes in practices and prevent tolerant attitudes towards discrimination could be a legal concept of presumed moral damage in discrimination cases, which would make such compensation inevitable for the perpetrator.

3.3. Implications of the Prisetskaya case

As said above, the case of Natalia Prisetskaya was a precedent to influence following judicial practice in similar cases.[10] However, the still existing provision of the General Regulations on air carriage provided airlines with the opportunity to refuse boarding to passengers in wheelchairs, or passengers on stretchers in the absence of necessary conditions being available on board the aircraft.

In a case[11] initiated by the NGO of persons with disabilities, the applicant (the Consumer Rights Protection Association) asked the Supreme Court to rule that paragraph 110(4) of the General Regulations shall be invalid, as it does not comply with the Air Code of the RF. According to the par. 110 (4), carriage of a passenger in a wheelchair or a passenger on a stretcher shall be made together with an accompanying person who provides the passenger with assistance during the flight. The applicant pointed out that the provision of the paragraph was discriminatory insofar that it allowed an arbitrary rejection of carriage to persons with disabilities using wheelchairs and justified the practice of airlines to avoid adapting aircraft to

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[9] A discussion on the issue has recently taken place in the Council of judges where the participants denoted that the current need is to legally establish clear criteria of reasonable and fair compensation, and that the subjective views of judges on moral damage are outdated and should be changed. See: "The Price of Insult will Rise: the chairperson of the council of judges urged to rise the size of compensation for moral damage", Rossiiskaya Gazeta, dated March 26, 2018, https://rg.ru/2018/03/26/razmer-kompensacij-za-moralnyj-vred-predlozhili-povysit.html (access 8.08.2018).

[10] As an example, a case with the similar circumstances was heard before the Tula regional court in 2009. An applicant, a blind person, was denied boarding to the aircraft of the same airline due to the same Regulations and the requirement of accompanying person. The court ruled similarly as in the Prisetskaya case. The company had to change the inner instructions as an effect http://perspektiva-inva.ru/protec-rights/juri/vw-852/ (access 8.08.2018).

[11] Decision of the Supreme Court as of 14 November 2012, case no. АКПИ12-1299, http://www.consultant.ru/document/cons_doc_LAW_139341/ (access 8.08.2018).

accommodate the needs of such persons. The Ministry of Justice supported the claim confirming that the contested provision infringes the right of persons with disabilities to access the air transport services by providing to the air carriers excessive discretion concerning the issues of transportation denial.

The Ministry of Transport as a defendant opposed the application stating that the provision as such does not contradict the law.

The court dismissed the claim and agreed with the statement made by the Ministry of Transport. However, the court ruled that the contested provision must be interpreted in accordance with the provisions of the Air Code of the RF and other preceding legal acts that do not allow arbitrary rejection of services. According to the law, air carriage services shall be accessible for everyone, and the court concluded that the contested provision as such does not allow denying boarding on the grounds of disability. Such denial can be justified only in specific situations, if a person's state of health requires special accommodation, which an air carrier is not able to provide. Concurrently, the impugned provision does not exempt the air carrier from the duty to offer such passenger a reasonable alternative. Moreover, according to the court, it is the duty of the transport authorities to adopt the rules on technical equipment of aircraft and requirements concerning accessibility thereof.

The interpretation given by the Supreme Court gave impetus to further changes in the General Regulations.

In 2016, the provisions were changed and amended with more detailed regulation. It currently envisages that a passenger with hearing or visual disability, as well as wheelchair user may board without an accompanying person. Persons with visual impairment may be boarded together with a guide dog. Only persons who are both blind and deaf shall have an accompanying passenger for assistance during the flight. A passenger who is stretcher-bound shall be provided with an additional place in the aircraft.

While the Supreme Court has still left room for discretion to air-carriers, it has at least limited its scope and induced clearer regulations leaving less opportunity to arbitrary denial of carriage.

4. Conclusion

Acceptance of the principle of non-discrimination and prohibition of disability-based discrimination was the first step implemented in Russia after ratification of the Convention, as happened in many other countries. However, the concept of disability in the Russian law needs revision and the concept of reasonable accommodation is obviously missing in the legislation. The judicial practice shows that the current legislation provides access to protection of the rights of persons with disabilities in court. However, it is just the beginning of the development of this legal field.

NGOs of persons with disabilities agree that in order to implement the Convention in full, the next step is to adopt special legislation on protection from disability-based discrimination. The existing legal mechanisms do not provide appropriate guarantees of the right to redress in cases of discrimination and the prohibition of discrimination in future needs more robust legal support. It is therefore high time to learn from international experience of the legal mechanisms of protection against disability-based discrimination.

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Abbreviation

RF – Russian Federation

UN – United Nations

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Social and Legal Situation of Handicapped Persons in the Russian Federation

Abstract: The article by K. Laskowska presents the evolution in the approach of the state and of society to handicapped persons in Russia in the past and in the present. The author points to a number of problems that have been present for years in relationships of handicapped persons with other people (lack of understanding and support, dislike, and rejection), as well as existential problems encountered by them in their daily lives (unemployment, low disability benefits). The author also presents the most important provisions of the Act "On social protection of handicapped persons in the Russian Federation" of 1995, which regulates many spheres of the state's assistance provided to such persons. In particular, the Act regulates the support related to housing, healthcare, information, transport, financial aid, etc. The deliberations lead to the conclusion that changes are needed that will lead to better social integration, as well as to better and more effective work of representatives of state authorities and institutions. What is needed is a single cohesive and efficient system that facilitates the functioning of handicapped persons in society.
Keywords: handicapped person, invalid, rehabilitation of handicapped persons.

1. Introduction

According to the data published by Rosstat, as of 15 January 2015, there were 13 million handicapped persons living in Russia, including approximately 605,000 children[1], and according to the Ministry of Health Protection and Social Development of the Russian Federation, there were approx. 13.2 million handicapped persons in Russia (approx. 9% of the population).[2] However, other data indicates that

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[1] Инвалиды 2018. Что изменится с этого года, https://doorinworld.ru/stati/invalidy-2016-chto-izmenitsya-s-etogo-goda (access 25.03.2018).

[2] П.В. Романов, Е.Р. Ярская-Смирнова, Инвалиды и общество: двадцать лет спустя, http://www.demoscope.ru/weekly/2011/0463/analit02.php (access 25.03.2018).

handicapped persons account for approximately 10% (i.e. 14.4 million) of the Russian population, which means that nearly one in four Russian families have a member who is handicapped. Studies conducted across society indicate that a majority of respondents have acquaintances who are handicapped and that 60% have experience in caring for such persons. Consequently, indirectly or directly, this problem affects many Russians.[3]

One must keep in mind that handicapped persons are not a homogenous group. They differ by their condition, sex, age, social status, education, and place of residence.[4] Also, the nomenclature used in reference to them is not clear. They are commonly referred to as "handicapped persons" but the official term is "invalid" and, in the literature, they are often referred to as «persons with limited health capacity».[5]

The purpose of this document is to describe the social and legal situation of handicapped persons in Russia. The author's intent is to present their past and present problems. Moreover, selected and, apparently, the most important laws that regulate the lives of handicapped persons are presented in the article.

2. Social situation of handicapped persons in the Russian Federation

For ages, the situation of handicapped persons was quite difficult. Due to the limitations they faced, they were low on the social ladder. "They were considered to be a burden, a social group that brought no benefits",[6] defective,[7] "unnecessary, inconvenient"[8] people. Their handicap was considered to be a punishment for their sins and a sign of possession by bad spirits, which condemned them to isolation, marginalisation in society, and exclusion from normal life, work, and schooling.[9] They often lived in poverty[10]. Sometimes handicapped persons were killed in order to eliminate them from the "healthy society".[11]

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[3] Н. Корнеева, Отношение общества к инвалидам заметно меняется, http://dislife.ru/articles/view/3823 (access 25.03.2018).

[4] П.В. Романов, Е. Р. Ярская-Смирнова, op. cit.

[5] А.К. Крылова, Отношение современного российского общества к детям – инвалидам, https://www.school-science.ru/2017/8/26822 (access 25.03.2018).

[6] Инвалиды в современном обществе, https://doorinworld.ru/stati/311-invalidy-v-sovremennom-obshhestve (access 25.03.2018).

[7] В.С. Баглай, Отношение общества к инвалидам: история и своременность, https://www.scienceforum.ru/2014/521/3136 (access 25.03.2018).

[8] А.К. Крылова, *op. cit.*

[9] В.С. Баглай, *op. cit.*

[10] Инвалиды в современном обществе, https://doorinworld.ru/stati/311-invalidy-v-sovremennom-obshhestve

[11] Инвалиды в современном обществе, http://www.ccdi.ru/novye-stati/invalidy-v-sovremennom-obschestve.html (access 25.03.2018).

During the times of the Kievan Rus and then Moscow Rus, the first monasteries were built where poor and ill persons, including handicapped persons, were provided with food and shelter. The first systems for providing aid to those in need were established by Tsar Ivan the Terrible and then perfected by Tsar Peter the Great. On 31 January 1712, the latter gave an order that mandated the construction of special hospitals and to an order that allowed for the construction of hospitals for the mentally ill. From that year until the start of the 20th century, aid to handicapped person consisted mostly in welfare aid based on a system of state and private means. In that period, the first social organizations that provided support to those in need were created. Later, however, the newly shaped Soviet society departed from those solutions. In the years 1920-1930, a state social security system was created, including production cooperatives that employed handicapped persons. Wages paid by those cooperatives were higher than disability benefits. Also, organizations were established that provided help to the blind and deaf. The aid system also functioned during the war. Special homes for invalids were established and efforts were made to ensure their employment.[12]

In the 1950's, after the victory in World War II, the state wanted to give the appearance that the USSR was "blooming" and handicapped people did not fit within that particular ideology. Therefore, efforts were made to separate them from society by placing them in various specialised institutions, such as dormitories, schools, special work places, or hospitals. This proved successful as the state's policy towards handicapped persons, implemented for decades, resulted in their isolation. Another stereotype that emerged was «society without handicapped persons» (how was this possible in a country with so many people maimed during the war?) and so a psychological barrier between healthy people and handicapped people was erected.[13]

After 1990, state policy towards the handicapped became compensatory in nature. The issues of monetary benefits and availability of services came into being and were subsequently governed by the Act on basic principles of social protection of handicapped persons in the USSR of 1990.[14] The Act guaranteed lack of discrimination, specific rights, and active involvement in the life of society.[15] In 1995, another breakthrough took place. This is when the Act on social protection of handicapped persons in the Russian Federation was adopted,[16] which «stimulated further development of the state's policy that maintained protection of handicapped

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[12] В.С. Баглай, *op. cit.*

[13] А.К. Крылова, *op. cit.*

[14] Закон СССР от 11.12.90 Н 1826 «Об основных началах социальной защищенности инвалидов в СССР», http://pravo.levonevsky.org/bazazru/texts25/txt25576.htm.

[15] П.В. Романов, Е. Р. Ярская-Смирнова, *op. cit.*

[16] Федеральный закон от 24 ноября 1995 г. № 181-ФЗ «О социальной защите инвалидов в Российской Федерации», http://www.consultant.ru/document/cons_doc_LAW_8559/.

persons as a minority that required rehabilitation in conditions of integration».[17] The Act will be discussed further in this article.

As the above information indicates, with time the situation of and the social attitudes to handicapped persons improved. They began to get social and financial aid and the first support institutions were established. Currently, they enjoy the same rights as all other citizens; they have their dreams, want to discover the world and travel, want to enjoy life and to have various skills.[18]

However, in spite of the changes that have occurred, the situation of handicapped persons is still not perfect. Nowadays healthy people are often unfriendly toward the handicapped, especially the blind (in public transit, in hospitals) and persons who are intellectually slow or possess a physical disability. Moreover, those persons suffer as a result of lack of adaptation in means of transport, lack of access ramps into various public buildings, as well as being forced to live in special homes for the handicapped away from society. Very few of them have jobs. Trapped within the four walls of their homes or at various institutions, they live in a world of diseases, full of complexes, depression, and personal experiences.[19]

The most difficult situation for them is in small towns and rural areas where appropriate aid is hard to come by. Life for the handicapped in big cities is easier. The results of research conducted among handicapped persons show a drop in satisfaction with the deterioration (in their opinion) of their situation in society, mostly due to the "disappearance of the tradition of supporting handicapped persons". They miss the Soviet aid system. They complain about unemployment.[20]

3. Current legal situation of handicapped persons in the Russian Federation

The starting point for the determination of the legal situation of handicapped persons is Art. 39 of the Constitution of the Russian Federation of 1993,[21] which guarantees social protection to everyone in the event of disability.

The detailed regulation of the legal situation of this social group in Russia is provided by the Federal Act of 24 November 1995, No. 181-FZ, "On social protection

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[17] П.В. Романов, Е.Р. Ярская-Смирнова, *op. cit.*

[18] Инвалиды в современном обществе, https://doorinworld.ru/stati/311-invalidy-v-sovremennom-obshhestve

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[20] Н. Корнеева, Отношение общества к инвалидам заметно меняется, http://dislife.ru/articles/view/3823 (access 25.03.2018).

[21] Конституция Российской Федерации от 12 декабря 1993 г., http://www.constitution.ru/10003000/10003000-4.htm.

of handicapped persons in the Russian Federation". Also, there are a number of secondary laws to the aforementioned Act.

Currently, the Act consists of 36 articles (6 chapters). In the preamble it states that the Act "defines the policy of the state in the area of social protection of handicapped persons in the Russian Federation". Its "objective is to ensure the same opportunities to handicapped persons as those enjoyed by other citizens in the area of exercise of civil, economic, political, and other rights and liberties provided for in the Constitution of the Russian Federation, as well as pursuant to the generally recognized principles and norms of international law and international treaties signed by the Russian Federation".

Chapter I of Art. 1 of the Act, titled "General provisions", defines the term "handicapped person" (called literally, an invalid). Pursuant to that chapter, a handicapped person is "a person who has health disturbances involving a disorder of the functions of the body due to diseases, consequence of injuries or other defects, which leads to a restriction of life functions and causes a need for providing such a person with social protection". This is a person who, either in whole or in part, has lost the ability to function on his or her own in some spheres of life, such as movement, communication, learning, or work. It is assumed that handicapped persons are assigned to a disability group and handicapped children are assigned to the "handicapped child" category. The group or category assigned depends on the extent of the person's bodily disturbances.

Handicapped persons are entitled to social protection, in the form of a specific system of means (including legal ones) that create conditions for overcoming the restrictions and difficulties in their functioning. Such a system should enable handicapped persons to participate in social life on an equal basis. Handicapped persons are also entitled to social support, which includes legally regulated social guarantees, with the exception of pensions (Art. 2). Art 3.1 of the Act contains a statement that in Russia discrimination based on disabilities, taking the form of restriction of deprivation of rights and liberties, especially in the political, cultural, and economic spheres, is prohibited.

In order to enforce the rights of handicapped persons, state authorities are required, in particular, to: define the state's policy in relation to handicapped persons; adopt acts of law in the area of social protection of handicapped persons and conclude relevant international agreements; define the general principles of organisation and implementation of medical and social evaluation and rehabilitation of handicapped persons; define the criteria and conditions for qualifying persons as handicapped; regulate the matter of availability to such persons of technical rehabilitation, communication and information technology; evaluate the activities of institutions involved in the rehabilitation of handicapped persons; prepare and implement federal target programs in the area of social protection of handicapped persons and control of their performance; approve and finance a list of rehabilitation means, technical rehabilitation means, and services provided to handicapped persons; create federal institutions that deal with medical and social evaluation, as well as monitoring their activities; coordinate and finance research on handicapped persons; help in the work of association of handicapped persons; define expenditures on social protection of handicapped persons; establish a uniform system for registration of such persons in the Russian Federation and for statistical monitoring of their socio-economic situation and demographic composition; define the requirements concerning equipment in work places for handicapped persons; prepare reports from the actions conducted as a part of performance of the obligations of the Russian Federation arising from the Convention on the Rights of Persons with Disabilities (Art. 4).

Art. 5.1 of the Act contains provisions related to a federal register of handicapped persons, which is an information technology system that contains certain information about such persons, including personal data, information about the disability group and the level of occupational disability, the period for which the group was established, their disorders, their rehabilitation, and the financial benefits paid to those persons. Moreover, it was assumed that contribution to the emergence of a disability is subject to material, administrative, civil, or penal liability (Art. 6).

The title of chapter II is "Socio-medical evaluation". Art. 7 of the Act provides that social and medical evaluation is the basis for qualifying a person as handicapped. The purpose of the evaluation is to determine the social protection means, including the rehabilitation needed to fulfill the handicapped person's needs. A list of such needs is created based on an evaluation of restrictions on daily life activities due to bodily disorders. The criteria for evaluation of the physical condition of handicapped persons are defined by competent authorities and institutions.

Socio-medical evaluations are performed by federal institutions overseen by competent bodies of the executive branch of the government, which is responsible for implementation of the social policy of the state and of law related to the social protection of society. Such institutions are required, in particular, to: "determine disability, its causes, its time, the needs of handicapped persons in various aspects of social protection; prepare individual programs for rehabilitation, habilitation of handicapped persons; study the level and the causes of disabilities in the population; participate in creation of comprehensive programs for rehabilitation, habilitation of handicapped persons, prevention of disabilities and social protection of handicapped persons; determine the extent of loss of ability to perform work; determine the cause of death of a handicapped person in cases where the laws of the Russian Federation provide for social support to the family of the deceased; [...] ensure conditions for independent evaluation of the quality of the conditions of provision of services by federal medical and social institutions". Information about those institutions is provided on websites (Art. 8).

The title of chapter III is "Rehabilitation and habilitation of handicapped persons". Art. 9 of the Act defines the terms rehabilitation and habilitation. According to the

Act, rehabilitation is "a system and process of full or partial restoration of the skills of handicapped persons for personal, social, and occupational activity" and habilitation is "a system and process for the shaping of skills not present in handicapped persons for personal, social, and occupational activity". Those undertakings are intended to reduce restrictions in the lives of handicapped persons so as to enable their social adaptation and integration. They include, most of all, improvement of the quality of life by way of medical procedures (surgeries, prosthetic devices, sanatoria), increasing the level of education, and participation in cultural and sporting activities. They also include access to technical means of rehabilitation, appropriate infrastructure (including communication and information technology infrastructure), as well as the access of handicapped persons and their families to information about rehabilitation and habilitation possibilities. In the light of Art. 10, a list of aid and support means, and services financed from the state budget, is prepared by the government of the Russian Federation.

Art. 11, contains a description of an individual program for the rehabilitation and habilitation of handicapped persons. It provides for a set of different (medical and occupational) means aimed to improve the health and activate handicapped persons. Some are provided free of charge while others (clearly stated) are payable. Consequently, the cost of certain benefits must be covered by the handicapped themselves or by the institutions (e.g. foundations) that take care of them. The aforementioned program is not mandatory. However, it is recommended. Consequently, each handicapped person can choose those elements that he or she finds the most useful, e.g. get a wheelchair, a prosthetic device, a hearing aid, etc. Moreover, handicapped persons may purchase the devices they need themselves. In such cases, the cost involved is reimbursed in accordance with the criteria specified in Art. 11.1 of the Act. A competent federal body of the executive branch of the government defines the procedure for and level of such reimbursement. A decision not to participate in an individual program, either in whole or in part, does not entitle handicapped persons to receive compensation in cash for devices and/or services that would otherwise be provided for free. Federal institutions performing socio-medical evaluations submit information from individual programs to competent bodies of the executive branch of government, to local government authorities, and to other authorities that provide support to handicapped persons. Then, after each of these bodies or authorities have performed their particular function, the evaluations are returned to the respective federal institutions that initiated them.

Art. 11.1 contains a list of technical means for the rehabilitation of handicapped persons. This includes: special self-service aids; special care products; special orientation aids (including guide dogs with a set of equipment); aids for receiving and exchanging information; special education aids; aids to education (including literature for blind persons) and employment; prosthetic devices (including prosthesis and orthopedic products, orthopedic shoes and special clothing, ocular prostheses, and hearing aids); special training and sports equipment; and special mobility devices (wheelchairs). The decision to provide such aids to handicapped persons is made based on determination of their needs resulting from their health condition. The costs of the aforementioned equipment and of their repairs are covered by the state budget, similarly the cost of maintenance and medical treatment of guide dogs, which is set at 17,420 rubles a year.

The title of chapter IV is «Support of the life of handicapped persons». Art. 13 of the Act guarantees the provision of qualified medical care to handicapped persons. It is decided that such care is provided pursuant to the Russian law as a part of implementation of the program of state guarantees related to free healthcare provided to citizens of the Russian Federation. Moreover, handicapped persons are guaranteed access to information, including free access to fictional and academic books (in braille for the visually impaired) as well as cassettes, all financed by the government and delivered to libraries. The language of communication for persons with hearing and speech impairment is the Russian sign language. As a part of assistance to handicapped persons, there is a system for translation of subtitles or sign language for television programs, films and videos. Such translations are performed by sign language translators who are properly educated and have appropriate skills (Art. 14).

Art. 14.1 provides for the participation of blind persons in certain transactions with the aid of the so-called facsimile (a copied hand signature). It is used for example to withdraw cash or to obtain a loan. In order to perform such a transaction, a blind person should present a document that confirms his or her identity, a notarial confirmation of authenticity of his or her hand signature with a facsimile copy of the hand signature, and a confirmation of disability issued by a federal state institution.

The Act also provides unlimited access to social, engineering, and transport infrastructure for the handicapped. This means, that the Act guarantees: «1) conditions for unhindered access to public, engineering, and transport infrastructure facilities (residential buildings, public buildings, industrial buildings and facilities, including those where sport, cultural, and other organisations are located), to places of recreation [...]; 2) conditions for unobstructed use of rail, air, water, road, and urban ground electrical transport and suburban and inter-city means of transport and information (including sound signals, light signals, traffic signals, and equipment that control pedestrian traffic in transport communication); 3) possibility of autonomous movement in the territory where public and transport infrastructure facilities are located, entry to and exit from such facilities, entry to and exit from means of transport, including use of wheelchairs; 4) support to handicapped persons with permanent eyesight disorder and loss of ability of autonomous movement and provision of help to such persons in public, engineering, and transport infrastructure facilities; 5) proper location of equipment and information carriers necessary to ensure free access of handicapped persons to public, engineering, and transport infrastructure and to service infrastructure [...]; 6) access to sound and visual information required by handicapped persons, as well as labels and other graphic and text information signs in braille code [...]; 7) entry to public, engineering, and transport infrastructure facilities by guide dogs that have documents confirming their special training [...]; 8) help in overcoming barriers that hinder access to services on an equal basis with others, provided by employees of organisations that provide services to the population». Consequently, bus/train stations, airports, bus/train/tram stops must be technically adapted to the needs of handicapped persons. In each of those facilities, 10% of all seats must be adapted to the needs of handicapped persons in the 1st, 2nd, and 3rd disability groups. They should be marked with the words «handicapped person» (Art. 15). Art. 16 provides for the responsibility of persons who do not comply with this regulation.

Art. 17 provides for a guarantee to provide housing to handicapped persons. Such persons and families with handicapped children who need better housing conditions may obtain an appropriate dwelling in accordance with a certain procedure. Such housing is provided under a rent contract. Its floor area may exceed the maximum limit on floor area per person (but not by more than one hundred percent). Housing may also be provided to persons suffering from serious chronic diseases. The fees paid for the housing and its repairs depend on the floor area of the dwelling. The tenants are entitled to receive specific discounts. Such housing may also be provided to handicapped persons living in social assistance institutions. Moreover, handicapped persons and persons with handicapped children are granted a 50% discount for housing and municipal services (including rent, house maintenance fees, payments for repairs of housing, water supply payments, and electricity payments).

The Act also regulates the matter of education of handicapped persons. The Act emphasises that the state supports and guarantees conditions necessary for education of handicapped persons. The Act enables human development and integration with the society. Therefore, the state guarantees free elementary, secondary, and higher education. Handicapped persons are entitled to teaching at home (Art. 19).

Art. 20 of the Act pertains to the employment of handicapped persons. It is assumed that companies should assign a minimum number of jobs to handicapped persons. The Act provides that conditions must be provided for the development of entrepreneurship among the handicapped, that training must be provided to handicapped persons for new jobs, and companies must be encouraged to hire such persons. Art. 21 provides that in companies employing more than 100 persons, 2-4% of the employees must be handicapped persons; in the case of companies with 35-100 employees, the requirement is 3%.

Art. 23 describes the working conditions that need to be ensured in the case of handicapped persons. The article emphasizes that employees have to create required work conditions in accordance with the individual programs of rehabilitation or habilitation of handicapped employees. Contracts on terms worse than those agreed with normally healthy persons are prohibited. It is prohibited to provide worse conditions to handicapped persons compared to other employees. Handicapped persons in group 1 and 2 may work no longer than 35 hours a week. Moreover, overtime, work on weekends, and work at night requires the consent of the handicapped person. Also, such work is only permitted if their state of health is appropriate. Handicapped persons are entitled to annual leave of at least 30 calendar days. Employers are required to create appropriate work conditions (Art. 24).

Art. 27 regulates the cash benefits paid to handicapped persons. The article provides for the state's duty to provide support in the form of cash payments (pensions, benefits, health insurance payments, payments for damage to health), as well as compensation in cases defined under Russian law. The article also provides that handicapped persons who require care and assistance receive medical services at home or in appropriate institutions, as well as telecommunication aids, special telephones (including those for subscribers with hearing impairment), household appliances, and other means facilitating social adaptation (Art. 28).

Art. 28.1 specifies the value of monthly cash benefits paid to handicapped persons. This is: 1) handicapped persons in group 1 – 2,162 rubles; 2) handicapped persons in group 2 – 1,544 rubles; 3) handicapped persons in group 3 – 1,236 rubles. Other cash benefits (pursuant to separate regulations) are paid to persons irradiated as a result of the Chernobyl disaster. The value of benefit payments is adjusted annually on the 1st of February based on the inflation rate for the previous year. The sums are paid by the field body of the Pension Fund of the Russian Federation.

Article 32 regulates the responsibility for violating the rights of handicapped persons.

It assumes the persons culpable of such violations under the Russian law. Any disputes concerning the determination of disability, the implementation of individual rehabilitation programs, the habilitation of handicapped persons, the provision of specific social protection, as well as disputes concerning other rights and liberties of handicapped persons, are resolved in the course of court procedures.

Chapter V is titled «Associations of handicapped persons». Art. 33 of the Act guarantees the right of handicapped persons to form public associations. It was found that such associations ensure equal opportunity with other citizens and are a form of social protection for the handicapped. Consequently, the state provides aid to such associations, including material, technical, and financial assistance.

In conclusion, the attitude toward handicapped people demonstrates one's humanity. Despite the positive changes that have been taking place, nowadays the handicapped still remain a weak and defenseless social group. They are frequently perceived as «special» and «different» instead of «equal» and «like anyone else».[22] Consequently, improvement of this situation requires involvement of both state and society. The state should constantly improve law, procedures, and the actions of

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[22] В.С. Баглай, *op. cit.*

officials, while society in general needs to increase the level of empathy and promote a willingness to provide both assistance and understanding. In the opinion of A. K. Krylova, what is required nowadays is more intensive social integration, which should consist not only in the improvement and adaptation of urban infrastructure but also in a change in the attitudes towards handicapped persons.[23] Effective social integration depends on many factors and on the persons and authorities involved in the process of changes. Such persons include not only handicapped persons and their families, but also state, social, and local agents and non-governmental organisations. Such cooperation should lead to improvement and higher quality of support and rehabilitation. The handicapped themselves can also play an important role in the cooperation process. «Creation of common strategies may influence the state policy and the lives of individual citizens, while being an important step in the development of civil society. Such processes reflect growing approval of the rights and human dignity of communities, renewal of social relations and political relations of individuals, the society, and the state».[24]

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[23] А.К. Крылова, *op. cit.*

[24] Романов П.В., Ярская-Смирнова Е.Р., *op. cit.*

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Dealing With Legal Capacity and Its Related Challenges in Uganda

Abstract: The paper deals with the concept of legal capacity as advanced in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) within the context of Uganda as a State party. The paper takes the format of analyzing what Uganda has done to comply with the Concluding Observations of the Committee on the Rights of Persons with Disabilities in as far as they relate to the subject of legal capacity and access to justice within Uganda. The paper examines the practical challenges, legal, societal and cultural that affect the country's ability to comply with Article 12. Within the paper, it is emphasized that Article 13 is important in creating a mechanism under which Article 12 is realized especially in the case of Uganda. The Paper briefly examines what can be done to ensure that Uganda better complies with Article 12 of the CRPD.

Keywords: Convention on the Rights of Persons with Disabilities, persons with disabilities, access to justice,

Over the last seventy years, disability around the world has evolved from curse, through being considered an aspect to charity, a medical condition that must be cured, to its current status as a social issue. The case is no different for the East African State of Uganda. For this country numbering about 41 million people, 14% of whom are regarded as being disabled, the very aspect of extending equal recognition to persons with disabilities within the law and practice of the country, remains a challenge.

Article 16 of the ICCPR[1] provides for the recognition of everyone everywhere on earth as a person before the law. This Article builds upon Articles 6 and 7 of the

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[1] International Covenant on Civil and Political Rights; Uganda ratified the Covenant together with its optional protocol in 1995. The Country was last reviewed by the Human Rights Committee in 2003.

UDHR[2]. Nearly seventy years after this international pronouncement, the right to full recognition before the law remains a dream for persons with disabilities especially those with mental disabilities. Despite, the successful enactment of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), particularly Article 12, equal recognition before the law remains unattained for many persons with disabilities. In this paper we briefly explore why successful implementation of legal capacity for all persons with disabilities in Uganda remains a challenge.

In April 2016, the Committee on the Rights of Persons with Disabilities (Committee)[3] considered the country report submitted by the Republic of Uganda. Uganda ratified the CRPD and its Optional protocol on the 25th of September 2008 without any reservations. The government of Uganda submitted its initial report in 2012 and came up for review in 2016. Within its Concluding Observations, the Committee made several recommendations to the Ugandan government. Amongst these is the repeal and elimination of legislation and practices that allow for deprivation of legal capacity on the basis of disability, and to adopt measures that prohibit deprivation of legal capacity on a customary basis. The Committee also called for the adoption of measures to ensure that all persons with disabilities have access to justice including the establishment of free legal aid for persons with disabilities.

Legal capacity and access to justice as principles within the CRPD are permanently intertwined. Legal capacity is captured under Article 12 of the Convention whereas access to justice is under Article 13. Article 12 of the Convention captures the two core prongs of legal capacity as, the enjoyment of inherent rights and the capacity to exercise or act on the said rights. In his paper on legal capacity within the CRPD, Professor Robert D. Dinerstein outlines the two prongs as stated above.[4] He further notes that whereas prong one is rarely contested, States and other duty bearers have continuously found it hard to comply with prong two. The reason for this is because unlike prong one which has over the course of nearly seventy years of the human rights regime become accepted, prong two is fundamentally revolutionary because it moves disability away from the medical model for which it was long associated to the social model. Other disability scholars have noted that this definition of equal protection under the CRPD was probably the most contested during the Convention's drafting process. This probably explains why State compliance with Article 12 has remained most problematic. However, for several States the entire Article 12 has remained a difficult one to comply with. This is because it calls for a fundamental

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[2] Universal Declaration of Human Rights; The Country accepts to be bound by the principles of the Declaration by virtue of its United Nations membership and the fact that it has ratified all the core human rights Treaties that operationalize the Declaration.

[3] The Treaty body created by the CRPD.

[4] R.D. Dinerstein, Implementing Legal Capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making, 19 Hum. Rights. Brief 8 (2012).

shift which is not only legislative but societal and behavioral. Article 13 is of extreme relevance to Article 12 because it creates a basis upon which Article 12, particularly prong two can be enforced, especially in circumstances where State compliance is less than what is desired. Access to justice and due process are the cornerstone of human rights because they ensure that no one suffers a wrong without recourse to redress.

The Committee's recommendations to Uganda were based on a range of concerns as will briefly be discussed. The most worrying trend in Uganda is the continued failure to amend legislation to comply with equal recognition before the law. Although the country retains several institutions such as the Uganda Law Reform Commission, First Parliamentary Counsel and Parliament's Department of Legal and Legislative Services, whose roles include the amendment of legislation to comply with International laws and obligations, the process remains extremely slow.

To date, disability as a crosscutting development issue is yet to be prioritized by the government. Whereas issues of gender have rightly been prioritized by the government through constant amendment and the introduction of a gender and equity certificate, the same cannot be said of disability. Efforts to pass a more progressive, all-encompassing and implementable Disability Act have stalled. The Parliament of the Republic of Uganda should be credited for enacting the Persons with Disabilities Act of 2006. However, because it was enacted as a Private members Bill, it become clear almost immediately that the law was inapplicable due to the absence of clearly defined State duties and sanctions for the breach of its provisions. Eight years after efforts to amend the current Act commenced, it remains on our Statute books even though there is unanimous agreement that the government has failed to and will not be able to implement its provisions.

In the particular case of legal capacity, its full enjoyment by persons with disabilities remains constrained by the Mental Treatment Act of 1964 which relies on the medical model that emphasizes institutionalization and substituted decision making as opposed to supported decision making which Article 12 of the CRPD promotes.[5] Other laws include the Evidence Act[6], Criminal Procedure Act[7] which amongst a range of restrictions limit evidence by persons with mental disabilities as opposed to subjecting it to veracity impeachment as the standard would be for any evidence.

Under the Civil Procedure Rules of Uganda, persons with mental disabilities (termed "persons of unsound mind" under the Rules) are permitted to file suits

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[5] Mental Treatment Act, Chapter 279, Laws of Uganda; The law provides for the adjudgment of a person as one with mental illness, his treatment within a psychiatric hospital and the management of the various psychiatric hospital. It emphasizes treatment and doesn't leave room for supported decision making and voluntary rehabilitation.

[6] Evidence Act, Chapter 6, Laws of Uganda.

[7] Criminal Procedure Code Act, Chapter 116, Laws of Uganda.

through a "next friend" and defend themselves through a "guardian *ad litem*".[8] Not only is the reference to persons with disabilities derogatory here and under several other Statutes, but the actual provisions limit legal capacity as will be observed. These provisions apply to minors and persons adjudged or found to have mental disabilities equally. That in of itself is a clear indication of the model of substituted decision making which although acceptable for minors should never be wholly applied for persons with mental disabilities. The Rules make no reference to periods of lucidity and are unreceptive of the fact that several people with mental disabilities are capable of acute decision making with or without support as maybe required. If this law is to follow Article 12 of the CRPD, it should emphasize decision making by the person with mental disabilities whose decisions can only be deferred to another for a limited period of time, and with the limitation of following the most discernable of wishes by the former.

The "Administration of Estates of Persons of Unsound Mind Act" is another curious piece of legislation.[9] Section 2 of the Act provides for the appointment of administrators of property owned by people who have been found to have mental disabilities or have been incarcerated under the Trial on Indictments Act provisions as shall be discussed below. The entire law substitutes the persons decisions for those of an appointed Administrator (decision maker) whose stated roles under section 4 is to the estate and not the owner of the estate. This Act makes for the clearest example of substituted decision making within the laws of Uganda. Fortunately, a new Mental Health Bill that provides for more involvement by a person who is subject to it and provides for other rehabilitative modes of service is before Parliament. There hope is that the law will be passed sooner rather than later.

Both pieces of legislation as noted in the previous two paragraphs do not lend themselves to the standards established under Article 12(4) of the CRPD. The continued presence of these kinds of laws on our Statute books undermines the objectives of the CRPD and, particularly, Article 12 in its totality.

It is common practice for actors within the Justice, Law and Order Sector (JLOS) of Uganda to deny persons with disabilities simple procedural rights like giving testimony, standing surety and appearing as assessors. This is particularly common for people with mental disabilities, the blind and the deaf. These violations are not based on law and normally remain unreported because JLOS reports are designed to collect information from duty bearers and active clients within the said institutions. On most occasions the reasons are not based on failure to fulfill the ordinary requirements but on an errant presumption based upon disability and the unconscious treatment of persons with disabilities as less than human. This procedural denial or failure to act on one's rights is a direct violation of Article 12 of the CRPD.

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[8] Civil Procedure Rules, Statutory Instrument 71-1, Laws of Uganda, Order XXXII (1).

[9] The Administration of Estates of Persons of Unsound Mind, Chapter 155, Laws of Uganda.

The good news is that recent trends have suggested a progressiveness by the Judiciary. In the two landmark decisions of CEHURD & Iga Daniel versus Attorney General,[10]and Eric Bushoborozi versus Uganda,[11] Courts have struck down archaic provisions of the law. In those decisions, judges struck down or modified sections 45(5) and 82(6) of the Trial on Indictments Act (TIA) that negated the rights of persons with mental disabilities from enjoying equal recognition before the law. The laws relied upon a medical model to disability that presupposed that any sign or history of mental disability regardless of current lucidity meant that such a suspect could not go through a full trial but would indefinitely become incarcerated as a "guest of the State" until evidence was produced to the contrary before the Minister of Justice to his satisfaction.

The case of Busoborozi was a high court matter where the applicant had killed his son after a period of having suffered from mental illness in 2002. He was acquitted under section 48 of the TIA on grounds of insanity but was promptly sent for institutionalized treatment and eventual incarceration under the above provisions. Nine years later, he filed an application challenging his detention and the powers of the Minister in the local high court circuit. The judge ruled in his favor and held the said powers of the Minister as being extra judicial.

The CEHURD case was a petition before the Constitutional Court of Uganda challenging a range of laws that discriminate against persons with disabilities through action and language. The Court struck down sections 45(5) and 82(6) of the TIA for being inconsistent with the Constitution of the Republic of Uganda. Following this decision, all courts are bound not to follow the said provisions and must proceed with execution of their roles through judicious discretion.

Although under the provisions that were struck down, the person with mental disability remained accused and not convicted, he or she was subject to forced institutionalization and treatment at a psychiatric hospital for a long period of time. Such a person could only be reproduced for their trial upon an order of the national Minister of Justice, satisfying that he or she was fine now and fit to stand trial or be released if already acquitted. Subjecting this simple procedure in of itself to the powerful Minister made it seem as though having a mental disability was a crime. As if this procedure was not bad enough, some persons with mental disabilities remained institutionalized or incarcerated for up to seventeen years without being found guilty by a Court of law. This kind of positive development and progressive thinking by judges is a signal towards the diverse mechanisms that can be deployed in the presence of a system that seems inherently sluggish to the adoption of change.

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[10] CEHURD & Iga Daniel versus Attorney General, Constitutional Petition no. 64 of 2011 https://www.cehurd.org/wp-content/uploads/2015/11/constitutional-petition-64.pdf.

[11] Eric Bushoborozi versus Uganda, HCT-01-CV-MC-0011 OF 2015 https://www.ulii.org/ug/judgment/high-court-criminal-division/2015/14.

Although issues of legal capacity continue to take the focus of the law and rightly so, other factors like custom, social and economic standing contribute to the actual failure to implement Article 12 of the CRPD. This is a point that was noted by the Committee when they called on the State to adopt measures that prohibit deprivation of legal capacity on a customary basis. The author has worked in rural areas and seen firsthand how arbitral methods against persons with disabilities can be used to restrict the right to be heard, the right to inheritance of land and sexual rights. These kinds of denials and restrictions are informed by nothing other than ones' disability which is a direct denial of legal capacity under Article 12. The reasoning behind such behavior is normally simplistic and discriminatory. Reasons are normally as flimsy as inability to work the land, inability to coherently communicate or the attempt to avoid the passing on of "undesirable" traits of disability. This is still common despite the fact that in cases such as those of land, Article 12 provides that a person with a disability should be supported to fully utilize this kind of resource. This kind of reasoning which is common amongst some but not all communities and is not limited to particular regions or groups is many times even more troubling than actual legislation that is inconsistent with the letter and spirit of Article 12. The fact that its spread out over different areas, manifests itself in distinct traditional and customary practices and affects persons with disabilities in divergent ways, makes its prohibition extremely challenging for the government. Every community requires initiatives that are tailored towards its own challenges to enable the people therein understand that persons with disabilities are indeed equal to everyone else before and beyond the law, have the same rights that the community guarantees to all its members and must be allowed and supported to exercise those rights for their own and the betterment of that community.

Whereas States must take measures to guarantee legal capacity to all persons with disabilities through the full implementation of Article 12, the rights of all these people to enforce their human rights as envisaged can only be possible with the enforcement and realization of the related Article 13 on access to justice. The same concern was noted by the Committee when they recommended the establishment of free legal aid services for persons with disabilities.

Despite commendable attempts to provide free legal aid to persons with disabilities by local disabled people's organizations with support from likeminded peers around the World, these efforts are insufficient due to the high costs involved and the enormous demand. The government has over the last five years been drawing up a policy on legal aid, but this has yet to become a reality. It is therefore imperative that Disabled People's Organizations within Uganda continue to work with and demand from all private legal aid service providers specialized services that will suit the needs of persons with disabilities until the government can fulfil its mandate. They must also continue to work with all legal aid service providers to demand that the government establishes legal aid services, especially for marginalized groups like persons with disabilities. Without robust access to justice for persons with disabilities they cannot realize and enforce the legal capacity guaranteed to them under Article 12 of the CRPD.

Finally, it should be noted that Article 12 of the CRPD is not a standalone within the Convention. In fact, it permeates the entire CRPD, is probably the most revolutionary provision therein and creates a bedrock upon which almost all the other rights must be realized. Therefore, a failure to guarantee and enforce legal capacity affects the way persons with disabilities enjoy the other rights. In Uganda's case, the biggest impact of the failure to accord equal treatment to persons with disabilities can be seen from education, health, employment and beyond. In the education sector, the provision of support services continues to be a problem especially for children with learning disabilities in both specialized and integrated schools. This failure to promote supported decision making from an early age starts a chain reaction of limitation of legal capacity that shall continue well into ones' adult life. The same is true of the health sector. As alluded to earlier in this paper, the medical model of disability continues in use not just within the Mental Treatment Act of 1964 but generally. This means that the practice of substituted decision making on behalf of persons with disabilities is common especially by their relatives.

It is therefore of great importance that legal capacity under Article 12 is not misconstrued as is common to refer to only persons with mental disabilities. The letter of the law tells us that it clearly refers to all persons with disabilities, and in the case of Uganda, the challenges experienced in realizing it maybe more common but certainly not limited to persons with mental disabilities. As a State party, Uganda must start to walk the talk and implement Articles 12 and 13 in their entirety if all the rights guaranteed to persons with disabilities under the CRPD are to be realized. A comprehensive review of incompliant laws is overdue, efforts to sensitize the public on improper practices that limit legal capacity must be scaled up and the government together with all other legal aid service providers must extend specialized services to persons with disabilities.

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Criminal Procedure Code Act, Chapter 116, Laws of Uganda; The law governs the proceedings of criminal trials before any Court within the jurisdiction of Uganda.

Dinerstein R.D., Implementing Legal Capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making, 19 Hum. Rights. Brief 8 (2012); The paper evaluates the meaning of legal capacity under the CRPD, especially in as far as it moves disability away from the medical model to the social model.

Eric Bushoborozi versus Uganda HCT-01-CV-MC-0011 OF 2015 https://www.ulii.org/ug/judgment/high-court-criminal-division/2015/14; The case interrogated the powers of the Minister of justice in making orders that affect accused persons appearing before Court. It found them to be an infringement on the autonomy and discretion of Court.

Evidence Act, Chapter 6, Laws of Uganda; The law regulated the reception, handling and weight given to evidence in criminal and civil proceedings within the jurisdiction of Uganda.

https://www.cehurd.org/wp-content/uploads/2015/11/constitutional-petition-64.pdf; The case dealt with the capacity to stand trial by persons with mental disabilities, derogatory language within the laws of Uganda and the powers of Court to make orders without interference.

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Kanter A.S., The Promise and Challenge of the United Nations Convention on the rights of Persons with Disabilities, 34 Syracuse J. Int'l L. & Com. 287 (2007) Provided by: Syracuse University College of Law Library; The paper highlights the fundamental developments ushered in by the CRPD, one of which is the recognition of legal capacity

Mental Treatment Act, Chapter 279, Laws of Uganda; The law provides for the adjudgment of a person as one with mental illness, his treatment within a psychiatric hospital and the management of the various psychiatric hospital.

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American Law, Global Norms: The Challenge of Enforcing Children with Disabilities' Right to a Free and Appropriate Education

Abstract: This essay critically analyzes the legal interpretation of the Supreme Court of the United States of what constitutes a "free and appropriate public education"[1] for children with disabilities. Through the lens of a case study of an American child with communication disabilities, this essay examines why US law should instead be informed by a social model of disability embraced by the Convention of the Rights of Persons with Disabilities (CRPD).[2] Related, the essay argues that American courts' current interpretation of whether a student with disabilities has received an "appropriate education" relies too heavily on a medical model of disability, which requires a child first to demonstrate sufficient competence to merit related supports. Were the Supreme Court to adopt instead a social model of disability, however, it might advise public schools to presume the competence of students with disabilities. One implication of this essay is that even within the relatively robust legal framework for disability rights that presently exists in the US, judicial interpretation and enforcement of the law is too-often guided by judges' ableist[3]

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[1] Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2018). Domestically, disability law has continued to expand over the decades leading up to and following the passage of the Americans with Disabilities Act in 1990.

[2] G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (May 3, 2008). Although the United States has not ratified the CRPD, as of October 2016, 168 countries had ratified the CRPD. Laurence R. Helfer, Professor of Law, Duke University, A Human Rights Approach to Implementing the Marrakesh VIP Treaty: Statement on behalf of the World Blind Union (Aug. 14, 2017). Thus, over 85% of UN member states are States Parties to the CRPD. *See Convention on the Rights of Persons with Disabilities (CRPD)*, Dep't of Econ. and Soc. Affairs, Div. For Inclusive Soc. Dev., https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (access 25.05.2018).

[3] For purposes of this Essay, Thomas Hehir's definition of ableism applies. Hehir defines ableism as "the devaluation of disability" that "results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell

assumptions. For CRPD States Parties, the implication of this argument is that members of the judiciary should be trained not only in existing legal standards, but also in disability history and theory that can guide the interpretation of the legal standards.

This essay critically analyzes the legal interpretation of the Supreme Court of the United States of what constitutes a "free and appropriate public education"[4] for children with disabilities. Through the lens of a case study of an American child with communication disabilities, the essay examines why US law should instead be informed by a social model of disability embraced by the Convention of the Rights of Persons with Disabilities (CRPD).[5] Related, the essay argues that American courts' current interpretation of whether a student with disabilities has received an "appropriate education" relies too heavily on a medical model of disability, which requires a child first to demonstrate sufficient competence to merit related supports. Were the Supreme Court to adopt instead a social model of disability, however, it might advise public schools to presume the competence of students with disabilities. One implication of this essay is that even within the relatively robust legal framework for disability rights that presently exists in the US, judicial interpretation and enforcement of the law is too-often guided by judges' ableist[6] assumptions. For CRPD States Parties, the implication of this argument is that members of the judiciary should be trained not only in existing legal standards, but also in disability history and theory that can guide the interpretation of the legal standards.

This brief essay proceeds in five parts. The first part sets forth a case study of a young American child's attempts to secure an education despite his communication and physical disabilities. The second part sketches the legal framework, defining the standard for a "free and appropriate public education" in the United States.[7] The third part elaborates the inherently illogical inconsistencies embedded in the current judicial standard in part by focusing on the case of pre-literate children with significant communication disabilities. The fourth part argues that a social model of disability would invite schools to presume the competence of students with disabilities and offer them related supports. The fifth part unpacks an implication of this case study for States Parties to the CRPD.

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independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids." Thomas Hehir, *Eliminating Ableism in Education*, 72 Harv. Educ. Rev. 1, 1 (2002).

[4] Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2018). Domestically, disability law has continued to expand over the decades leading up to and following the passage of the Americans with Disabilities Act in 1990.

[5] G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (May 3, 2008). Although the United States has not ratified the CRPD, as of October 2016, 168 countries had ratified the CRPD. Laurence R. Helfer, Professor of Law, Duke University, A Human Rights Approach to Implementing the Marrakesh VIP Treaty: Statement on behalf of the World Blind Union (Aug. 14, 2017). Thus, over 85% of UN member states are States Parties to the CRPD. See *Convention on the Rights of Persons with Disabilities (CRPD)*, Dep't of Econ. and Soc. Affairs, Div. For Inclusive Soc. Dev., https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (access 25.05.2018).

[6] For purposes of this Essay, Thomas Hehir's definition of ableism applies. Hehir defines ableism as "the devaluation of disability" that "results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids." Thomas Hehir, *Eliminating Ableism in Education*, 72 Harv. Educ. Rev. 1, 1 (2002).

[7] 20 U.S.C. §§ 1400, 1401(9) (2018).

Ensuring access to a quality education for children with disabilities matters. For the 15% of the world's population with disabilities,[8] the issue implicates nothing less than the core of pluralist democracies' claim to legally accommodate and realize the needs, preferences and rights of diverse individuals.

Keywords: children with disabilities, CRPD, education

1. Graham, an American Child with Disabilities

Four-year old Graham is a social, happy, loving American child. Graham requires assistive technology ("AT") in order to speak using alternative communication ("AAC").[9] Examining Graham's brain scans at birth, neurologists predicted that Graham would have at least an average, if not better, IQ. The nerve damage that Graham sustained at birth, however, prevents him from moving his mouth to speak, and requires him to receive his nutrition through a small port directly into his belly. He is a power wheelchair user. At age four, youth, inexperience, and illiteracy are also real limitations for Graham, as they are for any four-year old. In terms of inexperience, however, even after the best efforts of his family to offer him stimulation, he has likely experienced 1/1000th of the physical stimulation of a typically developing child as he begins his pre-school experience.

After his family's significant exertions,[10] Graham's "individualized education plan"[11] for his public education system includes limited AT supports. Luckily for

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[8] World Health Org., Summary Report on Disability 7 (2011), http://apps.who.int/iris/bitstream/handle/10665/70670/WHO_NMH_VIP_11.01_eng.pdf;jsessionid=07B144A83058FD47F3830EE1C47B7802?sequence=1.

[9] Augmentative and alternative communication" is "an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language." *Augmentative and Alternative Communication*, Wikipedia, https://en.wikipedia.org/wiki/Augmentative_and_alternative_communication (last visited May 20, 2018); see e.g. *Augmentative and Alternative Communication (AAC)*, Am. Speech-Language-Hearing Ass'n, https://www.asha.org/public/speech/disorders/AAC/ (access 25.05.2018).

[10] Graham's Special Education Director (SPED) protests including AT services in his individualized education plan. Although AT is a federally mandated service, the SPED tells Graham's mother and father that the District does not provide AT supports for children in preschool. Indeed, like many districts, the District does not employ an AT provider on a full-time basis, the SPED says, and she further claims she cannot locate one. Graham's family searches for a speech-trained, AT/AAC provider in the broader community, and presents this professional to the District as a candidate to provide Graham's necessary supports. After much bureaucracy, the SPED begrudgingly agrees to secure the necessary administrative approval to allow Graham's supports for his first year of preschool.

[11] In 2013-14, 13.5% of students had IEPs. Laura McKenna, *How a New Supreme Court Ruling Could Affect Special Education*, The Atlantic (Mar. 23, 2017), https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/ (access 25.05.2018).

Graham, AT is a federally-mandated service under the IDEA.[12] Yet at the conclusion of Graham's first year of preschool, when Graham is five, the School District attempts to withdraw all of Graham's AT services. The school district attempts to withdraw these supports despite the fact that Graham's "mean length of utterance" is woefully behind his peers, he has only a handful of vocabulary words available in his device, and his grammar is far from age-appropriate. The Special Ed Director argues that a "free and appropriate public education" (FAPE) only requires Graham to be presented with "yes/no" questions that he can answer, not to have a programmed device and be taught to use it to speak. After a long battle that year, the District reduces his previous 60 hours of AT services by ten valuable hours to 50.

The next year, Graham's AT provider, along with his school's educational team,[13] recommends to the District that Graham's supports remain steady at 50 hours a year. As Graham prepares to head to elementary school, Graham's mean length of utterance is falling even further behind his peers with each passing year. Although the team notes many ways that Graham is behind his peers socially and in his communication,[14] and the team knows that in elementary school Graham's curricular needs will increase, the team is unwilling to consider an increase in AT and speech supports for Graham.

In first grade, Graham struggles to participate in class, communicate his thoughts, and succeed in school. The school, however, says he is making sufficient progress to move to the next grade. In second grade, Graham's parents bring him to a private Speech Language Pathologist (SLP), who recommends for Graham an AAC device designed by a linguist that enables the user to communicate much more quickly and automatically, removing much of the fine motor burden required to spell out every word he utters. After Graham learns the system, the device will allow him to utter up to 50 words a minute instead of 12-15 words per minute he might if he had to spell each word himself (and assuming total accuracy in spelling).[15] The District,

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[12] 20 U.S.C. § 1401(1)-(2). (Effective Oct. 1, 2016).

[13] This AT provider is a different consultant from the previous year. She was hired by the District as an independent consultant and her child attends the District and receives special education services from the Special Education Director, arguably creating significant conflicts of interest for her in delivering her services. (Case study on file with author).

[14] Two weeks later, however, in a meeting at the elementary school with the SPED, the same AT provider changes her position, saying that just 20 hours of AT support for Graham's first year of elementary school is sufficient. The AT provider later discloses to Graham's mother that the District would require her to be a full-time employee were she to continue to provide this level of service for Graham, and she already supports children with communication needs in over 14 districts, so it will not work for her to become a provider. She also breaks confidentiality and discloses to a parent in another district that Graham has more AT services than any other child in the area. (Case study on file with author).

[15] Graham's parents locate relatively recent US Department of Justice guidance stating that the presumption is for schools to defer to the families and medical experts' advice of the appropriate

however, says it will not support Graham's new device at school, that he can continue to spell out each word he wants to say, which is sufficient for him to make "some progress." Graham's parents purchase the device with Graham's private insurance, letting the District know that his SLP and neurologist have recommended it. After a protracted battle, the District reluctantly concedes to "allow" Graham to use his SLP-recommended device at school.

At the end of his second-grade year, Graham's school reports that he has made just one month's progress in reading over the course of the whole school year, yet the school wants to keep him at the same level of services and pass him to the next grade. Each year, rather than increase Graham's in-class supports, the School District has argued to reduce them or reluctantly agreed to hold them steady. As long as he makes one month's progress in a year, he is making sufficient progress, the School District claims. That is all the law requires, they say.

2. American Law

Is the School District correct? What law or laws apply to Graham's education? As an American child, Graham lives in a federal political system in a country that embraces so-called negative rights, lacks a federal constitutional right to education,[16] and leaves the delivery and funding of education primarily to the local and state levels.[17]

Federal congressional legislation Title II of the ADA and Section 504[18] requires schools to offer students with disabilities to "receive to the full benefit of public services"[19] such as education and aspires to protect such students' right to "effective communication." The 1975 Individuals with Disabilities Education Act ("IDEA"), as amended in 1997 and in 2004, governs whether a child with one or more disabilities, like Graham, is receiving a "free and appropriate public education," (FAPE) even as he progressively slips academically and socially further and further behind his classmates.[20] The interrelationship between the ADA and the IDEA is complex and

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device for the student in order to procure the necessary support for his device. 28 C.F.R. §§ 35.130, 35.160 DOJ/OCR FAQ Nov. 2014 at p. 9.

[16] See, e.g. *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 35 (1973).

[17] *Id.*

[18] 34 C.F.R. § 104.33 (2018). Section 504 provides, "No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ." 29 U.S.C. § 701 (2018). The ADAA amended the ADA. 81 C.F.R. § 53204-01 (2016).

[19] 20 U.S.C. § 1411 (2018); 20 U.S.C. § 1401(1) (2) (2018) (defining assistive technology device and differentiating it from a medical device).

[20] 20 U.S.C. §§ 1400, 1401(9) (2018).

evolving.[21] Indeed, in dealing with inexperienced parents, school districts frequently conflate IDEA compliance with ADA compliance, neglecting to mention to parents like Graham's that the School District has "effective communication" obligations under the ADA, focusing instead on the "FAPE" standard of the IDEA. Therefore, as a practical matter, this essay focuses its analysis on concerns arising from the Supreme Court's interpretation of what constitutes "free and appropriate public education" under the IDEA (only).

In 2017 in the *Endrew* case, the Supreme Court of the United States held that a FAPE requires schools to provide children with disabilities the opportunity to make more than *de minimis* educational progress, but the Court otherwise left the standard largely unspecified.[22] In the earlier *Rowley* case, the Court had held that excellence in education for children with disabilities is not required.[23] The *Endrew* Court did not reject that conclusion, but Chief Justice John Roberts stated, in this unanimous decision, that a child's "educational program must be *appropriately* ambitious in light of his circumstances" and that "every child should have the chance to meet challenging objectives."[24]

The *Endrew* Court rejected the plaintiff's argument that students with disabilities are entitled to a "substantially equal" standard of education. Rather, the majority opinion tied the level of education a child with disabilities should receive to whether that child is "showing educational progress in light of their disabilities."[25] In other words, the child is entitled to more supports only if the child is able to demonstrate his or her capacity to do more. In the United States, enforcement of these laws are therefore left to the often-overwhelmed parents of children with disabilities.[26]

So is the School District right – is Graham's progress sufficient to conform to the requirement of "a free, appropriate public education?" As a practical matter, few lawyers in the United States would be willing to press forward with FAPE cases, in order to challenge how much progress is enough progress for a child like Graham. As a result, school districts know that they are unlikely to be challenged as long as they

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[21] The *Frye* case may be altering the relationship between the ADA and the IDEA, and lower courts are currently untangling the related consequences. Although the ADA is beyond the scope of this Article, Professor Kanter has helpfully analyzed the limitations of both the ADA's theoretical orientation and its predominant focus on discrimination. See Kanter, Arlene, *The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of People with Disabilities*, 63 Drake L. Rev. 821 (2015).

[22] *Endrew F. v. Douglas Cty. Sch. Dist.,* 137 S.Ct. 988 (2017).

[23] *Bd. of Educ. Hendrick Hudson Cent. Sch. Dist., Westchester Cty. v. Rowley*, 458 U.S. 176, 187 (1982).

[24] *Endrew F.*, 137 S. Ct. at 1000-01.

[25] L. McKenna, *How a New Supreme Court Ruling Could Affect Special Education*, The Atlantic (Mar. 23, 2017), https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/ (access 25.05.2018).

[26] For some challenges associated with this policy, *see, e.g.* Eloise Pasachoff, *Special Education, Poverty, and the Limits of Private Enforcement*, 86 Notre Dame L. Rev. 1413 (2011).

provide some services, and children like Graham may never reach even a fraction of their full potential.

3. The Supreme Court's current review standard for a free and appropriate public education creates a presumption of (in)competence for children with disabilities.

Whether a child with disabilities is receiving an appropriate education under United States law, then, turns on what that child can demonstrate he/she is capable of learning.[27] Despite the seeming logical symmetry of this standard, cases like Graham's highlight a number of urgent concerns the Court's interpretation raises.

First, with Graham in mind, the Court's standard raises a critical logical and epistemological concern: how do courts or school districts know of what the child is capable? If the standard is tied to the child's capacity, then it is critical to know that capacity. The conventional answer is that a developmental neurologist will test the child to determine his/her capacity. But that is simply not possible in many cases. Take the case of the non-verbal, preliterate child with severe physical disabilities, as is Graham in our case study. At present, there simply is not an appropriate intelligence test for a preliterate young child with disabilities like Graham. With existing intelligence tests, his capacity is largely unknowable. Developmental psychologists agree that existing intelligence tests are neither norm-tested nor appropriate for children with severe physical disabilities.[28] To offer one illustration of the ineptitude of standardized tests for preliterate, physically disabled children: the classic exam, the Bayley exam, requires the psychologist to hand the very young child a bell or some similar object and observe what the child does with the object. Tests such as these are simply absurd for children like Graham, who lack the motor control to reach for, grasp, or maintain a hold on a bell. Nevertheless, these norm-tested scales remain the currency of competence-markers.[29] Administrative courts and appellate courts are certainly no better prepared than are cognitive psychologists to ascertain the intelligence or capacity of a particular child, nor can they rely on existing tests.

Careful readers may object that while it may not be possible to gather accurate or precise assessments of a child's intelligence, a general baseline can be developed from

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[27] Typically developing children, by contrast, are presumptively enrolled in grade-level classes.

[28] J.F. Fagan, A Theory of Intelligence as Processing Implications for Society, 6 Psychol. Pub. Pol'y & L. 168, 170-176 (2000).

[29] Indeed, at great expense and investment of time, Graham has been subjected to over four of these tests in his short life. When he consistently scores low, the psychologist administering the test explains in writing that the results are not accurate, and elaborates the many ways the test does not measure his aptitude. She adds then that in fact he appears to be quite bright, listing many of her *ad hoc* perceptions of his intelligence.

these tests, and it is therefore most efficient for the school to proceed in distributing limited resources based on this approximate baseline.[30] Yet such a definition of efficiency prizes the District's resources in the short-term of the academic school year, failing to take into consideration the wasted cognitive potential of the child over the long-term, and the value for society of ensuring that the student has a strong educational foundation in order to pursue employment and be as independent as possible later in life. Indeed, state-run Early Intervention programs already recognize the need for resources to be offered to children with disabilities early in their development, before school age.

A related second concern, then, relates to the burden of proof. The Court's interpretation of the "appropriate" standard effectively places on the child the burden to prove that she is worthy of the supports in order to receive them. Thus a child with communication disabilities like Graham must first demonstrate that he is capable of reading at grade-level in order to secure the very supports he requires to read at grade-level. For a child like Graham, whose physical limitations prevent him from accessing the curriculum without extensive supports, the futility of such a standard is clear. Graham cannot read aloud or demonstrate his comprehension of text he has read without assistive technology. Yet Graham requires services and supports as well as modifications to the curriculum to be able to meet and keep up with the grade level. Each year that the system does not offer Graham these necessary supports to reach grade level, he slips further behind and becomes less and less capable of demonstrating that he is capable of functioning at grade level. Indeed, under the Court's current standard, it is likely that with each passing year, what is deemed to be "appropriately ambitious for him in light of the challenging circumstances"[31] will only minimally advance what he is already achieving.

The third concern is the perverse incentives these policies create for schools. The Court's standard offers school districts tremendous leeway, possibly even incentivizing schools not to discover the child's capacities, lest they need to provide supports for him to adequately access the curriculum. In this way, placing the impetus on the child to demonstrate capacity before offering him supports, even in unprovable circumstances, may effectively incentivize schools to have consistently low expectations for students like Graham. Even in the child's earliest developmental periods, schools are not required to "presume competency"[32] and allocate resources accordingly. Low expectations need not only be of concern to disability rights advocates and people with disabilities. Taxpayers, too, may well be worried that the

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[30] D. Grissmer, K. Grimm, S. Aiyer, W. Murrah, J. Steele, *Fine motor skills and early comprehension of the world: Two new school readiness indicators*, *46*(5) Developmental Psychology 1008-1017 (2010).

[31] *Endrew F. ex rel. Joseph F. v. Douglas Cnty. Sch. Dist. RE-1*, 137 S.Ct. 988, 1000 (2017).

[32] D. Biklen, J. Burke, Presuming Competence, 39 *Equity & Excellence in Education* 166 (2006).

Court's present legal interpretation of the "appropriate" standard is problematic. The concern is that the present interpretation creates the near-certain risk that a child like Graham will be far less likely to achieve independent employment. With an education that presumed his competence and sought to support him accordingly from an early age, however, he would not face as many obstacles to securing employment.

The next section explores the bias that the current standard perpetuates. In short, although children with disabilities are now provided with a free, appropriate public education in the United States, too often, educators, lawmakers, and the public still do not hold disabled children to a standard that would allow them to achieve their full potential.

4. Global Norms: By Embracing a Social Model of Disability, US Courts Could Help Students with Disabilities by Requiring Schools to Presume Competence

Some disability rights advocates might ask, why should a child be required to demonstrate ability in order to receive supports? Indeed, even a child who might not ever succeed academically at the same level as her peers deserves to have adequate supports to be included with her peers and to achieve her potential.

Although the United States has famously refused to ratify the CRPD,[33] disabled children in America could benefit from the social view of disability that the CRPD embraces. The current *Endrew* standard arguably derives from a medical model of disability. This model, under which, as Professor Liz Emens says, "a disability is a lack that requires costly filling"[34] predominates in American disability law. The *Endrew* standard implies that capacity is predetermined and that it must be proven in order for a person to receive supports. By contrast, under the CRPD, a disability refers "to a limitation which results in particular from long-term physical, mental or psychological impairments *which in interaction with various barriers* may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers."[35]

Adopting a social model of disability,[36] and examining impediments to an individual's ability to function, would uniquely assist American children like Graham

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[33] J. Lord and M. Stein, The Law and Politics of U.S. Participation in the UN Convention on the Rights of Persons with Disabilities, *in* S. Hertel and K. Libal (eds.), Human Rights in the United States. Beyond Exceptionalism 119 (Cambridge: University Press, 2011).

[34] Elizabeth F. Emens, *Integrating Accommodation*, 156 U. Pa. L. Rev. 839, 840 (2008).

[35] For an explanation of the background of the definition of disability in the CRPD, see A. Kanter, The Development of Disability Rights Under International Law: From Charity to Human Rights (Routledge: 2015, 2017).

[36] For a discussion of the social model of disability and how it differs from other models of disability, see A. Kanter, *The Law: What's Disability Studies Got to Do with It or An Introduction to Disability*

in achieving their potential in education. Were the Supreme Court of the US to embrace the theoretical approach which guided the drafting of the CRPD, American case law might well require a presumption of the young child's competence and an exhortation to the school to provide students with disabilities with the necessary resources to achieve *their full potential.*

5. Implication of this US Case Study for CRPD States Parties: Working to Overcome Judges' Theoretical Limitations

In order to ensure that lawmakers in countries that have ratified the CRPD accurately and thoroughly embrace the social model of disability in the CRPD, judges will need to be trained not only on the legal provisions of the treaty, but also in the social theories of disability that frame those provisions. If judges are made aware of and bear in mind the history of extensive legal and social discrimination against people with disabilities,[37] their interpretation of the CRPD's provisions will necessarily be more empowering. Armed with this background information and faced with a child like Graham and language perhaps requiring a "free and appropriate public education," a judge might require the School District to intensify supports for the child as he initially learns to read and speak.

In short, this analysis demonstrates one way that, in the absence of more specific legislation, judicial interpretation of existing law can be determinative for children with disabilities seeking to realize their educational rights – this can be true in both civil and common law systems. In order for provisions of the CRPD, for example, on accessibility, inclusive education, and communication, among others, to be interpreted progressively to realize the rights of children with disabilities, judges who have limited experience with disability, need to be trained on how social obstacles create and reify experiences of disability. Only once judges and lawmakers, most of whom are able-bodied and products of segregated educational systems themselves, are introduced to and begin to understand the comprehensive manner that social policies and societal attitudes create and reify lived experiences of disability will the law begin to change.

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[37] In fact, judges have frequently perpetuated the discrimination. See, e.g. *Buck v. Bell*, 274 U.S. 200 (1927).

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The Right to Education for the Persons with Disabilities. Special View on the Romanian Legislation

Abstract: The current study starts from the fact that the right to education – a fundamental human right – should be organized in such manner as to ensure equal opportunities for all persons. First of all, it refers to the prohibition of all forms of discrimination. Even though national and international regulations may state this clearly and in both general and specific terms, the right to education and its effective application remains a problem for certain categories of persons. The arbitrary separation of children with disabilities in special schools, the maladjustment of schools generally in meeting the needs of persons with disabilities and even the unavailability of special forms of education, remain realities in some states. In this context, the current study reflects on the way in which the right to education is guaranteed for persons with disabilities, focusing on the Romanian legislation and advocates the inclusive education of these persons.

Keywords: right to education, persons with disabilities, Romanian legislation, ECHR jurisprudence.

1. Introduction

In contemporary times, socio-economic and scientific evolution together with the growth and diversity of human ideals, have generated permanent expansion of human rights and fundamental freedoms. Among all these rights, a special place is held by the right to education because fundamentally it connects to the "true existence of other rights"[1].

In his paper, "*Didactica magna*"[2], Johann Amos Comenius synthesizes the role of education in the life of each individual, stating that "*the nature favors the child at birth only with the seeds of science, of morals and religion, these becoming assets of each individual only by education. The man cannot be a man unless he is educated*". The literature has stated that "without the mentioning of this right it cannot be seen the capacity of man in stating his skills. Its recognition represents a guarantee of the subsequent insurance of a qualification, specialization and professional improvement"[3].

Thus, the right to education is first of all recognized in Art 32 of the Romanian Constitution. Also, the importance of the education of children, youth and adults is clearly stated in Art. 4 of Law No. 1/2011[4], as well as in Art. 29 of the International Convention on Children's Rights[5].

According to Law No. 1/2011, the supreme purpose of education is to form the necessary skills for personal development and fulfillment, social integration and active citizenship within society, employment, the formation of a life concept based on humanistic and scientific values, on national and universal culture and on the stimulation of intercultural dialogue, education in the spirit of dignity, tolerance and respect for human rights and fundamental freedoms, cultivation of sensitivity to human issues, to moral and civil values and respect for nature and the natural, social and cultural environment.

Also, according to Law No. 272/2004 on the protection and promotion of the rights of the child[6], "The child has the right to receive an education which would allow him or her to develop his or her capacities and personality, in non-discriminatory conditions". In the same meaning, Art. 28 of the International Convention on Children's Rights recognizes non-discriminatory access to educational services.

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[1] F. Mahler, "Dreptul la educaţie – undrept fundamental al tuturor copiilor lumii", *Journal of Pedagogy*, Bucharest, 1979.

[2] J. Amos Comenius, *Didactica magna. Translation, notes, comments and study by Iosif Antohi*, Bucharest 1970, p. 31.

[3] A. Drăghici, *Protecția juridică a drepturilor copilului*, Universul Juridic Publ.-house, Bucharest 2013, p. 180.

[4] Published in the Official Gazette of Romania, No 18/10 January 2011.

[5] Ratified in Romania by Law No 18/1990, published in the Official Gazette of Romania, No 314/13 June 2001.

[6] Published in the Official Gazette of Romania, No. 557/23 June 2004 and entered into force on 1 January 2005.

2. The right to education for disabled persons in the Romanian legislation

Beyond the provisions abovementioned, which represent the general legal framework in the area of the right to education, Law No. 448/2006 on the protection and promotion of the rights of disabled persons[7], dedicates an entire section to the guarantee of access to education for disabled persons. Also, since 2010 Romania has ratified the Convention on the Rights of Persons with Disabilities[8] adopted in New York by the United Nations General Assembly on 13 December 2006.

Art. 15 of Law No. 448/2006 guarantees for disabled persons free and equal access to education, regardless of age, in accordance with the type and degree of handicap and related educational needs, as well as continuous learning and professional training for life. Choosing the type and form of education required and the educational unit that will provide it shall be the prerogative of the person with disabilities or, where appropriate, his/her family or legal representative.

In Romania, education for disabled persons represents an integrant part of the national educational system and the means by which it is achieved are: a) general education; b) integrated specialized education organized within the general education system; c) special education units; d) home education or education within healthcare units; e) other forms of learning.

Within the educational process, regardless of its level, the persons with disabilities have, according to Art. 18 of Law No. 448/2006, the right to: educational support services; the endowment with technical aids and equipment adapted to the type and degree of handicap and the use thereof; the adaptation of furniture in classrooms; school manuals and courses in accessible format for pupils and students with sight deficiencies; the use of assistive equipment and software for taking exams of all types and at all levels.

In order to support the integration of disabled persons within the general education system, the legislator has stated that the educational support for persons registered within the educational system shall be provided using supportive and itinerant teachers, where appropriate.

Also, with the purpose of guaranteeing the right to education for disabled persons a series of material incentives have been stated in which disabled pupils and/or persons with special needs shall benefit from free meals and accommodation in boarding schools, and students with a severe and accentuated handicap shall benefit, upon request, from a 50% discount on the cost of accommodation and meals in student canteens and hostels. Disabled children under school age, pupils and

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[7] Published in the Official Gazette of Romania, No 1/3 January 2008.

[8] Ratified in Romania by Law No 221/2010, published in the Official Gazette of Romania, No 792/26 November 2008.

students, along with their personal carers and/or professional carers as the case may be, shall, free of charge, have the right to attend summer camps once in each year, irrespective of the education form.

To ensure the access of disabled persons to education units and institutions, in accordance with Art. 19 of Law No. 448/2006, public authorities are required to take the following specific measures:

a) Promotion and guarantee of access to professional education and training programs for disabled persons;
b) Assurance of domiciled school education for immobilized disabled persons during mandatory school periods, and of school preparation, irrespective of the place of residence of the disabled person, including with the support of itinerant teaching staff;
c) Assurance of access to permanent forms of education, adapting them to the educational needs of disabled persons;
d) Support of the cooperation between special or mass education units with the family and community, with the view of ensuring an educational offer answering the individual needs of disabled persons;
e) Support in the preparation of teaching staff with regard to adapting educational practices for disabled pupils in usual education groups or classes;
f) Assurance of the possibility of a sportive activity by any disabled person, and the preparation of the didactic staff in view of appropriation by them of certain specific medical and technical notions;
g) Assurance of support educational services for disabled persons and their families, through experts in the field of special psycho-pedagogy;
h) Assurance of access to educational units and institutions.

In turn, Art. 24 of the Convention on the Rights of Persons with Disabilities establishes a set of obligations for the state-parties, Romania included, for the achievement of the right to education of persons with disabilities, without discrimination and in compliance with the principle of equal opportunities. The state-parties shall insure an inclusive educational system for all levels, as well as continuous learning, directed to: the full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity; the development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential; enabling persons with disabilities to participate effectively in a free society.

For the achievement of this right, the state-parties have the obligation to make sure that: a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability; b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live; c) Reasonable accommodation of the individual's requirements is provided; d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education; e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

Also, state-parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. Among the effective measures above listed in this meaning by the Convention, are to be mentioned: (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring; (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community; (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or both blind and deaf, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.

Not least, according to Art. 24 Para 5 of the Convention, the state-parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Therefore, Art. 24 of the Convention related to the right of education cannot be analyzed separately, but in correlation with equality and non-discrimination (Art 5), children with disabilities (Art. 7), awareness-raising (Art. 8) and accessibility (Art. 9).

3. The right to education for disabled persons – inclusive education

Although Art. 24 of the Convention on the Rights of Persons with Disabilities states the need for an inclusive education system at all levels for persons with disabilities, in many states, including in developed states which have ratified the Convention, persons with disabilities are frequently excluded from education based on disabilities or receive educational experiences far below those received by persons free of disabilities or, where children with disabilities are included in the normal educational system, without receiving an appropriate level of support[9].

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[9] L. Manea, *Accesul la educație al tinerilor cu dizabilități în România, cu focalizare pe învă*țământul secundar superior, vocaț*ional* ș*i universitar*, RENINCO Association, Romania 2016, p. 19.

For instance, in Romania, as recently noted by the European Centre for the Rights of Children with Disabilities[10], over 31,000 children with disabilities are arbitrarily segregated in special schools, almost 18,000 are outside any form of education, while schools in general remain inadequately capable of meeting the special needs of these children, and the prevalence of discrimination in education based on disabilities remains high.

Though our state has ratified the Convention before the adoption of the Law of national education, the concept of "inclusive education" is not covered by it. The provisions regarding the education of children with special needs refer to two special forms of education, segregated and integrated. On the other hand, legislation introduced subsequent to the Law of education has provisions regarding centers for inclusive education (former special segregated schools), but as already mentioned[11], a strange form of inclusion has been reached, that of incorporating children with different disabilities in the same study formations, which is not very productive.

From analysis of the national regulations in this area, it seems that integration and inclusion are confused with each other, even though the two notions have different meanings in the international documents which specifically refer, to special educational needs and to disabilities. The concept of inclusion represents the base of the Convention and has the nature to stimulate inclusive education for all persons with disabilities, to all educational levels – primary, secondary and tertiary, and the legislation should therefore cover inclusive education not only in terms of primary education, but also for the pre-vocational or vocational training, of programs for adult transition and adult education[12].

Unfortunately, the Romanian legislation regarding special education "reveals an old conception and ignores the non-absolute vision, proposed by the inclusive education, the need to combine the equality and equity between students, of personalizing the educational approach and path"[13].

Given that the UN Committee for Persons with Disabilities has clearly stated that the right to education for these persons can be achieved in a real and effective manner only through inclusive education, it is necessary to change the legislation as it presently stands to bring it in line with Art. 24 thus bringing an end to the ambiguity that exists in the education of persons with disabilities.

In this regard, according to General Comment No. 4 to Art 24, the National Implementation, adopted by the UN Committee on the Rights of the Persons with

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[10] http://www.cedcd.ro/.

[11] L. Manea, *op. cit.*, p. 22.

[12] *Ibidem.*

[13] E. Vrăsmaş, M. Livius, T. Vrăsmaş, *Studiu privind legislația referitoare la educația copiilor cu dizabilități și alte cerințe educaționale speciale (SEN) din perspectiva educației inclusive*, *„REPERE Magazine"*, vol. 8 no. 1/2014, University of Bucharest Press, 2014, p.17.

Disabilities on 2 September 2016, "*States parties must ensure a comprehensive and inter-sectoral commitment to inclusive education across Government. It cannot be realized by education ministries in isolation. All relevant ministries and commissions with responsibilities that cover substantive articles of the Convention must commit to and align their understanding of the implications of an inclusive education system in order to achieve an integrated approach to work collaboratively towards a shared agenda. (…) Partnerships should also be forged with service providers, OPDs, media, wider civil society organizations, local authorities, students associations and federations, universities, and teacher education colleges*".

Therefore, it is emphasized the importance of the signatory states for the Convention to end the scholar segregation and to insure the right to education by integration within the education system as a whole.

4. ECHR jurisprudence. Case file Çam v Turkey

The decision of the European Court for Human Rights of 2016, ruled in the case file Çam *v Turkey*[14] underlines that "*the denial of a person to participate in the educational process, based on a disability, shall be considered as discrimination and a violation of the right to education of that person*".

This case is based on a request (no. 51500/08) submitted against the Republic of Turkey, by a state national, Ms. Ceyda Evrim Çam (the plaintiff) has notified the Court that on the 22 October 2008, based on Art 34 of the Convention for the protection of human rights and fundamental freedoms (the Convention).

The plaintiff refers to a violation of her right to education (Art 2 of the Protocol 1 of the Convention) and that she has been the victim of discriminatory treatment based on her disability (Art. 14 of the Convention).

In fact, the plaintiff, a blind person, applied to take part in the entrance competition for the Turkish National Music Academy attached to Istanbul Technical University (the Music Academy) for the 2004-2005 academic year. On 21 and 31 August 2004 she had taken the practical selection tests performing on the bağlama, which she passed. On subsequently applying for admission, the Music Academy had rejected the plaintiff's application on grounds of her disability.

During the internal process initiated by Ms. Çam, in their defense, the Board of the Istanbul Technical University has claimed that the plaintiff had not submitted a medical report certifying her fitness to study at the Music Academy, a requirement necessary for all candidates and that, in the absence of appropriate equipment and teaching staff with the necessary expertise required, the Music Academy was not

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[14] ECHR, Decision in the case file Çam v Turkey (Request No 51500/08, 23 February 2016).

able to provide education for blind students or for other persons with disabilities, regardless of their nature.

On 14 October 2004 the Administrative Court dismissed the request of the plaintiff. On 18 April 2006 the applicant's parents, acting in her name and on her behalf, lodged an appeal on points of law with the Council of State against the decision of the Administrative Court, which has been rejected. This too failed to bring satisfaction and in consequence a request was submitted for the case to be heard before the European Court of Human Rights (ECHR).

The ECHR admitted the case, considered the evidence and in its conclusions decided that "*the refusal to enroll the applicant in the Music Academy was based solely on the fact that she was blind and that the domestic authorities had at no stage considered the possibility that reasonable accommodation might have enabled her to be educated in that establishment. (…) the Court considers that the applicant was denied, without any objective and reasonable justification, an opportunity to study in the Music Academy. It therefore finds that there has been a violation of Article 14 of the Convention, in conjunction with Article 2 of Protocol No. 1*[15]."

5. Conclusions

The analysis of the legal provisions and of the jurisprudence, allows us to conclude that in order to be in accordance with the position of the UN Committee for Persons with Disabilities, Romania should initiate the reform of its educational system. This obligation for reform belongs to decision-makers and concerns the desegregation of pupils and students, and the guarantee of the right to education for persons with disabilities culminating in their full integration into the country's educational system. The General Comment No 4 to Art. 24 of the Convention on the Rights of Persons with Disabilities, adopted by the UN Committee – CRPD in September 2016, expresses the evolution achieved by the practice of other states and by the development of research in this area. Also, it states that for education to be of benefit to persons with disabilities an environment adjusted to their needs must be created, with the isolation of children with disabilities in special schools not being a solution.

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[15] *Ibidem.*

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Children with Disabilities in the Committee Ministers of the Council of Europe's Soft Law

Abstract: The rights and freedoms of disabled children have for a long time been a very important subject for the international protection. The Council of Europe actively participates in this process creating a legal standard to respect the rights of this special social group. A very important contribution is assigned to the Committee of Ministers of the Council of Europe, which, as a statutory body, issued a recommendation for member states according to which states should create legal protection for disabled children. The subject of the following article is to analyse legislative acts. Although they are the acts of the so called soft law, they play an important role in creating the legal standard for the rights and freedoms of disabled children. The role of these documents is a lot bigger if you consider the fact that there is nowadays no treaty that pays attention to the issue of protection of disabled children and discusses these issues in any great detail. Therefore, recommendations detail international legal regulations, i.e. the Convention on the children's rights or the Convention on the rights of disabled people referring to the protection of the rights of disabled children only to a minor extent. The analysis included three recommendations of the Committee of Ministers, which focused on the subject of disabled children in the following areas: their integration in social life, deinstitutionalisation, education and integration of children with autism spectrum disorders.

Key words: disability, disabled children, social integration, deinstitutionalisation

The notion of disability has been changing throughout history. It was largely dependent on historical, socio-cultural, and geographical factors as well as knowledge of society and the values that dominate in it. The disabled, despite their constant presence in societies, have often been considered outsiders[1]. As sick individuals, they were often stigmatized and isolated from society as in ancient Inca, or literally physically suppressed as in ancient Sparta. More recent times put a gloomy shadow of

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[1] G. Borowski, Sposoby wspierania osób niepełnosprawnych na przestrzeni dziejów – wybrane przykłady, „Niepełnosprawność – zagadnienia, problemy, rozwiązania", 2012, no. IV (5)/99, p. 2; B. Seyda, Dzieje medycyny w zarysie, Warszawa 1973, p. 26.

the Second World War and the criminal activity of Nazi Germany on whose territory (and the territory of the occupied countries) there was a systematic extermination of the population, including many people with physical or mental disabilities.

Very special groups of people with disabilities include children who for many years, and even until recently, have been treated as "the accident", social "margin" without the opportunity for normal education, therapy or socialisation. Children with physical and mental defects "were given" to closed institutions, health centers or private care centers. With the post-war development of human rights law, both in the area of national law systems and the international law systems, children with disabilities were entitled to legal protection as a group especially vulnerable to discrimination due to their physical and mental deficits[2]. In Europe, in the system of the international human rights law, the legal protection of disabled children is implemented by both international regional organisations, the Council of Europe, the European Union and Organization for Security and Co-operation in Europe as well as the UN – the organisation of universal i.e. global extent[3].

The subject of the following considerations is the law-making activity of the Committee of Ministers of the Council of Europe (hereinafter: CMCoE) on the protection of the rights of children with disabilities. Three latest CMCoE recommendations regarding the protection of the rights of children with disabilities have been analysed. It should be stressed that the Council of Europe has quite a rich practice in implementing issues related to the protection of children's rights, including disabled children in the process of establishing soft law. The category includes legal acts issued by the statutory organs of the Council of Europe, i.e.: the Committee of Ministers and the Parliamentary Assembly, as well as by treaty bodies established in treaties adopted by member states under the aegis of the Council of Europe (e.g. the European Social Committee).

The recommendations of the Committee of Ministers of the Council of Europe play a very special role in the legal protection of children with disabilities. This is influenced by a few aspects, surely by the fact that in the legal system of the Council

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[2] M. K. Pallab, G. L. Darmstadt, Childhood Disability in Low- and Middle Income Countries: Overview of screening, prevention, services, legislation, and epidemiology, „Pediatrics", vol. 120, Supplement 1, July 2007, p. S21; D. Mont, Measuring Disability Prevalence, Social Protection Discussion Paper no. 0706, The World Bank, Washington, D.C., March 2007, p. 35.

[3] More: B. Byrne, Hidden contradictions and conditionality: conceptualisations of inclusive education in international human rights law, „Disability & Society", 2003, no. 28(2), p. 232-244; C. Latimier, J. Šiška, Children's rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities, Brussels 2011, Inclusion Europe, p. 26.; UNICEF, Promoting the rights of children with disabilities, „Innocenti Digest", 2007, no. 13, p 17; J. Arsenjeva, Briefing paper: "Implementation of the UN Convention on the Rights of Persons with Disabilities in the EU External Relations", European Parliament 2013, p. 11; M. Ballesteros, K. Jurkiewicz, N. Meurens, Member States Policies for Children with Disabilities, European Parliament 2013.

of Europe, no treaty dedicated solely to the protection of the rights and freedoms of children with disabilities has yet been established. There are, however, treaty obligations regarding in general the rights of children and people with disabilities. The regulations refer to the legal and recent situation and problems of disabled children, which do not change the fact that there is a lack of comprehensive regulation regarding the protection of the rights and freedoms of children with disabilities. Therefore, nowadays, The Council of Europe has a regulative mosaic in this scope which consists of the acts referring to the rights and freedoms of children with disabilities, thus, often in a limited form – this is a catalogue of legal acts and documents from treaty law to soft law[4] to the declarations and positions acts placed at the summits of the Council of Europe[5]. It seems to be a very important argument that is in favour of choosing the subject because the recommendations significantly show the problem of the lack of unification of legal standards of protection of children with disabilities in the system of the Council of Europe. It is visible in the numerous references to legal acts and documents on the protection of the rights and freedoms of children with disabilities that appear in the recommendations of CMCoE. Regardless of this, all soft law acts make codes of good practice, they affect legal systems of the member states and encourage in their activities to apply different legal and non-legislative solutions, which involve the actions that improve the legal and actual situation of disabled children.

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[4] For example, recommendations of the Parliamentary Assembly of the Council of Europe, particularly: Recommendation 1666 (2004) on "A Europe-wide ban on corporal punishment of children", Recommendations 1601 (2003) on "Improving the lot of abandoned children in institutions" and Recommendation 1698 (2005) on "The rights of children in institutions: follow-up to Recommendation 1601 (2003)". http://website-pace.net/en_GB/web/apce/documents (access 17.12.2018).

[5] Declarations and rules adapted during the conference and summits taking place in the Council of Europe and other documents: International Classification of Functioning, Disability and Health (ICF) (2001), and to the International Classification of Diseases (ICD-10) of the World Health Organisation; Final Declaration of the 2nd European Conference of Ministers responsible for Integration Policies for People with Disabilities held in 2003 in Malaga, Spain, "Progressing towards full participation as citizens"; The Third Summit of Heads of State and Government of the Council of Europe (Warsaw, 16-17 May 2005); Declaration of the European Ministers responsible for Family Affairs at their 28th session (Lisbon, Portugal, 2006), which underlines the necessity to adopt programmes aimed at providing appropriate support for families with children with disabilities; Report of the High Level Task Force on Social Cohesion in the 21st century (2007), which attaches a fundamental role to human rights as the cornerstone for cohesive societies along with human dignity and recognition, with particular attention to the interests of vulnerable or potentially vulnerable groups; "Building a Europe for and with children" 2009-2011 Strategy, which pursues and enhances the Council of Europe's commitment to children's rights and the eradication of violence against children, with special focus on particularly vulnerable children, without parental care and/or with disabilities; Guidelines of the Committee of Ministers of the Council of Europe on child-friendly justice (as adopted on 17 November 2010) and Guidelines on child-friendly health care (as adopted on 21 September 2011).www.coe.int (access 15.12.2018)

1. Integration as a chance to normalise the life of children with disabilities as an objective recommendation of the Committee of Ministers of the Council of Europe.

Integration which refers to disabled children may be viewed in a narrow sense as a guarantee for these people to the right to education and work in the normal social structures. In the broad sense, integration is a process that prepares disabled children for life in society as well as shaping proper interpersonal relations between capable and disabled people. Literature stresses that integration is viewed in a mutual treatment of capable and disabled children in which the same rights are respected, in which the identical conditions for maximum overall development are created for both groups of people[6]. The aim of integration is to enable the people with disabilities to lead a normal life on the same principles as for other members of the particular social groups. Integration suggests enabling all levels of education – elementary, general, and vocational to all handicapped youth[7]. It also enables cultural achievements and various forms of active pastime that healthy young people practise. The main aim of integration is to prepare disabled people for a dignified life in the open community and actively undertaking various social, family, professional and cultural roles. CMCoE recommendations indulge these values and integration aims. It is worth stressing that all CMCoE recommendations[8] are built on the mutual

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[6] A. Solish, P. Minnes, A. Kupferschmidt, Integration of Children with Developmental Disabilities in Social Activities, „Journal on Developmental Disabilities", 2003, Vol. 10, no. 1, p. 115-122; O. Sinyavskaya, S. Vassin, Social Integration of Youth with Disabilities. Papers prepared for the UN workshop on "Social Integration of Youth with Disabilities", Independent Institute for Social Policy, St. Petersburg December 22-24, 2003, p. 1-49, http://www.socpol.ru/eng/publications/pdf/Disability_eng.pdf (access 14.12.2018).

[7] D. A. White, R. A. Dodder, The relationship of adaptive and maladaptive behaviour to social outcomes for individuals with developmental disabilities, „Disability & Society", 2000, no. 15(6), 897-908.

[8] Resolutions and recommendations of the Committee of Ministers of the Council of Europe, notably: Resolution (77) 33 on placement of children, which stresses that placement should be avoided as far as possible through preventive measures of support to families in accordance with their special problems and needs; Recommendation No. R (79) 17 concerning the protection of children against ill-treatment; Recommendation No. R (84) 4 on parental responsibilities; Recommendation No. R (87) 6 on foster families; Recommendation No. R (94) 14 on coherent and integrated family policies; Recommendation No. R (98) 8 on children's participation in family and social life; Recommendation Rec(2002)8 on child day-care; Resolution ResChS(2004)1 on collective complaint No. 13/2002 by Autisme-Europe against France and the decision of the European Committee of Social Rights on the merits of the complaint; The Revised Strategy for Social Cohesion (2004); Resolution ResAP(2005)1 on safeguarding adults and children with disabilities against abuse; Recommendation Rec(2005)5 on the rights of children living in residential institutions; Recommendation Rec(2006)19 on policy to support positive parenting; Recommendation Rec(2006)5 of the Committee of Ministers to member States, referred to as the Council of Europe Disability Action Plan 2006-2015; Recommendation CM/Rec(2009)8 of

legal basis which directly or indirectly protects the rights and freedoms of disabled children. Preamble recommendations make reference to legal acts and they can be divided into two groups: standards of the Council of Europe and the United Nations[9]. Treaties of the Council of Europe, notably: the terms of Article 15.*b* of the Statute of the Council of Europe[10], The Convention for the Protection of Human Rights and Fundamental Freedoms[11], European Social Charter (Revised)[12], The European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment[13], The European Convention on the Exercise of Children's Rights[14] and The Convention on Contact concerning Children[15]. Treaties of the United Nations, notably: The Convention on the Rights of the Child[16] and The Convention on the Rights of Persons with Disabilities[17].

2. Recommendation CM/Rec (2013)2 of the Committee of Ministers to member States on ensuring full inclusion of children and young persons with disabilities into society.

Recommendation (2013)2[18] concerns the problem of inclusion of children and young people with disabilities into society. Both literature and practice have long been showning that disabled people, including children, have to be aware of the rights and

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the Committee of Ministers to member States on achieving full participation through Universal Design; Strategy and Council of Europe Action Plan for Social Cohesion, as adopted by the Committee of Ministers in 2010; Recommendation CM/Rec(2011)12 of the Committee of Ministers to member states on children's rights and social services friendly to children and families; Recommendation CM/Rec(2012)13 of the Committee of Ministers to member States on ensuring quality education; The Council of Europe Strategy for the Rights of the Child 2012-2015 (now is: Council of Europe Strategy for the Rights of the Child (2016-2021)). https://www.coe.int/en/web/children/legal-standards (access 12.09.2018).

[9] For example: the United Nations: Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993).

[10] Statute of the Council Of Europe 5.05.1949, European Treaty Series no. 1.

[11] The Convention for the Protection of Human Rights and Fundamental Freedoms , European Treaty Series no. 1.

[12] The European Social Charter (Revised), European Treaty Series no. 163.

[13] The European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, European Treaty Series no. 126.

[14] The European Convention on the Exercise of Children's Rights, European Treaty Series no. 160.

[15] The Convention on Contact concerning Children, European Treaty Series no. 192.

[16] The Convention on the Rights of the Child, United Nations Treaty Series vol.1577, p. 3.

[17] The Convention on the Rights of Persons with Disabilities, United Nations Treaty Series vol. 1577, p. 3.

[18] Recommendation CM/Rec (2013)2 of the Committee of Ministers to member States on ensuring full inclusion of children and young persons with disabilities into socjety, CM/Del/Dec(2013)1181/6.2.

obligations that stem from full participation in social life. The Recommendation in its first adnotations stresses that children and young people with disabilities should take an active part in social life and be at the same time its integrative part[19]. They should have the chance for: social and professional development, getting a job, establishing strong social and family bonds with the respect of having equal status of an equal citizen[20]. Unfortunately, discrimination of disabled children (often multilayered), including the lack of access to appropriate sources and support in development of their perspectives often limit the chances of developing their abilities and contribution in social life. Therefore, it is very important to build a strategic approach by states coordinated by various sectors[21], e.g. education, professional inclusion, and cultural life of disabled people so that they can become autonomous and active participants in society[22] . The subject scope of the recommendation covers four areas: promoting their full inclusion in society, their participation in the selection and decision making, support for the empowerment of children and young people with disabilities and inclusive education that facilitates full citizenship.

Promoting full affiliation in society. Recommendation strictly emphasises the basic principle of the system of protection of human rights in the Council of Europe, namely stressing that protection and respect for human rights of all people with disabilities is a fundamental duty of each and every member state. It is stressed that violation of the rights of disabled people, including children and young people, makes them disadvantaged and hinders their active participation in society in all its aspects: political, public, economic, social or cultural[23]. This often translates directly to their level of life, sometimes even in poverty. Reviewing literature as regards poverty, it can be assumed that disability can be one of the social risk factors that significantly affects the quality of life of a particular person and his/her family[24] .

This aspect plays an important role in the activities of the countries which should aim for strengthening a social role and the position of children with disabilities in their early life thanks to positive program actions, incentive and other ways like education on human rights.

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[19] Zob. szerzej: B. Olszewska, Integracja dzieci i młodzieży niepełnosprawnej szansą na normalizację życia społecznego, w: (red.) G. Dryżalowskiej, H. Żuraw, Integracja społeczna osób niepełnosprawnych, Warszawa 2004, p.113.

[20] Point 1 Recommendation CM/Rec (2013)2.

[21] N. Groce, et al., Disability and Poverty: The need for a more nuanced understanding of implications for development policy and practice, „Third World Quarterly“, vol. 32, no. 8, 2011, pp. 1493-1513.

[22] Points 2 and 3 Recommendation CM/Rec (2013)2.

[23] Point 4 Recommendation CM/Rec (2013)2.

[24] J. J. Błeszyński, M. Orłowska, Poziom partycypacji społecznej rodzin z dziećmi ze spektrum zaburzenia autyzmu, in: S. Neslušanová, M. Niklová, E. Jarosz (ed.), Sociální pedagogika ve světle společenského, institucionálního a individuálního ohrožení, Brno 2015, p. 649.

Participation in choosing decisions and making them. Recommendation emphasises the fact that children and young disabled people should have a chance in making decisions about their life. This concerns both active political, public, economic, social and cultural life. Here there is a role of parents, caretaker, educatiors, etc. It is especially important in supporting and making mutual decisions about their life.

Support for empowerment of children and young disabled people. The aspect of the so called empowerment concerns appropriate education (applied to their age and possibilities) on the rights and duties of disabled children as well as realising about the ethical and cultural norms that are present in a given society[25]. Building awareness in disabled children plays a significant role in promoting social integration and the possibility of using their potential[26].

Inclusive education and facilitating full citizenship. The Recommendation emphasises that all children and young people with disabilities have the same aspirations and aims as people without disabilities in the areas of education, work, vocational training and independent living. Therefore, it is crucial that schools and educational institutions, parents, guardians, etc. recognise the importance of meeting the aspirations of children and young people with disabilities[27]. The process of social integration between healthy and disabled children requires two-way educational interactions[28], i.e. developing and strengthening a positive attitude and behaviour of capable children towards disabled children and strengthening self-esteem in a disabled child, his/her motivation and the ability to have contact and build relationships with other children, and positive emotional attitude to them[29]. It is worth noting that the concept of inclusive education was included in several important international documents, i.e.: The Salamanca statement on principles, policy and practice in special needs education (1994)[30], Standard Rules on the

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[25] Point 7 Recommendation CM/Rec (2013)2.

[26] Point 10 Recommendation CM/Rec (2013)2.

[27] Points 13 Recommendation CM/Rec (2013)2.

[28] O. Abosi, T. L. Koay, Attaining Development Goals of Children with Disabilities: Implications for Inclusive Education, „International Journal of Special Education", 2008, vol. 23, p. 1-10.

[29] A. Maciarz, Z teorii badań społecznej integracji dzieci niepełnosprawnych, Kraków 1990, s. 67 i nast.; J. Zabłocki, Integracja szansą wychowania nowego pokolenia, Płock 2002 , p. 76 and next.

[30] More than 300 participants representing 92 governments and 25 international organisations met in Salamanca in 1994 to further the objective of Education for All by considering the fundamental policy shifts required to promote the approach of inclusive education, namely enabling schools to serve all children, particularly those with special educational needs. Organised by the Government of Spain in co-operation with UNESCO, the Conference brought together senior education officials, administrators, policy-makers and specialists, as well as representatives of the United Nations and the Specialised Agencies, other international governmental organisations, non-governmental organisations and donor agencies. The Conference adopted the Salamanca

Equalization of Opportunities for Persons with Disabilities (1993)[31], The Convention on the Rights of Persons with Disabilities *and its* Optional Protocol (2006)[32] and European Disability Strategy in the European Union (2010-2020)[33].

The idea of inclusive education has also been confirmed in the revised European Social Charter of the Council of Europe as well as in the Council of Europe Disability Action Plan 2006-2015[34] and in the next document – Council of Europe Disability Strategy 2017-2023[35].

3. Recommendation CM/Rec(2010)2 on deinstitutionalisation and community living of children with disabilities

The Recommendation CM/Rec(2010)2[36] concerns the mainstream of migration in the member states of the Council of Europe from institutional care to local care (deinstitutionalisation) with respect to disabled children. In Europe, hundreds of thousands of children with various physical and mental impairments, often abandoned or neglected children, live in large, isolated centers. By definition, the institutions are to provide care, food and shelter; however, the evidence delivered over the years indicates that they are unable to provide services for the people or support that guarantees full social inclusion. Physical separation from local communities and families drastically limits the ability and readiness of people living or growing in such

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Statement on Principles, Policy and Practice in Special Needs Education and a Framework for Action. These documents are informed by the principle of inclusion, by recognition of the need to work towards "schools for all" – institutions which include everybody, celebrate differences, support learning, and respond to individual needs. http://www.right-to-education.org/resource/salamanca-statement-and-framework-action-special-needs-education (access 20.09.2018) More information, see: Better Education forAll: WhenWe're Included Too A Global Report People with an Intellectual Disability and their Families Speak out on Education forAll, Disability and Inclusive Education, by Instituto Universitario de Integraciónenla Comunidad (INICO), Salamanca 2009, Spain.

[31] Among the major outcomes of the Decade of Disabled Persons was the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities by the General Assembly of the United Nations on 20 December 1993 (resolution 48/96 annex). https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html (access 20.09.2018)

[32] A/RES/61/106, http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf (access 20.09.2018)

[33] https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM%3Aem0047 (access 20.09.2018)

[34] https://www.coe.int/en/web/disability/action-plan-2006-2015 (access 20.09.2018)

[35] https://www.coe.int/en/web/disability/strategy-2017-2023 (access 20.09.2018)

[36] https://www.coe.int/en/web/disability/adopted-texts (access 20.09.2018)

places to fully participate in general life[37]. "Four decades of work on improving the living conditions of children with disabilities has taught us that there is no such thing as a good institution" (Professor Gunnar Dybwad, an activist who fights for the rights of people with disabilities)[38]. Placing a disabled child in a specialised institution is a common practice and is a basic way to deal with the problem in many countries of the Council of Europe. Institutionalisation of help often means "cutting off" the child from the natural environment and family which causes irreversible damage to his/her psyche.

According to international legal instruments of the Council of Europe and Article 3 of the UN Convention on children's rights, it is the child's good that is most important. Whereas, one should realise that placing children in institutionalised care centers raises serious concerns that this may impinge upon the children's good will and respect for their rights. Therefore, the Recommendation asks the member states to take appropriate legal measures to replace institutional services with environmental services. It is underlined that deinstitutionalisation requires a series of general actions which support a strategic approach at the national level involving all interested persons. Deinstitutionalisation is a long process that should cover all policies that affect the lives of children with disabilities[39]. This process indicates that the following pivotal aspects should be taken into consideration: building a national system which identifies the needs of disabled children, drafting mutual support programs for parents, provision of various services (support for families, psychosocial support, financial support, educational support, pedagogical support, etc.), appropriate consideration of the individual needs of children and their families, availability of various means for families to enable them to temporarily deprive themselves of care for disabled children, which is to prevent psychosocial crises and, thus, prevent crises, continnual planning in relation to disabled children from pre-school age, through education in all levels to adulthood, promoting and supporting active family involvement and responsibility (Annex, point 21-2.7). The actions of public authorities, strategic planning, co-ordination on national, regional and local level in the context process of deinstitutionalisation should include four main strategies: preventing institutionalisation, preventing any prolongation of the anticipated short-term stay in a particular institution, deinstitutionalisation of the children with disabilities who are currently in institutions and making social services

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[37] See more: S. Shah, M.Priestley, Disability and social change – private lives and public policies, Bristol 2011; Z. Woźniak, Niepełnosprawność i niepełnosprawni w polityce społecznej – społeczny kontekst medycznego problemu, Warszawa 2008; A. Wójtowicz-Pomierna, Polityka państwa wobec osób niepełnosprawnych: dylematy systemowe, w: A.I. Brzezińska, R. Kaczan i K. Smoczyńska (red.), Diagnoza potrzeb i modele pomocy dla osób z ograniczeniami sprawności, Warszawa 2010.

[38] Ibidem.

[39] Point 2, Appendix to Recommendation CM/Rec(2010)2.

available[40]. It is altogether stressed that deinstitutionalisation is to be treated as a continual process which is resheduled and evaluated[41]. In particular cases, when there is child abuse and negligence and the child cannot live in the family or foster family, a small home environment, similar to the natural home environment, should become an alternative for deinstitutionalised care forms[42].

The Recommendation also implies the need of important financing and support for numerous environmental services for disabled children and their families so that they are not placed in these institutions. This concerns: regular assessment of the needs of disabled children and their families, co-ordinated healthcare and social care, early intervention programmes and the actions of general and specialised education[43].

4. Recommendation CM/Rec(2009)9 of the Committee of Ministers to member states on the education and social inclusion of children and young people with autism spectrum disorders.

Recommendation (2009)9[44] was prepared by the Committee ad hoc, i.e. the Committee of Experts on education and children with autism, which was established in 2004 as a consequence of the decision of the European Committee of Social Rights on infringement of laws in France related to the rights of people with autism[45]. The Committee conducted broad research regarding the notion of autism in the member states of the European Union, the analysis of statistics regarding the situation of children with autism, especially in the education sector, and exchange of information and experience at national level. It all enabled to draft recommendations for the education and integration of children with autism[46].

The Recommendation emphasises that there is universality, indivisibility and interdependence of all human rights and fundamental freedoms and the need for people with autism disorders to be guaranteed full use of them without any

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[40] Point 4, Appendix to Recommendation CM/Rec(2010)2.

[41] Point 5, Appendix to Recommendation CM/Rec(2010)2.

[42] Point 12, Appendix to Recommendation CM/Rec(2010)2.

[43] Points 22.1-22.4, Appendix to Recommendation CM/Rec(2010)2.

[44] Recommendation CM/Rec(2009)9 of the Committee of Ministers to member states on the education and social inclusion of children and young people with autism spectrum disorders, https://www.coe.int/en/web/disability/adopted-texts (access 15.11.2018).

[45] The European Committee of Social Rights, Decision 13/2002 of November 2003 in the case Autisme – Europe v. France. https://www.coe.int/en/web/turin-european-social-charter/processed-complaints/-/asset_publisher/5GEFkJmH2bYG/content/no-13-2002-international-association-autism-europe-iaae-v-france?inheritRedirect=false (access 25.09.2018).

[46] G. Palmisano, The Protection of People with Autism in the Framework of the Council of Europe and the European Union, in: V. D. Fina, R. Cera (ed.), Protecting the Rights of People with Autism in the Fields of Education and Employment International, European and National Perspectives, New York – Dordrecht – London 2015, p.15

discrimination (preamble). It points out that the lack of promotion of citizens' rights with autism disorders and the lack of equal opportunities for them is a violation of their human dignity. Therefore, the Recommendation indicates the Council of Europe member states to encourage the education and social integration of children and adolescents with autism disorders by: integrating children with autism into their policies, legislation and practice, including the involvement of non-governmental organizations representing children and adolescents with autism disorders and their families in implementing and monitoring the measures introduced and promoting the integration of children with autism in the areas that are not under the direct responsibility of public authorities, but in which they have a specific impact or play a particular role. The annex to the Recommendation points out that people with autism disorders are full members of Europe and having a particular level of education they may be included into society and be actively present in it. Consequently, autism is a category of development disorders, often causes dysfunction of social integration of those who suffer from it and their families and environment. People with autism have specific needs, they need a special approach and understanding[47]. Therefore, the member states should establish the proper law and policy and provide structures which facilitate the illness and social integration, improvement in life conditions and promoting development and independence of people with this illness[48]. According to the legal instruments of the Council of Europe and the UN Convention on disabled people's rights, member states ought to place a ban on discrimination, including people with autism, not only in education but also in social care and other public policies, they should also support broad early identification and analysis, individual assessment of such people, develop a sense of social awareness on autism, and introduce training for parents and experts. Further, they should offer support for equal education opportunities and support for social inclusion[49].

5. Summary

In conclusion, the Committee of Ministers on protection of disabled children's rights is the answer not only to changing attitudes and social awareness, but also on the increasing number of disabled children and, thus, on growing needs in the implementation of their rights and freedoms. Disabled children are a part of every society, they should find a place in it and the possibility to meet needs and promote development. The recommendations of the Committee of Ministers of the Council of Europe are clearly focused on two objectives. The first is a better understanding of the concept of integration, which concerns not only children with disabilities, but also

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[47] Part I, point 1-2, Appendix to Recommendation CM/Rec(2009)9.

[48] Part II, point 1, Appendix to Recommendation CM/Rec(2009)9.

[49] Part II, point 2-3, Appendix to Recommendation CM/Rec(2009)9.

their families and the community in which they live. The second is the presentation of measures relating to different areas of life that should be taken into consideration to ensure full social participation of children with disabilities and their multidirectional development. In addition to international standards and undertaken declarations and initiatives to which they make recommendations, they show a proper social model of disability in which obstacles faced by people with disabilities are eliminated. They are evidence of the humanitarian trend of social change on these people, opposing their isolation and discrimination. Certainly, the development of the idea of integration of disabled children is due to an increase of social awareness, better preparation and maturity of the educators, development of psychological and pedagogical science, law improvement, greater parental awareness of disabled children and necessity due to many children with different disabilities.

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When Everything Old is New Again: Amish Career and Technical Education

Abstract: In this qualitative study, the authors briefly describe the Amish formal education system, discuss career and technology education in Amish communities and examine the possible transfer of the model to public schools. Forty-six Amish schoolteachers, school board members and successful businessmen were interviewed. Findings include religion, family and work ethic are the foundations of Amish culture. Schools need to continue to make the learning practical for real life applications. Employers look for the "right" attitude and ability to learn. Workers must be able to transfer knowledge among differing contexts. An extra year of schooling might be beneficial for a variety of career and technical training programs since they do not offer career and technical education in the schools. In conclusion, apprenticeship programs in the public schools and non-Amish businesses would be well served to emulate the training approach found in Amish business communities.

1. Introduction

The demand for vocationally trained skill labor continues to evolve in terms of requisite skill sets worldwide (Eichhorst, Rodriguez-Planas, Schmidl & Zimmermann, 2015, pp. 314-337). With the aging of the baby boomer population in the U.S., the need to train and develop workers in the trades continues to expand. "Educational settings must match individual's gifts all of the time" (Schrag, 2008, pp 287). There has been a mostly static curriculum in the Amish school districts throughout the U.S. for the last 30 years. Formal education ends at age 14 for Amish students. This relatively brief academic education must provide them the essential tools to be successful during their work as entrepreneurs or employees in manufacturing, service and agricultural careers.

A study of the Amish educational system would be beneficial in generating questions and critical reflections within the context of foundations and assumed pedagogy of the American educational system. Perhaps the most widely known and misunderstood religious order are the Amish. While many may *know of* the Amish, they *know not* the Amish. This is especially true regarding Amish education in terms of the overall goals of educating in the Amish communities and the specific structures and pedagogy employed. While there have been attempts at explaining organization among Amish schools (Dewalt, 2006; Fisher & Stahl, 1997), as well as debating the effectiveness of these schools (Fischel, 2012) and extolling aspects of Amish educational practices (Junkins, 2014), there is scant research about career and technical education (formerly called vocational education) in the Amish educational system. The purpose of this paper is to examine the structure and effectiveness of career and technical education within the Amish community, and how it might transfer to public education.

The authors have spent years cultivating relationships with members of Amish communities throughout the United States and have conducted interviews and observed in both schools and Amish-owned businesses in numerous Amish communities in three states. This was a qualitative study with 46 participants conducted over a 3-year period in several large Amish communities in the upper Midwest of the United States. Multiple interviews were held with the same individuals during this study. Findings include the importance that religion, family, work ethic, education, community and culture play in ensuring a successful citizen within the Amish communities. In this paper we will 1) briefly describe Amish formal education, 2) discuss career and technology education in Amish communities and 3) examine the possible transfer of the model to public schools.

2. Education in the Amish Community

As Knotts and Keesey (2016) note, no two communities are exactly the same. There will be similarities in structure and practice, but each community is an individual. This is especially true in regards to education. Due to the landmark United States Supreme Court ruling in Wisconsin v. Yoder in 1972, Amish communities may end the formal education of their children after the eighth grade. Typically, children attend a one or two-room schoolhouse and are seated in rows according to their grade; first grade through eighth in one room, or (if there are enough children) grades one through four in one room and grades five through eight in another. The curriculum consists of reading, writing, arithmetic, history, geography, and health. The teachers working with each grade individually, while the other grades attempt independent work. Curriculum in the seventh and eighth grades typically integrate scenarios and problems involving real-life applications that will be faced in the world when school is completed. Often, older children help with instruction for the younger grades. Lunch and recess are looked forward to with anticipation and, since the schools are without electricity, there is virtually no technology available or used. Teachers have no formal pedagogical training but attend regional staff development regularly and benefit from local systems of support and training. Each school has a school board made up of three to five local Amish men whose responsibilities are to provide resources for the school, hire teachers, collect school taxes, and consult with parents and teachers.

Though the Amish formal education ends after the eighth grade, the rigor and relevance that constitutes the curriculum enables Amish students to be employed in good stead outside the Amish community. Once eighth grade is completed, Amish children begin to prepare for careers through apprenticeships in a chosen field or one at which they have exhibited a particular aptitude. Young men typically enter agrarian, manufacturing, or crafting-medium endeavors while young ladies enter retail or service businesses before starting families. Learning continues after formal education stops. It simply takes the form of hands on experience and continued self-directed learning via reading.

Although each school is unique, there is one constant in Amish education. Foremost, the "Amish maintain educational distinctiveness through administrative and curricular choices that are compatible with their life-styles and values" (McConnell & Hurst, 2006, p. 238). The set of beliefs that form the core of the Amish communities are evident in the schools. The basic premise of education mirrors that of the community. The school, just as the community, exists for a greater good and service to others is an important part of that premise. Preparing children for participation in their community has always been the overarching goal of Amish education.

Amish Education for Students with Special Needs

The Amish address the education of their special needs students differently than is done in mainstream American schools. The way that American schools attend to special education can be traced back to Public Law 94-142, or the Education for All Handicapped Children Act of 1975 (as it was called at the time). Prior to the enactment of this Federal law, the education of special needs students was an afterthought, and after an intense examination the United States Congress saw ten wrongs:

- Outright exclusion of special needs children (10 million in number)
- Unique needs were not met
- Excluded from appropriate programs
- Evaluations were wrong and inadequate
- No goals or measure of progress

- Segregation from non-special needs students
- No related services
- Parents not involved
- No access to children's records
- No impartial grievance forum

Therefore, certain mandates were established for educating special needs children. There is free public education for all special needs students between ages 3 and 21, and students are placed in the Least Restrictive Environment (LRE). Each identified student has an Individualized Education Program (IEP) in which the goals for the students are determined as well as a description of the services they are to receive, the evaluation criteria, and the extent of their participation in the regular education program. Setting the student's IEP are the parents, the special education teacher, a regular education teacher, a school administrator, someone to interpret and explain the diagnostic and educational data, and other parties invited by the parents or the school. The IEP is reviewed annually. Senator Robert Stafford called Public Law 94-142 an act of love rather than a law. Later, further Federal laws concerning working with special needs individuals came in the Individuals with Disabilities Act (IDEA) of 1990 and its revision in 1997. Clearly, the education of special needs students in American public schools is articulated and specific.

The Amish approach the education of their students with special needs differently than is done in public schools and have no mandates or specifics. They approach it from a community perspective; that is, the community takes care of all of its members. They have addressed, from the start, an issue mainstream America has not solved. Participant 1 shared how the Amish fully confronted the issue of who takes care of a special needs individual who is an only child (or adult) whose parents have passed away. If the child has no living relatives, a member of the church (typical size is 12-15 families) will legally adopt the child/adult and bring them into their homes to be cared for as if they were a child of that family!

3. Methodology

The participants

This qualitative study, conducted over a 3-year period in major Amish communities in Indiana, Ohio and Pennsylvania, sought to determine if the vocational education programs in Amish communities could and/or should be replicated in the public school systems across the U.S. A series of in-depth, multiple interviews with 46 Amish schoolteachers, school board members and successful businessmen (ages 32 to 70 plus years) examined how a formal school education that ended for students when they reached fourteen years old could prepare them for a life in the 21st century. (See Appendix for interview questions)

Farming is no longer the primary business of most people in the Amish communities. Edgier (2005) reported that "A more recent major problem is to determine a vocation other than farming which traditionally has been a main stay among the Old Order Amish" (p. 422), and McConnell and Hurst (2006) emphasized the need for economic alternatives for the Amish. In fact, today, only "10% of the Amish farm full time" (participants 1, 4, 5, 6, and 9). This is primarily due to demand for farmland in Amish communities and its resultant high price. Many Amish farm part time and work full time off the farm. Construction, light manufacturing and the service industries (e.g. retirement communities and retail shops) are often the primary sources of income for the community members.

Today's Amish communities conduct a significant amount of business with people outside their immediate community (participants 1, 4, 5, 6, 17, 34, and 41). There is simply not a large enough population in any one community to be self-sustainable without trading outside their society. In a society where computers drive many of the procedures and processes in manufacturing, how do the Amish compete so successfully with such limited formal education? Are there aspects of their educational system we can/should incorporate into the public school systems in the U.S.?

Data collection

This qualitative study was conducted with personal interviews using a combination of purposively sampling strategies –reputational case, maximum variation sampling and concept/theory-based participants. Using prolonged fieldwork, interviews were conducted in schools, businesses and homes of the participants.

Validity was enhanced by prolonged and persistent fieldwork by two researchers as well by member checking and participant review of the handwritten interview notes. Reflexivity was accomplished through the maintenance of field logs by the researchers.

4. Analysis and Findings

Several findings emerged from this study.

- Religion, family and work ethic are the foundation of the Amish culture.
- Because there are fewer farmers each year in Amish communities, there is growing concern over the possible loss of work ethic because the young people have fewer responsibilities at home.
- Teachers and businessmen alike confirmed a continuing need for innovation and application in all areas of their lives that does not contradict the basic tenets of the community. This is necessary to keep them competitive in the markets they depend on outside of their communities.

- Workers must be able to transfer knowledge among differing contexts.
- Employers look for the "right" attitude and ability to learn.
- The work ethic that is learned in the home and school is vital.
- Schools need to continue to make the learning practical for real life applications.
- An extra year of schooling might be beneficial for a variety of vocational training since they do not offer vocational training in the schools. Some of the participants suggested referring to it as a transition year. For example– students are eagerly sought after who can work in masonry, weld, operate a keyboard, and or possess basic accounting skills.
- Some Amish businesses are allowed by their bishops to use computers for their work with specific software for that endeavor. Those businesses will have onsite generators rather than being connected to a public power grid.
- After formal education, the boys become an apprentice in an occupation of their choosing or one in which they have shown an aptitude.
- Girls typically work in retail shops and service businesses such as restaurants and nursing homes.
- Sometimes the apprenticeships do not work out and the boys/girls need to find other employment.
- The rules of the Occupational Safety and Health Administration (OSHA) are carefully adhered to by all of the participants in this study.

5. Conclusions

The cornerstones of religion, family and work ethic support the foundation of the Amish communities and education helps to build on that foundation. The education Amish children receive equips them to be successful citizens not only in their communities, but outside the community as well. Participants in the study shared instances of Amish children thriving in businesses and work outside of their community, such as computer programming and graphic art. Where did they learn the needed skills? From their foundational education and subsequent on-the-job training. Life in an Amish community does not negate or discourage work-related innovation and creativity.

Today's Amish communities conduct a significant amount of business with people not only outside their immediate community, but outside their state and even the nation. Many of the Amish business owners with whom we spoke have regular business dealings on an international level. A question asked earlier was how do the Amish compete so successfully with such limited formal education? The answer is relatively simple: their education, while concise, is thorough. Each community is dedicated to preparing their children to take their place in the community, and their education ensures this. Upon completion of school, their education is not finished. Certainly, an apprentice system contributes to their on-going education, but just as significant, the Amish stress the importance of self-directed learning and within their community. This is accomplished through reading. Outstanding libraries exist within Amish communities with volumes ranging in topics from classic literature to mechanical engineering. Many Amish are as adept in discussing 18th century French philosophers as they are discussing dairy farming.

Over the years the Amish have adapted their lives as determined by advances in technology. While preferring not to use electricity, Amish businesses employ natural gas lighting and generators. While not driving motor vehicles themselves, many communities allow and even encourage hiring others outside the community to transport not only them but their manufactured and agrarian products as well. Consequently, it comes as no surprise that many of the participants in this study suggested adaptations in schools as well. Because computer competence is becoming essential to most workplaces in one form or another, perhaps keyboarding might be taught; not on actual computers but simply the keyboard or keyboard model. Many Amish business use computers loaded with appropriate software (no music or games) and a basic knowledge of keyboarding would facilitate the apprenticeship process. Others suggested a possible transition year, such as a ninth grade, to begin teaching vocation specific skills such as welding, masonry, and accounting. This, too, might benefit both the employee and employer.

Time and again, participants who owned or supervised businesses stressed the importance of a potential employee and apprentice's attitude. They look to hire from within the community and value the individual's willingness to work and ability to transfer knowledge and skills in one context to another. They appreciate that since these traits and abilities are important in the community as a whole, they are emphasized in schools. It should be noted that the participants look for these same attitudes when they hire individuals from outside the community, which is done regularly. Some participants did express that, with a decline in the number of Amish engaged in farming, they were concerned that the work ethic of the young may begin to wane in the absence of after-school farm-related chores. Youth in the Amish community are like youth outside of the community who are not certain of which career trajectory they should take. There do occur instances when an individual must try their hand at a few endeavors before they find their occupational calling.

In short, the Amish system of career and technical education works very well – for the Amish. It has helped maintain a quality life style for its members. Transferring their formal educational philosophy and practice to the public school system could prove to be problematic. The secular society of the United States would not allow it. There are, however, pieces of their career and technical education programs that warrant consideration. In particular, we could be well served to seek ways to foster the increased use and support of apprentices. For example, apprentices were paid a living wage at all of the businesses where the interviews were conducted. They could see first-hand monetary rewards for doing well and excelling as well as possible monetary deterrents. This proved to be a motivator. Public schools often provide various career and technical education programs at the high school level and many provide a multitude of hands-on experiences. Rarely, though, are the experiences of the students totally immersed as a worker, that is, be successful or don't get paid or see advancement. Those programs that do offer a form of apprenticeship certainly see the benefits in terms of motivation and conscientiousness. The Amish practice of apprenticeship is built on what was received in formal education through eighth grade and supplemented with hands on training and self-directed learning. Education did not stop at the completion of eighth grade; it simply took a different route.

Testifying before a subcommittee of the Senate Committee on Appropriations, Herman Bontrager, a member of the Amish community, put it very succinctly: Amish vocational training is primarily accomplished through apprenticeships in the context of their extended families. They do not utilize high schools or vocational schools, technical schools, or colleges for training. Apprenticeships adequately meet the training needs of Amish young people and help to keep them integrated in the Amish community during those crucial adolescent years. This system keeps the children off the streets, out of prisons, and makes them contributors to the welfare of the community at a very early age. It is important to the Amish to train children to do the best they can in their work and do it safely. (United States Congress, 2001, p. 25).

These words are applicable for those outside the community as well. Certainly, we want to meet the training needs of all of our students and help make them contributors in the community at-large. Most importantly, we want to acknowledge and meet the demand for vocationally trained skilled labor both locally and globally. In their societies, adequate training for Amish doesn't necessitate secondary or post-secondary education. Many outside of their communities agree that training for much of the workforce may not require a two or four-year college degree, but rather, proper career and technical training. Perhaps if we look at it in just the right light, what is old can influence what is new, and a community can provide a blueprint to impact the world.

6. Appendix

Questions for the participants

1. How many years of formal education do the students in your community receive?
2. Are they in parochial or public schools?
3. What are the instructors' credentials?
4. What subjects are taught in your school?

5. What is the amount of time and type of practical hands-on experience in the classroom for vocational education?
6. Is there vocational education in the school?
7. Do you use the apprenticeship system in the workplace?
8. How long is it?
9. What is the remuneration structure for apprentices?
10. Do they provide their own tools?
11. How many hours per day do they work?
12. Do they receive insurance and benefits?
13. In general, are they satisfied?
14. In general, as the employer, are you satisfied?
15. Have you ever hired a trainee who did not work out?
16. What were they missing?
17. Do you use teams for choosing a new hire?
18. Do you use teams in the workplace?
19. What are the guidelines used in forming a team?
20. What would you like to see changed in your school system to better prepare your apprentices for the workplace?

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The Concept and Entitlements of the Unemployed with Disabilities

Abstract: Under Polish law, the disabled who are unemployed are included in the group of the unemployed in a specific situation on the labour market. This means that the legislator recognises the difficulties this group faces in finding suitable employment. It has therefore introduced a number of mechanisms to make it easier for this group to enter or re-enter the labour market. However, making use of them is often hindered by the fact that the person concerned must first acquire the status of a disabled person under the Act on Vocational and Social Rehabilitation and Employment of Disabled Persons. He or she then has to meet numerous conditions included in the Act on Employment Promotion and Labour Market Institutions in order to obtain the status of an unemployed person. In principle, the only entitlement that is granted is the priority to be assigned to special programmes. However, district labour offices are not obliged to run such programmes. Therefore, in the Polish legal system there is a large gap in terms of helping the unemployed with disabilities to enter the labour market or return to the labour market. Considering the fact that many employers complain about the shortage of workers, stimulating the professional activity of the disabled could be of huge importance for the country's economy.
Keywords: unemployment, disability, employment, professional activation

1. Introduction

Notwithstanding that unemployment is a complex and multi-faceted issue that should not be reduced to a mere statistic, at the end of the first quarter of 2018 it stood at 6.8% (4.4% according to the methodology of the Labour Force Survey)[1] its lowest recorded level in decades, which is conducive to the improvement of living standards. However, demographic factors, duration of unemployment, the quality of workplaces, the length of service of the unemployed and their characteristics, which

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[1] Registered unemployment in the first quarter of 2018, Central Statistical Office, Warsaw 2018, p. 13-14.

may result in difficult access to the labour market, are also of significance here. Such characteristics include in particular age, gender and disability. Therefore, the structure of unemployment and its causes is not to be overlooked. After all, employment is one of the most important factors affecting social status and plays a vital role in the life of every individual. This role is greater for the unemployed with disabilities. It is also gaining new relevance in terms of vocational and social rehabilitation and the social integration of people with disabilities.

The legislator recognises the complexity of the problem of unemployment among people with disabilities. This issue is subject to legal regulations under two acts: the Act of 27 August 1997 on vocational and social rehabilitation and employment of persons with disabilities[2] (hereinafter: the Act on vocational rehabilitation) and the Act of 20 April 2004 on employment promotion and labour market institutions[3] (hereinafter: the Act on employment promotion). Yet, it is difficult to state that these laws complement each other, instead they are in a certain correlation. This phenomenon can be noticed already in an attempt to determine the personal scope of the concept of the unemployed with disabilities.

2. The concept of the unemployed with disabilities

Pursuant to the Act on vocational rehabilitation, in Article 2(2) the legislator indicated quite enigmatically that "an unemployed person with disabilities is an unemployed person with disabilities within the meaning of the provisions on employment promotion and labour market institutions". The reference to the Act on employment promotion is not very helpful. This normative act does not define this concept but, curiously enough, it makes use of it. The legislator indicated only in Article 49(6) of the Act that the unemployed with disabilities are persons who are in a specific situation on the labour market. At the same time, it does not define the concept of the unemployed with disabilities nor the specific situation on the labour market.

Consequently, when determining the personal scope of the concept of the unemployed with disabilities, it is necessary to juxtapose the legal regulations contained both in the Act on employment promotion and the Act on vocational rehabilitation. In this respect, it should be noted that the legal concept of an unemployed person with a disability, or as defined by the legislator of a "disabled unemployed person", consists of two elements. First of all, the person must acquire the status of a disabled person under the Act on vocational rehabilitation. Secondly, the conditions set forth in the Act on employment promotion must be fulfilled in

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[2] Uniform text Journal of Laws of 2018, item 511.

[3] Uniform text Journal of Laws of 2018, item 1265.

order to qualify for registration as an unemployed person in the relevant district labour office.

The concept of disability has been subject to numerous regulations in international legislation. The United Nations Convention on the Rights of Persons with Disabilities[4], adopted on 13 December 2006 includes in its Article 1 persons with disabilities who suffer from long-term physical, mental, intellectual or sensory impairment which, in interaction with various barriers, may impair their full and effective participation in society on an equal basis with others. This view is reflected in the Act on vocational rehabilitation. In Article 3(1), the legislator distinguished three degrees of disability: severe, moderate and mild. The description of the degrees of disability has been elevated to the rank of a normative definition by including them in Article 4. A person with severe disability can be considered to have been seriously disabled if he or she is impaired and, at the same time, incapable of work or able to work only in a sheltered environment. Furthermore, it is also a person who requires the permanent or long-term care and assistance of other persons in order to perform social roles due to their inability to live independently (Article 4(1)). By contrast, a moderate degree of disability refers to a person with impaired physical fitness, unable to work or able to work only in sheltered working conditions or requiring temporary or partial assistance from other persons in order to perform social roles (Article 4(2)). A mild degree of disability means that a person has a reduced physical fitness which results in a significant impairment of the ability to perform work, compared to that of a person with similar professional qualifications and full mental and physical capabilities, or who has limitations in the performance of social roles which can be compensated for by means of equipment with orthopaedic appliances, aids or technical means.

A diagnosed disability can also be mentioned in the case of a medical certificate issued by a physician certified by the Social Insurance Institution on the basis of the footnotes of the Act of 17 December 1998 on Pensions from the Social Insurance Fund[5] (hereinafter: the FUS Act). Such certificates are treated in the same way as defined degrees of disability. A certificate of complete inability to work pursuant to Article 12(2) of the FUS Act and a certificate of inability to lead an independent life pursuant to Article 13(5), are treated as equal to a certificate of a severe degree of disability. Complete inability to work, determined on the basis of Article 12(2) of the FUS Act, is treated as a decision on a moderate degree of disability. On the other hand, a certificate of partial inability to work is equated with a mild degree of

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[4] Journal of Laws of 2012, item 1169.

[5] Uniform text Journal of Laws of 2018, item 1270.

disability pursuant to Article 12(3) and a decision on the advisability of retraining pursuant to Article 119(2) and (3).[6]

Consequently, it must be concluded that the disability must be recognised by a competent authority once the statutory conditions have been satisfied. A person who subjectively assesses his or her fitness as limited but who does not have a disability certificate[7] issued by a recognised body[8] cannot therefore be considered disabled.

The second element of the concept of an unemployed person with a disability is the definition of an unemployed person contained in Article 2(1) and (2) of the Act on employment promotion. This definition refers to disability in only one aspect. In contrast to fully functional unemployed people, who need to be able and ready to work full time, people with disabilities are required by the legislator to be able and willing to take up at least part-time paid employment for the type of work in question. It is worth noting that people with severe or moderate certified disabilities and with certificates issued by a physician appointed by the Social Insurance Institution (ZUS) may perform paid work at workplaces adapted to the degree of disability and the nature of impairment of the body's fitness[9], as well as in the form of teleworking. Moreover, according to Article 15(1) of the Act on vocational rehabilitation, in the case of disabled persons with a certified mild disability, working hours may not exceed 8 hours per day and 40 hours per week. This standard is undoubtedly in correlation with Article 129(1) of the Labour Code[10], which indicates the maximum permissible standard for working time of the same amount, while developing this standard by limiting the working week to an average of five days, and the reference period should not exceed 4 months with certain exceptions. However, in the case of persons with moderate or severe disability, the working time may not exceed 7 hours per day and 35 hours per week (Article 15(2) of the Act on vocational rehabilitation). At the same time, regardless of their degree of disability, they cannot work overtime or at night. Therefore, the Act on employment promotion does not require a disabled person to be able and ready to perform work within the maximum permissible working hours provided for by the Act on vocational rehabilitation.

As far as other prerequisites for acquiring the status of an unemployed person are concerned, they remain the same for people with disabilities as for people who are fully fit. These numerous prerequisites were divided by the legislator into two

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[6] See H. Pławucka, Risk of inability to work for disability benefits - structure and content, (in:) P. Bieniek, O. Rawski (ed.), Inability to work as a risk in social disability insurance, Warsaw 2014, pp. 31-54.

[7] See E. Staszewska, Commentary to Art. 49, (in:) Z. Góral (ed.), Act on employment promotion and labour market institutions. Practical commentary, Warsaw 2016, p. 509.

[8] See M. Paluszkiewicz, Commentary to Art. 6, (in:) M. Włodarczyk (ed.), Act on Vocational and Social Rehabilitation and Employment of Disabled Persons. Commentary, Warsaw 2015, p. 126.

[9] Judgment of the Supreme Court of 8 December 2000, II UKN 134/00, Lex no. 46842.

[10] Uniform text Journal of Laws of 2018, item 917, as amended.

groups: positive prerequisites and negative prerequisites. In the first group, the main indications are being unemployed and not doing any other gainful activity, as well as not learning (with some exceptions). In the second group of prerequisites, on the other hand, there are those related to age. A person can be considered unemployed if he/she is over 18 years of age and has not reached retirement age (60 for women and 65 for men). Additionally, an unemployed person is not a person who, among others, has acquired the right to a retirement pension, disability pension, social pension and does not receive pre-retirement benefit, pre-retirement allowance, rehabilitation allowance, sickness allowance or maternity allowance. The negative prerequisites also include not running a business activity or not owning agricultural real estate with an area exceeding two hectares after conversion. In principle, it can be stated that according to the Act on employment promotion, an unemployed person is not a person who does not have a job and is looking for a job, but a person who does not have a job, is looking for a job and does not have any means of subsistence[11].

3. Entitlements of the unemployed with disabilities pursuant to the Act on employment promotion and labour market institutions

As has already been mentioned, pursuant to the Act on employment promotion, the unemployed with disabilities, apart from, among others, the young unemployed up to 30 years of age, the unemployed over 50 years of age or the long-term unemployed, were recognised as unemployed in a specific situation on the labour market. This view of the legislator stems from the assessment of how real it is to be able to find employment for these people. There is no doubt that the risk of being out of work among them is higher than among other groups, which leads to the conclusion that people are not equal in terms of unemployment.[12] Many factors influence the ease or difficulty of re-entering the labour market. Some of them result from the economic situation of the state and employers, as well as from demographics and the overall economic situation. Others are related to the characteristics of an unemployed person: disability, age, gender, place of residence. As a result, it is not surprising that the legislator has provided for some assistance for the unemployed who are in a specific, i.e. difficult situation on the labour market.

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[11] More broadly: Z. Góral, Definition of the unemployed in the Act on Employment Promotion and Labour Market Institutions, "Praca i Zabezpieczenie Społeczne" 2011, no. 5, p. 23; K. Jaworska, Social Treatment of Unemployment, Olsztyn 2016, pp. 145-161.

[12] Z. Góral, Diversification of the Legal Status of the Unemployed (in:) M. Matey-Tyrowicz, L. Nawacki, B. Wagner (ed.), Labour Law and Challenges of the 21st Century. The Jubilee Book of Professor Tadeusz Zieliński, Warsaw 2002, p. 193; E. Staszewska, The concept of "persons in a specific situation on the labour market" in the light of the Act on Promotion of Employment and Labour Market Institutions, "Zeszyty Prawnicze UKSW". 2010, no. 10, p. 233.

This special support, provided for the unemployed with disabilities in the amendment of the Act on Employment Promotion of 12 May 2014, which entered into force on 1 January 2015,[13] was much more extensive than it is now. For example, it may be pointed out that this group of the unemployed had priority in being sent to perform intervention works, public works or internships. Furthermore, the district labour office was obliged to present the unemployed with disabilities with a proposal of employment, other gainful employment, training, internship, vocational training of adults, employment in intervention works, public works within 6 months from the date of loss of the right to the benefit due to the expiry of the period of its receipt and, in the case of the unemployed without the right to the benefit, within 6 months from the date of registration. After 1 January 2015, this group of the unemployed has only the priority of being able to participate in special programmes.

In the Act on employment promotion, the legislator defined the concept of special programmes twice. The first of these definitions can be found in the glossary to the Act. According to it, special programmes are a set of activities aimed at adjusting professional qualifications and skills or acquiring new ones, as well as supporting those threatened with liquidation or existing and created jobs (Article 2(1), item 27b). The other definition is contained in Article 66a (1). In its wording, special programmes are aimed at the economic activation of persons who are identified in this provision. This raises the question of the relationship between these two objectives set by the legislator for the special programmes. There is no doubt that the concept of professional activation has a broader scope than just the adaptation or acquisition of qualifications and professional skills. The Regulation of the Minister of Labour and Social Policy of 14 May 2014 on special programs[14] may provide some guidance in this respect. In § 4 of the regulation, the minister pointed out that when defining the scope and forms of assistance under the special programme, measures should be planned combining labour market services or instruments with specific elements supporting employment.

The concept of labour market services and instruments needs to be clarified here. In Article 35 (1) of the Act on employment promotion, the legislator indicated that the basic services of the labour market are employment intermediation, vocational counselling and provision of professional information, assistance in active seeking of employment and organisation of training courses. This wording leads to the conclusion that apart from these basic labour market services, there are also other services which are of a different nature. The analysis of the entire Act on employment promotion indicates that labour market services encompass all activities undertaken by public and private institutions in order to help the unemployed find suitable

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[13] Act of 12 May 2014 amending the Act on employment promotion and labour market institutions and some other acts, Journal of Laws of 2014, item 598.

[14] Journal of Laws of 2014, item 638.

employment[15] and employers find the right employees. Taking into consideration the specific situation of people with disabilities on the labour market, labour market services are also aimed at supporting them in choosing an adequate profession, taking into account individual predispositions and conditions prevailing on the labour market.[16]

On the other hand, labour market instruments, pursuant to Article 44 of the Act on employment promotion, are intended to support labour market services. This means that they are instruments which promote full and productive employment by bringing the unemployed back to the labour market. This is particularly evident in the case of e.g. subsidised employment in various forms, which is a kind of bridge between unemployment and professional activity.[17]

In view of the above, it should be stated that the special programme, in which the unemployed with disabilities are to participate, aims to activate them, in particular by adjusting their professional qualifications and skills or acquiring new ones, and by supporting jobs at risk of liquidation or existing jobs,[18] and to this end all available labour market services and instruments that help achieve this objective may be employed. However, other forms of activation may be used only as an aid. Thanks to special programmes, a starost can therefore finance non-standard measures targeted at the unemployed with disabilities,[19] so that they can return to the labour market more quickly or enter it for the first time. Yet, access to these mechanisms in the case of this particular group of the unemployed may be limited if the district labour office does not run any special programmes. The legislator did not order these labour market institutions to organise special programmes, but only presented them with such an opportunity. Consequently, if the district labour office, competent due to the place of residence of the unemployed person with disabilities, does not run such a special programme, the unemployed person will be able to use the services and instruments of the labour market on the same basis as the unemployed who are fully fit, i.e. without the right of priority.

In this respect, it should be noted that the legislator has shown far-reaching inconsistency. On the one hand, it firmly states that the unemployed with disabilities find themselves in a specific, i.e. difficult, situation on the labour market and that they therefore need special assistance to enter it. On the other hand, it did not guarantee that such special programmes would be implemented in every district labour office. As a result, the unemployed with disabilities do not enjoy any facilitation in the use

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[15] See M. Włodarczyk, "Adequate employment" in the Act on Employment and Counteracting Unemployment, "Praca i Zabezpieczenie Społeczne" 1998, no. 7-8, p. 38.

[16] S. Ricca, Public Employment Services. A handbook for employers, Warsaw 1995, p. 40.

[17] M. Kabaj, Programme for Countering Poverty and Unemployment, Warsaw 2000, p. 67.

[18] M. Paluszkiewicz, Commentary to Article 66a, (in:) Z. Góral (ed.), *op. cit.* p.126.

[19] A. Wasilewska, H. Rogala, Special Programmes - an opportunity to be taken, "Służba Pracownicza" 2012, no. 3, p. 16.

of assistance provided for in the Act on employment promotion, especially as it may be very difficult for them to acquire the status of an unemployed person due to the number of prerequisites of a negative nature.

4. Entitlements of the unemployed with disabilities pursuant to the Act on vocational and social rehabilitation and employment of persons with disabilities

Certain regulations concerning assistance to the unemployed with disabilities in returning to the labour market are provided for in the Act on Vocational Rehabilitation. The Act contains Chapter IV, Entitlements of the Unemployed. However, the act basically makes reference to the Act on employment promotion. One of the novelties provided for by the Act on Vocational Rehabilitation is the possibility of providing one-off assistance to the unemployed with disabilities to start up a business, agricultural activity or to start up a business in the form of a social cooperative.[20] This assistance is financed from the funds of the State Fund for Rehabilitation of the Disabled, and not from the funds of the Labour Fund, as is the case under the Act on employment promotion. And the condition of acquiring the right to this aid is not using such aid from the Labour Fund in the past. Unemployed persons with disabilities may receive up to six times the average salary if they commit themselves to doing business for at least 12 months. In the event of an intention to run a business for a period of at least 24 months, the financial support for setting up a farm or a social cooperative may amount to up to 15 times the average salary. Facilitating access to labour market

5. Conclusion

The analysis of the solutions of both legal regulations leads to the conclusion that the Act on employment promotion is aimed at facilitating access to the labour market by the unemployed also those with disabilities, and the Act on vocational rehabilitation focuses rather on the disabled who are already in the labour market and on incentives for the employer to employ this disabled person, e.g. by way of employment subsidies. Nevertheless, the literature indicates that only programmes financed by the State Fund for Rehabilitation of Persons with Disabilities, social employment and the social economy constitute instruments for facilitating access to labour market the unemployed with disabilities.[21] However, this claim is stigmatising already at its roots. Omission of the rich range of services and instruments of the

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[20] See K. Jaworska, Social Cooperatives, “Studia Prawnoustrojowe” 2010, no. 11, p. 341.

[21] M. Garbat, Professional activation of people with disabilities - barriers and costs, Zielona Góra 2013, p. 40.

labour market results in marginalisation of forms of assistance provided for in the Act on employment promotion.

There is no doubt that there is a certain gap in the Polish legal system in terms of supporting people with disabilities in their return to the labour market. Given the fact that only 28.9% of people with disabilities of working age are economically active,[22] this gap should be covered as soon as possible.

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[22] Persons with disabilities on the labour market, Ministry of Family, Labour and Social Policy, Warsaw 2018, p. 4.

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The protection provided by the CPRD for persons with schizophrenia in the field of employment – from a Polish perspective

Abstract: The rights of persons with schizophrenia are protected by the Convention on the Rights of Persons with Disabilities, not only because schizophrenia fulfills the legal definition of disability resulting from the CRPD, but also because it fits with the definition described in other acts of international law. The Polish legislator also perceives schizophrenia as a disability. The CRPD has many provisions connected with the employment of persons with schizophrenia. The most relevant provisions which have influence on this case are the general principle of nondiscrimination, the right to participate in social-life, the right to rehabilitation, the awareness-raising obligation of the state, equal protection of the benefits of the law, equality in employment and the prohibition of discrimination in trade unions. Poland, as a party to this convention, is obligated to implement its provisions. In fact, Poland has implemented the basic provisions of this treaty, but more specific provisions encounter difficulties, especially in awareness-raising and in professional activation.

Key words: schizophrenia, disability, mental illness, rights of persons with disabilities, employment

1. Introduction

As a group, people with schizophrenia are not a typical of persons with a disability. Public opinion does not view them as being disabled, rather it sees them as being mentally ill and therefore they tend to be avoided, misunderstood, and criticised. This is especially true in the field of employment where those suffering from schizophrenia are not treated equally[1].

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[1] J. Tesch, Chancen und Probleme der Früherkennung, Behandlung und Rückfallprophylaxe von Menschen mit Schizophrenie unter Berücksichtung aktueler Forschung. Schlussfolgerungen für die sozialpädagogische Arbeit, Hamburg 2008, p. 60.

In this paper I wish to analyse the legal status of schizophrenia as a disability and the rights of persons affected by the disorder arising from provision of the Convention on the Rights of Persons with Disabilities (CRPD).

2. Schizophrenia as disability in the legal sense.

If we are to talk about the protection of people with schizophrenia as being disabled, we need to focus on proving that they are indeed disabled in the legal sense.

It is in fact difficult to point to one, clear, exhaustive legal definition of what constitutes a disabled person. The definitions contained in art. 2 of the CRPD falls short of containing a definition of disability,[2] but in the preamble to the Convention it is offered that disability is strictly connected with interactions between disabled person and the world and is described as "conception"[3].

The CRPD contains two conditions to include disorder as a disability:

- the long-term character of impairment(s);
- the impairment ought to hinder "full" and "effective" participation in social life "on an equal basis"[4]

The long-term character of schizophrenia is quite clear. It is important to mention that these conditions are inclusive – where an impairment fails to fulfill these two conditions, it doesn't automatically mean that the impairment is not a disability,[5] Schizophrenia causes impairments which impede participation in social life "on an equal basis". The clearest evidence of this, is the fact that Polish Social Insurance Institution spends around 920 million zlotys annually on people with an incapacity to work connected with schizophrenia[6] and, among those people diagnosed with schizophrenia, only 19% do work[7]. Generally, the symptoms of schizophrenia can be divided into positive and negative with both types bearing the potential to badly influence the social life and careers of those suffering from the disorder. Positive symptoms such as hallucinations, delusions, and false beliefs, typically cause incomprehensible behaviour, that can produce a destructive influence both in

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[2] Art. 2 Convention on the Rights of Persons with Disabilities New York, 13 December 2006 United Nations, Treaty Series, vol. 2515, p. 3 available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html in short CRPD.

[3] Preamble CRPD.

[4] Art. 1 CRPD.

[5] V.D. Finna, Article 1 [Purpose] [in:] V.D.Fina, R.Cera, G.Palmisano, (edit.), The United Nations Convention on the Rights of Persons with Disabilities: A Commentary, \Rome 2017 p. 89-101.

[6] A. Kiejny, P. Piotrowski, T. Adamowski (edit.) Schizofrenia: sytuacja w Polsce. Perspektywa Społeczna. Sytuacja w Polsce : Report of Jansen Poland, Warsaw 2010, p. 26.

[7] *Ibidem*, p. 37.

social life and in the workplace. Negative symptoms such as anhedonia, alogia, and apathy, invariably lead to a lowering of motivation to participate in social interaction and work life. It is also worth mentioning that limitations in the social potential of schizophrenics (largely related to a decreased level of competence and cognition in social life) also impacts on their ability to work.[8] This analysis allows to conclude that in the light of Convention on the Rights of Persons with Disabilities, persons with schizophrenia can, in the legal sense, be perceived as disabled.

This view can perhaps be supported by another definition drawn from the ILO Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159). This Convention defines a disabled person as a person whose ability to:

- secure,
- retain,
- advance,
- suitable employment is reduced[9].

The characteristics of schizophrenics described above allows to say that schizophrenia relates to a reduced capacity to secure, retain, and advance in suitable employment where, in this context, the term "suitable" relates to the person and is understood as meaning an individual possessing an acceptable level of education, professional ability and interpersonal presence, sufficient to secure a place on the job market. Clearly a person with a reduced level of social competence is disadvantaged in this regard which, by itself, serves to indicate that schizophrenics are disabled persons within the meaning of the referenced Convention.

It is also important to note that according to the definition of disability presented by World Health Organization (WHO), schizophrenia falls into the category of being a disability. The WHO standpoint on disability states that disability is strictly connected to a limitation in work and social life[10].

In like manner, it is interesting to note that the Polish legislator, in quite direct terms, tells us that schizophrenia can be a reason to recognise someone suffering from this disorder as being a person with a different level of disability.[11]

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[8] S.M. McGurk, K.T. Mueser, Cognition and work functioning in schizophrenia, [in] : P.D. Harvey Cognitive Impairment in Schizophrenia: Characteristics, Assessment and Treatment, Cambridge 2013, p. 98-104.

[9] Vocational Rehabilitation and Employment (Disabled Persons) Convention (No. 159). Treaty Series, vol. 1401, p. 235 available from: https://treaties.un.org/doc/Publication/UNTS/Volume%201401/v1401.pdf (access 29.04.2018).

[10] Information on the website of WHO : http://www.who.int/topics/disabilities/en/ (access 19.04.2018).

[11] Consolidated text: Journal of Laws 2011, item 721 as amended.

3. Schizophrenia and employment – in light of the Convention on the Rights of Persons with Disabilities

The basic source of law associated with the protection of rights of persons with disabilities is the aforementioned CRPD. This Convention comprehensively details the rights of persons with disabilities but relevant to employment, persons with schizophrenia are not all provisions of this convention.

Before analyzing the particular obligations of states, it's important to outline the legal significance of provisions of the convention, it's *expressis verbis* determined by art. 4 of the CRPD. The provisions of the Convention require implementation, which means that they have no direct effect[12]. Therefore, every obligation of a state party to the CRPD, cannot be considered as grounds for a claim against the state, or against any other body, but in legal practice the Convention should be considered by the courts and administrative authority. It is also an obligation for the legislator to implement appropriate rules.

The first principle of the Convention imposes the general prohibition of discrimination, which is firmly connected with the right to effective legal protection against discrimination. State Parties to the Convention also have an obligation to provide appropriate legislation with clear indication in its provisions that discrimination against persons with a disability is prohibited[13].

Here it is important to take into consideration that this is general principle which appears to be very broad and seems to be applied only when an act of discrimination is not directly connected with any specific provision of the act – "*lex speciali derogat legi generali*" the definition contained in the CRPD, the principle of non-discrimination speaks about a very broad meaning of discrimination (direct and indirect discrimination)[14] which has many implications for the labour situation of schizophrenics. The principle of non-discrimination is expressed in two articles of the CRPD – art. 3 and art. 5, each taking a different legal character. On the one hand, art. 3 defines the general principle of non-discrimination, while on the other, art. 5 identifies the direct connection between equality and non-discrimination and defines the role of States Parties in respect thereof[15].

Under the provisions of art. 5 of the CRPD States Parties recognise "that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law" (point 1), and that States Parties

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[12] V.D.Fina, Article 4 [General Obligations] [in:] : V.D.Fina, R.Cera, G.Palmisano, (edit.), *op. cit.*, p.149.

[13] *Ibidem.*

[14] D. Ferri, The Conclusion of the UN Convention on the Rights of Persons with Disabilities by the EC/EU: some reflections from a "constitutional" perspective, Centro di documentazione europea – Università di Catania- Online Working Paper 2010 – Serie Speciale/n. 4, Catania 2010.

[15] Article 3, V. Finna [in:]: V.D. Fina, R. Cera, G. Palmisano, (edit.) *op. cit.*, p.120-126.

shall "prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds" (point 2)[16], which both carry significance in relation to the legal situation of persons with schizophrenia. In many acts of public law (the most important being the Labour Code, but the Civil Service Act can also be cited by way of example) we can find legislation relating to working conditions, terms and conditions of employment and benefits such as the right to annual leave periods, the right to sick leave, etc. These conditions and rights are binding in law and under the provisions of the CRPD disabilities in all its forms including mental illness cannot be used as a reason to limit either their worth or their availability. Neither can the taking of sick leave for example be used as a reason to limit or diminish other leave periods. States Parties have an obligation to provide an effective means to protect these conditions, benefits and the rights attached thereto and particularly so in relation to all disabled people provisioned for under the umbrella of the CRPD.

People suffering with schizophrenia face specific problems relating to this disorder. The nature of the condition is such that it manifests in a wide variety of forms from mild to severe, from unaccountable anxiety to a total withdrawal where a person with the disorder prefers the isolation of their own company to the exclusion of all around them[17]. It can be appreciated therefore that lack of understanding and misplaced attitudes on the part of employers and coworkers can have serious consequences in relation to the stability and wellbeing of a person with schizophrenia and particularly so in cases where symptoms of paranoia exist[18].

An essential obligation of States Parties connected with the employment of persons with schizophrenia on employment is awareness-raising, not just in the workplace but in society as a whole. Researchers in the field of medicine and social science indicate that the most important barriers faced by persons with mental illness, especially schizophrenia, in terms of employment are the prejudices of managers and co-workers, work-place culture and low expectations leading to self-stigma of these persons[19]. In fact, self-stigma is usually associated with the social environment,[20] which means that the raising of awareness in society is crucial in encouraging people with schizophrenia to actively participate in the labour

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[16] Art. 5 CRPD.

[17] S. Bevan, J. Gulliford, K. Steadman, T. Taskila R. Thomas and A. Moise, Working with Schizophrenia: Pathways to Employment, Recovery & Inclusion, The Work Fundation, Lancaster 2013, p. 49.

[18] *Ibidem,* p. 77-81

[19] M. Hampson, R. Hicks, B. Watt, Understanding the Employment Barriers and Support Needs of People Living with Psychosis, The Qualitative Report, 21(5), Davie 2016, p. 870-886.

[20] H. Yoshi, Self-stigma of Schizophrenia Patients with Work Experiences and Reasons Not to Disclose Their Illness, British Journal of Education, Society & Behavioural Science vol. 5(2), Hoogly 2014, p. 203-204.

market. The provisions of the CRPD impose on States Parties the obligation to fight against the creation of stereotypes, promote knowledge about the work capability of persons with disabilities and take action to strengthen social respect for them in society. Measures suggested to attain these goals in the Convention include social campaigns, educational programmes in schools, and state support initiatives linked with achieving these objectives[21]. It needs to be underlined that the Convention falls short in detail on how or in what form these campaigns, programmes and objectives should be accomplished. It merely outlines the prerequisites and suggests that States Parties should "organize", "promote", "encourage" appropriate institutions or offices to support programmes created and run by NGOs and private entities – or so it seems.

The next obligation connected with the employment of persons with schizophrenia, is to provide independent life and inclusion in the community (art. 19 CRPD). In the foreground of this article lies the principle of equality. However, this obligation does not directly express the right to participate in the labour-market. Nevertheless, it is clear that "participation in the community" has to be linked with participation in the labour market. Moreover, it is hard to say how we are to understand "with choices equal to others" in this regard[22]. Also, the CRPD lacks a limitation clause similar to the limitation clause found in the ECHR and other similar conventions. Provisions connected with employment also have no similar clauses. It seems that the answer here is in the wording "appropriate measures". The discretionary character of this clause serves to indicate that States have a wide range of lawful measures, which leads to the suggestion that they also have the right to restrict access to some professions due to objective reasons with regard to the principle of non-discrimination.

For persons with schizophrenia, work is one of the most important aspects in the processes of rehabilitation and revalidation, and participation in the labour market as one of the surest and quickest ways to regain mental health. Especially in the case of schizophrenia, supported employment programmes are particularly effective.[23] Supported employment programs also known as employee assistance program (EAP) consist of assistance to employees who have personal problems typically connected with some form of mental illness.[24] In reference to this fact, the provision of art. 26 CRPD which addresses rehabilitation should be analysed. Art. 26 *expressis*

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[21] Art. 8 CRPD.

[22] Art. 19 CRPD.

[23] E.W. Twamley, D.V. Jeste, A.F. Lehman, Vocational Rehabilitation in Schizophrenia and Other Psychotic Disorders: A Literature Review and Meta-Analysis of Randomized Controlled Trials, The Journal of Nervous and Mental Disease: August 2003 – Volume 191 – Issue 8, Philadelphia 2003, p. 515-523.

[24] F. Dickam, Ingredients of an Effective Employee Assistance Program [in:] M.A. Richard (edit.) EMPLOYEE ASSISTANCE PROGRAMS: Wellness/Enhancement Programming (4th Ed.), Springfield 2009, p. 48-56.

verbis indicates employment as one of the fields in which States Parties are obligated to organise rehabilitation programmes: "States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes: (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths" [25].

The question here in relation to the foregoing: is does the CRPD promote the support of employment programmes? It seems to the author that in light of the principle of equality, participation in social life and articles connected with health in the CRPD which provide persons with disabilities rights to appropriate support connected with special needs[26], if it was commonly known that supporting employment programs dedicated to rehabilitate people by their inclusion in work-life, such as the EAP, more countries could efficiently help in socializing people with mental illness.

The Convention also contains provision directly connected with work and employment[27] Therein we can distinguish that three important principles have been established: the right to equality in employment, the equal protection of work and employment, and the prohibition of enslavement of persons with disability in the workplace.

In relation to the first two principles the CRPD affirms that, "States Parties recognize the right of persons with disabilities to work, on an equal basis with others" and "shall safeguard and promote the realization of the right to work […] including through legislation (art. 27 1). It also indicates the obligation of states in relation to disability-based discrimination in employment affirming that States Parties shall, "Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment" (art. 27 1(a)). In essence this means that all matters relating to discrimination should be directly and clearly included in the legislation of States Parties. With regard to the equal protection of work and employment the CRPD states that States Parties shall take steps to, "Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work" (art. 27 1(b), and to "Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others" (art. 27 1(c). This seems to indicate that States are obligated to introduce appropriate guarantees to procedures (for example in Poland civil procedure) and appropriate facilitation to courts. In the case of persons with schizophrenia, it means that testimonies of persons with mental illness have to be treated respectfully. It also means that persons with schizophrenia cannot be discriminated against in trade unions.

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[25] Art. 26 CRPD.

[26] Art. 25 CRPD.

[27] Art. 27 CRPD.

It needs to be underlined that in the private sector States are not obligated to apply affirmative action programmes (here the word "may" is used). Nevertheless, if affirmative actions are applied generally to persons with disabilities which seems to accord with the Convention, especially in relation to the principle of equality of opportunity[28] and general principle of non-discrimination, the application of affirmative action to only selected groups of persons with disabilities would break with the Convention. Therefore, this would mean that the rules of the Convention would be breached if persons with schizophrenia were to be left out of affirmative programmes (it having been demonstrated in this paper that schizophrenia is in fact a disability).

To conclude this section, the connection between social protection and the labour situation of persons with schizophrenia needs to be looked at. The CRPD imposes on states the obligation to ensure access for all persons with disabilities to social protection programmes.[29] One of the most important obligations of the states resulting from the CRPD is the obligation to ensure the equal participation of persons with disabilities in social life (also highlighted in this paper). Here it is important to mention that social protection generally can itself be a barrier to participate in social life and employment[30] and this can also breach the CRPD.

4. Situation of protection of persons with schizophrenia as persons with disability rights in employment in Poland

The CRPD was signed by Poland on 20 March 2007 and ratified on 6 August 2012[31]. That means that the CRPD is now included in national law and Poland has taken upon itself the obligations of the Convention. This section of the paper assesses Poland's performance in respect the obligations arising from the CRPD, particularly in relation to persons with schizophrenia.

First, it is important to indicate that polish law recognised schizophrenia (and other mental disease) as being a disability. Polish law broadly defines disability-based on measures relating to participation in social life[32]. This means that Poland associates the basic obligations arising from the CRPD with persons suffering schizophrenia – it recognises their disability.

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[28] Art. 3 par.5 CRPD.

[29] Art. 28 CRPD.

[30] S.P. Harris, R. Owen, K.R. Fischer, Structural and Cultural Rights in Australian Disability Employment Policy, [in:] C.J. Schlund-Vial (edit.) M. Gill (edit): Disability, Human Rights and the Limits of Humanitarianism, Farhnam 2014.

[31] Official Website of polish Obdusman: https://www.rpo.gov.pl/pl/content/konwencja-onz-o-prawach-os%C3%B3b-niepe%C5%82nosprawnych-0 (access 28.04.2018).

[32] O. Komorowska, Osoba Niepełnosprawna w Polsce i Niemczech – wybrane aspekty prawne, „Studia Prawno-Ekonomiczne", vol. LXXXIII, Łódź 2011, p. 311-322.

The general principle of non-discrimination because of disability is implemented as well as provisions connected with the protection of the rights of disabled persons. However, it can be seen that, in practice, the protection of the rights of disabled persons in employment raises some issues connected with its implementation (e.g. the retroactive effect of these provisions) but this is not a problem that relates specifically to Poland, other European countries also have concerns with full application of the rights to persons with disabilities in certain areas[33].

One problem that is specific to Poland and which impacts implementation of the principle of non-discrimination is that in many fields of employment, persons with schizophrenia are excluded by Polish law. By way of example persons with schizophrenia cannot be employed in the police force, fire department, state security services or border guards regardless of their capability to work in these positions[34]. Persons with schizophrenia are also excluded for employment as teachers and if a teacher already in employment is subsequently diagnosed with schizophrenia (under Polish law schizophrenia is a condition that can be used to qualify a statement of incapacity to work[35]) the contract of employment with that teacher has to be terminated[36]. Professional persons with schizophrenia can also have problem with employment or job retention if they are a barrister[37] or medical doctor[38] which results from general clauses.

It is not the goal of this paper to list all instances where Polish law states that schizophrenia is a reason to prevent or terminate an employment contract or inhibit the issue of a license to practice in a profession, so the author will limit himself to the conclusion that under Polish law there are many instances that can restrict the employment of persons with schizophrenia.

Nevertheless, it is necessary to underline where the limitation of access to a profession is justified. The answer here stems from the wording used in the CRPD, i.e. "equal basis"[39] for all, regardless of their disability, which in connection with the principle of non-discrimination means that the limitation of access to a profession is presupposed to be strictly connected with the individual patient's condition. This results from the fact that, if limitation of access relates specifically to the condition of

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[33] Paper on website of project „Lodołamacze": Zakaz dyskryminacji osób niepełnosprawnych w zatrudnieniu : http://lodolamacze.info.pl/pliki/materialy-poradniki/zakaz_dyskryminacji_ON.pdf (29.04.2018).

[34] Journal of Laws 2018, item 2035 as amended.

[35] A. Kiejny, P. Piotrowski, T. Adamowski (edit.) *op.cit* p. 23

[36] Art. 23 Journal of Laws 2018 item 967 as amended

[37] Wyrok WSA w Warszawie VI SA/Wa 1940/16 http://orzeczenia.nsa.gov.pl/doc/BDB1B4F868 (12.12.2018)

[38] Art.9 Journal of Laws. 2018 item. 617 as amended; see also: K. Żaczkiewicz – Zborska, WSA: zawieszenie lekarza podejrzanego o schizofrenię, https://www.prawo.pl/prawnicy-sady/wsa-zawieszenie-lekarza-podejrzanego-o-schizofrenie,58167.html (12.12.2018)

[39] Art. 27 CPRD

the individual, we cannot say that the basis of limitation is the "state of disability" (in this case schizophrenia) but rather that the limitation results from the individual's incapacity to work in the profession.

In relation to the above examples, we can say that any statement made that past or present schizophrenia provides grounds for automatically declaring an incapacity to work in a particular profession (which medical science confirms[40]) is of a discriminatory character.

The above also connects with situations where an individual is excluded from recruitment or when someone is excluded from recruitment because he displays symptoms of schizophrenia during an interview (the Polish Society of Antidiscrimination Law notes a case when after the interviewee freely admitted that he suffers from mental disorder, the interview was ended[41]).

It's also worth noting, that if a disability occurs as a result employment, the employer is obligated to adapt a working environment that meets the needs of the person so disabled, and if that is impossible to achieve the employer can dismiss that person. Dismissal can only be used as a last resort[42].

Awareness-raising was mentioned above as one of the most important issues for equal opportunities in employment for persons with schizophrenia. In Poland, programmes have been initiated connected with awareness-raising in this field, but the last such project which could be found came to an end in 2011.[43] According to the findings of the Centre for Public Opinion Research in 2012, many Poles still possess a reluctance to see persons with mental illness in some professions[44]. According to the research findings of CBOS in 2002, social awareness about schizophrenia was low[45]. This means that the further application of awareness-raising programmes connected with schizophrenia is necessary and it would be desirable that Polish authorities bring this into being as soon as possible.

It is difficult to analyse the application of every obligation under the CRPD separately because to-date none have actually been fully applied. This results from the fact that in Poland, a programme specifically dedicated to the problems of

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[40] W. Wolfgang Fleischhacker et al., Schizophrenia—Time to Commit to Policy Change, Schizophrenia Bulletin 2014 vol 40 Oxford p. 165 – 195

[41] K. Kędziora, M. Wieczorek, Komentarz do przepisów antydyskryminacyjnych na podstawie praktyki stosowania wybranych regulacji prawa krajowego [in:] W. Klaus, *Równi, ale różni, prawo a równe traktowanie cudzoziemców w Polsce,* Warszawa 2013 p. 159 – 160

[42] M. Kułak, Glosa do wyroku SN z 12.4.2012 r., II PK 218/11, Kwartalnik Krajowej Szkoły Prokuratury i Sądownictwa 2015 vol. 1 (16), Kraków p. 86 – 91

[43] Wsparcie osób z zaburzeniami psychicznymi na rynku pracy II – podręcznik dobrych praktyk , PFRON 2011

[44] M. Omyła – Rudzka, Komunikat z Badań: Stosunek do osób chorych psychicznie BS/147/2012, Fundacja Centrum Badania Opinii Społecznej, Warszawa 2012.

[45] B. Wciórka, J. Wciórka, Komunikat z Badań: Polacy o schizofrenii (I). Społeczne Rozumienie Słowa Schizofrenia BS/9/2002 Fundacja Centrum Badania Opinii Społecznej, Warszawa 2002.

persons with schizophrenia or other forms of mental disease has yet to be initiated. The National Program for the protection of mental health has been involved in the promotion of employment for persons with schizophrenia (and other mental illness) but to be honest, while this looked good on paper, what is indicated by the Supreme Audit Office[46] and that what is perceived by the medical community[47] tells a different story. The National Programme for the protection of mental health contains elements which can be recognised as the application of obligations resulting from the CRPD. This programme in years 2011 – 2015 was described by the NIK as a failure[48]. A follow-up programme was launched in 2017, along the same lines as its predecessor, and is due for completion in 2022[49]. In the field of employment specifically, the Ministry of Family, Labour and Social Policy also has obligations to fulfill in this regard[50].

Analysis of the legislative activity of this ministry indicates that until May 2018, the ministry has not undertaken any legislative initiative in connection with these programs[51].

The above analysis leads to the simple conclusion that Polish legislation applies only the basic obligation connected with the CRPD. In point of fact, there is no reason why Poland should not apply the obligation, it doesn't cost money and all that is required is a simple change to the law. More complicated obligations relevant to the promotion of employment for persons with schizophrenia, support for the employers who engage persons with schizophrenia and obligations connected with employment such as rehabilitation – is a problem for Poland.

Nevertheless, it is important to outline that some methods of support for the employment of persons with schizophrenia exist, we can mention subsidies to employers, the refund of costs relating to employee training, and lower PFON payments[52]. We need to remember that support for the employment program in the private sector is optional within states, and that persons with schizophrenia have specific needs and their needs are different from those of other persons with disabilities. This means that if the Polish legislator perceives the needs of specific

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[46] Informacja o wynikach kontroli: Realizacja zadań Narodowego Programu Ochrony Zdrowia Psychicznego KZD.430.006.2016 available from: https://www.nik.gov.pl/plik/id,12692,vp,15090.pdf (access 28.04.2018) in short: KZD.430.006.2016.

[47] A. Cybula-Fujiwara, D. Merecz-Kot, J. Walusiak-Skorupa, A. Marcinkiewicz, M. Wiszniewska, Employees with mental illness – Possibilities and barriers in professional activity, Med Pr. 2015; 66(1): 57-69, Łodź 2015.

[48] Informacja o wynikach kontroli…. *op. cit.*

[49] Consolidated text Journal of Laws 2017 item 258 as amended.

[50] *Ibidem.*

[51] This resulted from list of legislative initiatives on website of Government Center of Legislation https://legislacja.rcl.gov.pl/.

[52] E. Trzcińska, Osoby z chorobami psychicznymi na rynku pracy, „Zeszyty Naukowe. Zbliżenia Cywilizacyjne", no. XIII (1)/2017, Włocławek 2017, p. 100.

groups of persons with disabilities, e.g. blind persons, but fails, or does not want, to perceive the specific needs of persons with schizophrenia, this can be interpreted as a form of discrimination in relation to other groups of persons with disability.

5. Conclusion and postulates

The first conclusion to be drawn here is that it has been proven beyond reasonable doubt that persons with schizophrenia are indeed persons with disabilities in the legal sense. This results not only from the provisions of the CRPD but also from other acts of an international order and Polish law.

The CRPD contains many provisions both relevant and applicable to persons with schizophrenia in the field of employment. The most important provisions are: the provisions connected directly with employment, the provisions connected with the general principle of non-discrimination, the provisions expressing the right to equal participation in social life, and the provisions expressing the right to health and the right to rehabilitation.

Measures introduced by the Polish legislator to ensure the equality of schizophrenia sufferers in the labour market seem to be insufficient. Poland has attempted to improve the situation for persons with the disorder, but it needs to be said that they require more attention to be paid to their employment needs by the Polish government.

In particular, a greater role has to be played by the National Programme for Mental Health Protection in this regard. Realisation of this programme would certainly improve the participation[53] of this group in the labour market which would be a step forward in realising not only the provisions of the CRPD but also its underlying objectives.

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[53] A. Cybula-Fujiwara, D. Merecz-Kot, J. Walusiak-Skorupa, A. Marcinkiewicz, M. Wiszniewska, *op. cit*.

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The New Provisions on Access to Protected Works for Visually Impaired Persons – One Small Step for Copyright, One Giant Leap for People with Disabilities[1]

Abstract: Due to different types of physical, intellectual or mental impairment, every sixth person in the European Union encounters obstacles related to full participation in social, cultural, artistic and economic life. Although the EU has taken several legal steps to counteract discrimination and strive for equal opportunities, disabled persons still have limited access to cultural goods such as printed material for example. However, this may soon change due to the adoption at international level of the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who are Blind, Visually Impaired or Otherwise Print Disabled and, within the EU, the implementation of Regulation (EU) 2017/1563 and Directive 2017/1564. The aim of this article is to assess these legal acts within the context of their impact on ensuring equal treatment in access to works protected by copyright for people with disabilities.
Keywords: Copyright, disability, visually impaired persons, Marrakesh Treaty

1. Introduction

Due to different types of physical, intellectual or mental impairment, every sixth person in the European Union (hereafter: EU) encounters obstacles related to full participation in social, cultural, artistic and economic life[2]. Given the aging population within the EU, it is highly likely that within the next few years the number of people

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[1] This paper is the result of research conducted within the project 2015/19/D/HS5/03150 "The limits of pluralism of intellectual property protection and the legal situation of disabled persons in IP law" financed by the National Science Centre, Poland.

[2] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM/2010/0636 final.

with disabilities will significantly increase, and therefore legal provisions will have to respond in a more positive way to the needs of those suffering impairment.

The problem of disability among EU citizens has been noticed and in response several legislative initiatives[3] have been taken to counteract discrimination and strive for broadly understood equal opportunities. For example, the EU and its member states acceded to the United Nations Convention on the Rights of Persons with Disabilities signed in New York on 13 December 2006 and adopted the European Disability Strategy 2010-2020. However, this raises the question of whether, in addition to clearly perceiving the issue, the EU and member states will take specific actions to fulfil the obligations set out in the mentioned legal acts in order to meet the needs of people with disabilities so that they may participate in the social and economic life of the EU on equal terms with non-disabled people.

The involvement of disabled people in social, economic and cultural life should include among others the opportunity to participate in cultural and artistic life, both as creators and recipients of various artistic events, along with access to information, knowledge, goods and services. This participation is not only important because of the need to ensure a level playing field in society but also because of the positive impact it has on the treatment of various disabilities. This can be assured with the adoption of legal provisions. However, in my opinion, this goal should be achieved in small but consistent steps while introducing uniform and comprehensive provisions aiming at ensuring increased participation of disabled persons in all areas of life, is not possible due to its complex objective and subjective scope, resulting mainly from the various types and degrees of disability.

An important step towards ensuring equal functioning of the disabled in society is the WIPO Treaty adopted on the international forum – The Marrakesh Treaty to Facilitate Access to Published Works for Persons Who are Blind, Visually Impaired or Otherwise Print Disabled, adopted on 27 June 2013 (hereafter: Marrakesh Treaty or the Treaty) and the follow-up EU acts: Regulation 2017/1563 of the European Parliament and of the Council of 13 September 2017 on the cross-border exchange between the Union and third countries of accessible format copies of certain works and other subject matter protected by copyright and related rights for the benefit of persons who are blind, visually impaired or otherwise print-disabled (hereafter:

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[3] See Article 10 of the Treaty on the Functioning of the European Union (hereafter: TFEU), which require the EU to combat discrimination based on disability in defining and implementing its policies and activities, and Article 19 TFEU which gives the EU the right to take appropriate action to combat discrimination based on disability, and the Charter of Fundamental Rights, in addition to prohibiting discrimination based on disability (Article 21 of the Charter), also provides for respecting the rights of persons with disabilities to take advantage of measures to ensure their independence, social and professional integration and participation in community life (Article 26 of the Charter).

Regulation 2017/1563 or the Regulation)[4] and Directive 2017/1564 of the European Parliament and of the Council of 13 September 2017 on certain permitted uses of certain works and other subject matter protected by copyright and related rights for the benefit of persons who are blind, visually impaired or otherwise print-disabled and amending Directive 2001/29/EC on the harmonisation of certain aspects of copyright and related rights in the information society (hereafter: Directive 2017/1564 or the Directive)[5].

The aim of this article is a short presentation of the above mentioned legal acts and their assessment within the context of their impact on ensuring equal treatment in access to works protected by copyright for people with disabilities.

2. The Marrakesh Treaty as a new beginning

The Marrakesh Treaty is the first international legal act, which refers to access to works for people with disabilities. Its objective scope is however very limited. In general, the beneficiaries of the Treaty are people with so-called print disability, classified according to three categories. Firstly, the Treaty applies to blind people, that is those who are totally or largely devoid of sight from birth or as the result of accident, disease or age. Secondly, the Treaty provides access to works for visually impaired persons or persons who have a perceptual or reading disability, which cannot be improved and who therefore are unable to read printed works to substantially the same degree as a person without such impairment or disability. Lack of the possibility to overcome a visual disability by wearing glasses or undergoing surgery qualifies for inclusion in this group. Moreover, this inability to correct eyesight should not be confined just to limitations and obstacles in the development of medicine and techniques to improve vision, it should also take into account financial constraints. Refusal to honour the rights of a visually impaired person simply because they lack the financial resources to benefit from correctable treatment, is not justifiable on humanitarian grounds.

The third group of beneficiaries was broadly defined and therefore it is possible to include in this category various other types of disability. It is made up of people who have any form of physical disability that makes them unable to hold or manipulate a book or to focus or move the eyes to an extent normally acceptable for reading. For the purpose of exercising the rights provided by this act, the Treaty does not require evidence of having a particular type of disability. This absence of obligation to provide formal documentary evidence of disability probably arises from the belief that formalities of any kind would cause unjustified restrictions on access to works to be imposed and secondly, that persons without any form of disability that prevents

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[4] OJ L 242, 20.9.2017, pp. 1-5.

[5] OJ L 242, 20.9.2017, pp. 6-13.

them from reading will have no interest anyway in using the rights specified in the Treaty.

All of the above mentioned beneficiaries have the right of access to works within the meaning of Article 2 (1) of the Berne Convention for the protection of literary and artistic works[6], but only in the form of a text, notation and/or related illustrations, whether published or otherwise made publicly available in any media through the right to convert them to an accessible format copy[7].

The term "accessible format copy" means any work reproduced in an alternative manner or form that beneficiaries are able to acquaint themselves with, e.g. braille code, enlarged print, electronic and aural versions of a book. Some of these formats, such as e-books, are also available for use by fully abled people, therefore the Treaty expressly limits the right to make copies to only those required for the exclusive use of beneficiary persons. However, where applicable, the act of creating a copy of a work in an accessible format does not have to be performed by the beneficiaries themselves but may be undertaken by a person acting on their behalf (e.g. a parent, guardian or carer), or by non-profit making entities (providing activities for beneficiaries in education, training, adaptive reading or access to information) which are duly authorised or recognised by the relevant authorities in each country[8].

Beneficiaries, people acting on their behalf and authorized entities when converting a work require to meet certain conditions, including the necessity of having lawful access to the work or copy thereof, and introducing to that work only such changes that are needed in connection with its conversion to an accessible format[9]. The Treaty not only allows making a copy of works in an accessible format without the consent of the rights holder, but also ensures the right to its distribution, including cross-border transfer between states that are party to the Treaty, which aims to limit the duplication of efforts to adapt the work in a way corresponding to the needs of people with print disabilities. States may however decide to limit the rights granted by the Treaty to works in a format enabling access for disabled people

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[6] Berne Convention for the Protection of Literary and Artistic Works of 9 September 1886, completed in Paris on 4 May 1896, revised in Berlin on 13 November 1908, completed in Berne on 20 March 1914, revised in Rome on 2 June 1928, in Brussels on 26 June 1948, in Stockholm on 14 July 1967, and in Paris on 24 July 1971, and amended on 28 September 1979.

[7] Article 2 (b) of the Marrakesh Treaty defines "accessible format copy" as a copy of a work in an alternative manner or form which gives a beneficiary person access to the work, including to permit the person to have access as feasibly and comfortably as a person without visual impairment or other print disability. The accessible format copy is used exclusively by beneficiary persons and it must respect the integrity of the original work, taking due consideration of the changes needed to make the work accessible in the alternative format and of the accessibility needs of the beneficiary persons.

[8] Article 2 (c) of the Marrakesh Treaty.

[9] See more Article 4 (2) (a) (b) of the Marrakesh Treaty.

that are not available on reasonable terms on the open market[10]. Such limitation favours the stimulation of authors, and especially publishers and producers, to make copies of works available in accessible formats on their own initiative. This same effect may also be achieved as a result of inadequate clarification in the Treaty of some issues important to the parties involved, e.g. remuneration for using the works in connection with the restriction or exclusion of rights of entitled entities which, pursuant to Article 4 (5) of the Treaty, is left to the discretion of each state; likewise other issues such as remuneration to an author resulting from interference in his work as a result of its conversion to an accessible format. In such instances, a state may decide to either exclude or establish a low level of such remuneration thus providing an incentive for suitably adapted works to be published commercially at source.

3. Regulation No. 2017/1563 and Directive 2017/1564: further EU steps for the better good

Recognizing the necessity to provide access to works for people with disabilities that prevent them from reading standard printed materials, the Treaty was negotiated by the European Commission (hereafter: the EC) [11] in the name of the EU as a whole, and the EC was duly authorized to sign the act[12] which took place on 30 April 2014. Subsequently, on 21 October 2014, the EC presented a proposal for a Council decision on the conclusion of the Marrakesh Treaty on behalf of the EU[13].

However, the EC proposal failed to obtain the required majority in the Council with some member states[14] expressing doubt on the exclusive competence of the EU in this matter. Consequently, the EC submitted a request to the Court of Justice (hereafter: CJ) calling for an opinion on EU competence in respect the Marrakesh Treaty and a clear answer to the question of whether the EU possessed the exclusive competence to conclude the Treaty. The CJ confirmed the opinion presented in this case by the Advocate General Nils Wahl[15], and acknowledged that the EU did indeed possess the exclusive competence to conclude the Treaty[16].

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[10] Article 4 (5) of the Marrakesh Treaty.

[11] Council Decision on the participation of the European Union in negotiations for an international agreement within the World Intellectual Property Organisation on improved access to books for print impaired persons; 16259/12 EU RESTRICTED.

[12] Council Decision 2014/221/UE of 14 April 2014 on the signing, on behalf of the European Union, of the Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired, or otherwise Print Disabled, OJ EU L 115/1.

[13] COM/2014/0638 final – 2014/0297 (NLE).

[14] The Czech Republic, France, Lithuania, Hungary, Romania and the United Kingdom, presented the view that it is not within the EU exclusive competence to sign the Marrakech Treaty.

[15] The Opinion of Advocate General Nils Wahl in case 3/15 presented on 8.09.2016.

[16] The CJ Opinion in case 3/15 of 14.02.2017, ECLI:EU:C:2017:114.

Ahead of obtaining the CJ's opinion in this case, the EC began work on legislative proposals for implementation of the appropriate provisions in EU law in accordance with the Treaty. These proposals were presented on 14 September 2016, as the drafts of future Regulation 2017/1563 and Directive 2017/1564.

The aim of Regulation 2017/1563 is to provide and define the rules of export and import for non-commercial purposes of copies in accessible formats for the use of beneficiaries, as agreed between the EU and third states party to the Treaty[17]. On the other hand, the purpose of Directive 2017/1564 is to improve the availability of copies of works in accessible formats and to ensure the circulation of such copies on the internal market. Regulation 2017/1563 will apply in the case of exchanging copies of works between an entity from within the EU and a country outside this area that is party to the Treaty. In many aspects however, the Regulation refers to the provisions implementing Directive 2017/1564[18] of the member state from which the parties share or obtain access to works in accessible format. The national rules implementing Directive 2017/1564 will also regulate access to such works for beneficiaries domiciled in the EU. Therefore, they will apply both in domestic and cross-border relations, i.e. within the EU and internationally.

Although the provisions of Regulation 2017/1563 and Directive 2017/1564 are formulated to accord with the content of the Treaty, they nevertheless contain certain modifications.

Firstly, the EU acts extend the circle of beneficiaries indicated in the Treaty to encompass people who, while not affected by visual or other physical disabilities, have impairments in perception or reading ability[19], including dyslexia or other limitations of learning ability (autism, reduced intellectual functioning and the like), which make it impossible for them to read printed works to substantially the same degree as a person without such limitation[20].

Secondly, the EU legislator chose not to include in Directive 2017/1564 the optional provision of the Treaty relating to prior verification of the availability of a work in the appropriate format on the market which, according to Article 4 (4) of the Treaty[21], should be investigated by beneficiaries, persons acting on their behalf or by authorised entities, before physically performing the act of making a copy of the work in accessible format[22]. The withdrawal of this requirement was due to

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[17] See recital 5 of the preamble to Regulation 2017/1563.

[18] See Articles 3 and 4 of Regulation 2017/1563.

[19] The Marrakech Treaty refers to people with limited ability to perceive or read, which results from the limits of visual function (Article 3 (b) of the Marrakech Treaty).

[20] Article 2 (2) (c) of Regulation 2017/1563 and Article 2 (2) (c) of Directive 2017/1564.

[21] See more: L.R. Helfer, M.K. Land, R.L. Okediji, J.H. Reichman, Facilitating Access…, pp. 122-123.

[22] See. Article 4 (4) of the Marrakesh Treaty, which allows the contracting parties to create an exception or a restriction of copyright only if the market is not able to offer the beneficiaries the opportunity to purchase the copies of works in an accessible format at a reasonable price.

doubts related to the practical application of such provision, concerning for example the manner of prior availability of the work, potential exclusion of the possibility of making a copy of the work available on the market in another form of accessible format, and affordability of the copy.

However, although the use of works already available on the market in accessible formats is financially attractive and limits the waiting time for obtaining a particular work, in practice this may not be that significant due to linguistic differences that exist between member states and third countries. Therefore, given that in the majority of cases this would mean reproducing a particular work in multiple languages, the actual incidence of cross-border exchange of adapted works is likely to be quite small. In addition, such exchange would have to take place on the basis of national provisions (only harmonised by Directive 2017/1564) due to the lack of uniform rules applicable throughout the EU. This in fact may adversely affect the cooperation of relevant entities in cross-border exchange which, due to differences in the content and application of national provisions, could serve to limit the ability of beneficiaries to access adapted works.

Another point worth mentioning, is that neither Regulation 2017/1563 or Directive 2017/1564 address the provision contained in Article 7 of the Treaty[23] relating to the prohibition of restricting access to works by rights holders by way of applying technological measures that prevent access to and reproduction of a work. The obligation to introduce measures necessary to ensure the rights against such circumvention in relation to the use of works for the non-commercial benefit of people with disabilities, already exists in Article 6 (4) of Directive 2001/29[24]. However, national provisions limiting the use of technological reproduction measures should also refer to the new provisions aimed at implementing Directive 2017/1564. Otherwise achievement of the aims provided for in Regulation 2017/1563 and Directive 2017/1564 will be significantly jeopardised.

4. Final remarks

The Marrakesh Treaty opened a new chapter in the debate on the legal situation of persons with disabilities in intellectual property law, namely on access for people with print disabilities to works protected by copyright. It imposed the obligation to provide exceptions and limitations to copyright and related rights in order to create and distribute copies of works in formats accessible for people who, because of their

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[23] On the bases of Article 3 (5) of Directive 2017/1564, Member States have only to ensure that the exception referred to in Article 3 (1) cannot be excluded by contractual provisions.

[24] Directive 2001/29/EC of the European Parliament and of the Council of 22 May 2001 on the harmonisation of certain aspects of copyright and related rights in the information society, OJ L 167, 22.06.2001 pp. 10-19.

disability, are not able to read the traditional printed form, and also to allow cross-border exchange of these copies[25].

The Treaty as well as the EU acts aimed at its implementation in EU law, undoubtedly constitute a significant and valuable contribution in providing access to printed materials[26] for people with disabilities that prevent them from reading, and thus promote respect for their inherent dignity[27]. By limiting the scope of copyright protection, people with print disabilities attained the right of access to works in alternative accessible formats, a right which they did not have under any previously applicable legal act.

In assessing the adopted legal acts, one needs to take into account the fact that the content of the Treaty reflects a compromise between the position of rights holders defending limited access to their works and representation of the needs of access to such works by people with disabilities[28]. Therefore, the very fact of accepting a treaty which aims at providing access to works for persons that, due to impairment, cannot benefit from general exceptions and limitations from the exclusive rights of the rights holder, is highly satisfactory. The real consequences of the adoption and application of the Treaty, Regulation 2017/1563 and Directive 2017/1564, is that it may not lead to access to works for people with print-disability that is an absolute equal to that enjoyed by fully able-bodied persons. The EU legislator was aware of this fact and in the preamble to Directive 2017/1564 it is not stated that this act should provide equal rights on access to works, only rights that are “substantially equivalent” to those of a person free of such impairment[29].

The discussed legal acts are, however, an attempt to improve the current situation and prove the need to move towards implementation of the principle of equal treatment. Requiring all member states to set up the legal systems seeking to meet

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[25] L. Zemer, A. Gaon (in: Copyright, disability and social inclusion: the Marrakesh Treaty and the role of non-signatories, “Journal of Intellectual Property Law & Practice” 2015/10, p. 849) points out that the Marrakesh Treaty has a historical dimension for three reasons. As the first international legal act in the field of copyright it refers to exceptions and restrictions on copyright, raises the issue of access to works for people with disabilities, and regulates cross-border access to works protected by copyright.

[26] R.M. Hilty, K. Koklu, A. Kur, S. Nerisson, J. Drexl, S. von Lewinski, Position paper of the Max Planck Institute for Innovation and Competition concerning the implementation of the WIPO Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print-Disabled, International Review of Intellectual Property and Competition Law 2015, p. 709.

[27] F.J. Martinez Calvo, The role of libraries in the implementation of the Marrakesh Treaty for persons with a print disability, http://library.ifla.org/913/1/070-calvo-en.pdf, p. 8.

[28] S. von Lewinski, The Marrakesh Treat…, *op. cit.,* p. 125; see also C. Sganga, Disability, Right to culture and copyright: which regulatory option? “International Review of Law, Computers & Technology” 2015/29, p. 97.

[29] Recital 7 of the preamble to the Directive 2017/1564.

the needs of some disabled to access to information and culture, which they must comply with by 11 October 2018[30], may be important but is only the first step towards improving the access to works for people with disabilities[31].

The introduction of specific provisions to a state's legal systems may, hopefully, result in actions aimed at enabling disabled persons suffering health problems that limit their ability to use traditionally printed material, to acquaint themselves with a wider variety of works thus improving the currently bad situation in this regard, although of course, the extent of this improvement cannot be clearly predicted. The new provisions will probably play a much greater role in the process of balancing the access to works than the current Article 5 (3) (b) of Directive 2001/29/EC, which member states could, but were not forced to implement in their respective national legal orders. The generally formulated content of Article 5 (3) (b) of Directive 2001/29/EC and its optional nature caused that the present conditions of access to intellectual works for people with disabilities differ significantly from existing needs in this area. Likewise, Directive 2017/1564 also contains very general provisions and therefore member states have considerable leeway in implementing the Directive's aim by adopting national provisions which, taking into account the experience gained so far with regard to providing access to works for the disabled within the EU, can only be assessed negatively. That is why the member states now have an important role to play in the process of facilitating access to works for people with disabilities by precisely formulating the content of national legislation, thus eliminating the generalised nature of exceptions which invariably leads to the occurrence of shortcomings.

It would also be appropriate for the member states to introduce adequate mechanisms for submitting complaints and claims by beneficiaries in cases of improper performance of duties by authorised entities. The adoption of such a provision in national legislation, which was in fact proposed for introduction by the European Parliament in the process of adopting Directive 2017/1564, would likely increase effective access to works for persons with print disabilities. In addition, member states should set out in detail the terms and conditions of the system for reimbursement of the costs related to copy making.

As an advocate of equal treatment of persons with disabilities, which must necessarily take place at the rights holders' and authors' expense, I firmly believe that the provisions should be the beginning of the discussion on the rights of disabled people, not the goal itself.

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[30] Regulation 2017/1563 will apply from 12/10/2018; Member States have until 11.10.2018 to implement the provisions of Directive 2017/1564.

[31] Recital 15 to Directive 2017/1564.

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The European Union and the UN Convention on the Rights of Persons with Disabilities. Selected Institutional Aspects of Implementation

Abstract: The European Union is a party to the United Nations Convention on the Rights of Persons with Disabilities. A broad scope of the UNCRPD provisions makes it covered by different types of EU competence – exclusive and shared. In result, the EU and its Member States may exercise their competence in Convention issues to a different extent – depending on the matter concerned. Considering that it becomes clear that a particular mechanism of cooperation between them is required. It should serve a proper implementation of the Convention.
This contribution aims at presenting the basic rules governing the cooperation between the Council, the Commission and the Member States in relation to UNCRPD's implementation as settled by the relevant Code of Conduct. The analysis starts with the status of the EU as a party to the Convention and the division of competence between EU and Member States in Convention-related matters. Then, the rules for establishment and presentation of EU and Member States positions regarding the Convention issues are described. Next, the problem of focal points and nominations to Convention organs as a part of the implementation process is referred to. The last part concerns briefly the evaluation of the institutional aspects of UNCRPD's implementation which was done by Convention bodies.
Key words: European Union, UNCRPD, implementation, institutions, coordination

1. Introduction

According to art. 2 of the Treaty on the European Union (TEU)[1] the prohibition of discrimination remains one of the foundations the Union is based on. At the same time discriminatory treatment of certain categories of persons may be grounded

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[1] *Treaty on the European Union* (Consolidated version 2016) (OJ C 202, 07.06.2016).

in various types of criteria. Disability is one of them[2]. In this light it is obvious that the Union – on different levels – aims at counteracting possible manifestations of discrimination, also in relation to persons with disabilities. It finds it reflection in a number of EU primary law provisions – Treaty on the functioning of the European Union (TFEU, art. 10, 19)[3] or the Charter of Fundamental Rights of the EU (ChFR, art. 21, 26)[4] which confirm Union's involvement in the combat against discrimination, including discrimination on grounds of disability.

Simultaneously there is no doubt that what might be an element of enhancing Union's standards of non-discrimination is the EU's participation in international agreements protecting the rights of persons who, because of their personal attributes, are exposed to discrimination. Participation of the EU in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) of 2007 seems to be one of the examples in that context. The European Union is a party to this agreement since 2009 and considers it a relevant and efficient pillar for promoting and protecting the rights of persons with disabilities, to which the EU (and its Member States) attach the greatest importance[5]. In result, the EU's accession to the Convention is a measure designed to improve the protection of disabled persons with regard to the prohibition of discrimination included in EU law.

The fact that the EU is a party to the UNCRPD produces a row of problems worth analysis. The aim of this contribution is to present and asses a set of selected legal-institutional conditionings of the implementation of the UNCRPD to the Union law. The Convention is an agreement the EU and the Member States (MS) are parties to. It includes also aspects covered by exclusive EU competence and the competence shared with Member States as well[6]. In this light it became necessary to establish a mechanism of cooperation and coordination of EU institutions and Member States activities which would assure a correct and efficient implementation of the UNCRPD in accordance with its provisions. The hypothesis adopted in the

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[2] For a definition of "disability" and "disabled person" see e.g.: C. Viale, Lexicon of Human Rights. Les definitions des droits de l'homme, Leiden, Boston 2008, p. 44-45.

[3] *Treaty on the Functioning of the European Union* (Consolidated version 2016) (OJ C 202, 07.06.2016).

[4] *Charter of Fundamental Rights of the European Union* (OJ C 202, 07.06.2016).

[5] See: *Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities (2010/48/EC)* (OJ L 23, 27.1.2010), recital 4 of the preamble.

[6] More about the nature of so-called mixed agreements see e.g. in: E. Neframi, Mixed Agreements as a Source of European Union Law [in:] E. Cannizzaro, P. Palchetti, R. A. Wessel (eds.), International Law as Law of the European Union, Leiden 2011, p. 325-349; M. Niedźwiedź, Umowy międzynarodowe mieszane w świetle prawa Wspólnoty Europejskiej, Warszawa 2004; J. Sozański, Porozumienia międzynarodowe Wspólnot i Unii Europejskiej w świetle norm *acquis commununitaire* oraz Konstytucji dla Europy, z uwzględnieniem orzecznictwa Trybunału Sprawiedliwości: studium prawnotraktatowe, Toruń 2007, pp. 440-449.

following considerations assumes that existing mechanism seems to reflect properly the division of powers between the Union and member States and to enforce their close cooperation. In this dimension it includes arrangements which seem logical and justified with regard to the implementation of an international agreement falling within the competence of the EU and Member States.

This contribution, at the same time, does not aim at giving an exhaustive picture of the problem concerned, but rather at presentation of the basic issues linked to the cooperation between the Council (Presidency), the Commission and the Member States within the context of UNCRPD's implementation.

2. European Union as a party to the United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted on 13 December 2006 and it was opened for signature on 30 March 2007. It includes 50 articles and its main goal is to *promote and protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity* (art. 1). The Convention (and Optional Protocol) entered into force on 3 May 2008.

From the perspective of the EU and its participation in the Convention art. 42 – 43 of the UNCRPD are particularly important since they provide for a possibility to become a party to the Convention also for entities other than states. The Union is not a state and what remains a relevant category in case of the EU is so-called regional integration organisation (RIO). It is defined by the Convention as an *organisation constituted by sovereign States of a given region, to which its member States have transferred competence in respect of matters governed by the present Convention* (art. 44 (1)). The Convention is open for signature also to them (art. 42) and is subject to their formal confirmation (art. 43). It means that RIOs (including the EU), after signing the UNCRPD, should adopt a formal act expressing their consent to be bound by the Convention.

The Convention was signed by the European Community[7] on the 30 March 2007, however the European Commission was empowered to conduct negotiations concerning the UNCRPD already in 2004. The formal confirmation of the Convention – required in case of RIOs – materialized itself in November 2009 on the basis of the Council Decision (2010/48/EC) concerning the conclusion by the EU of the Convention. In relation to the Union the UNCRPD entered into force in January 2011.

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[7] In this contribution, however, the references are made to the European Union as a legal successor of the European Community according to art. 1 TEU.

According to art. 216 TFEU international agreements concluded by the EU are binding upon the Union and its institutions and Member States as well. The UNCRPD is not an exception in that respect. It is, however, worth underlining that by confirming formally the Convention, the EU has made a reservation to one of the UNCRPD provisions, namely to its art. 27 (1), which means that the principle of equal treatment on the grounds of disability does not have to be applied by Member States in armed forces. Nevertheless, the Convention as an act of international law became an integral part of Union's legal order[8]. As such, in line with the view embedded in the judicature and the EU law doctrine, it has supremacy over Union's secondary law[9]. This defines its status and position in the hierarchy of EU law sources and might cause certain consequences from the perspective of interpretation and application of EU secondary law[10].

And what is the status of the EU as a party to the Convention? What's important is the fact that the Convention references to "State Parties" refer also to regional integration organisations however only within the limits of their competence (art. 44 (2)). In consequence the EU (and other RIOs) – to the extent of their competence – are bound by the same obligations as State Parties to the Convention, including, inter alia, the obligation to provide effective mechanisms for the Convention's implementation or reporting duties. It means at the same time that the Union, on similar rules and with regard to its competence, benefits from rights attributed to State Parties. It may e.g. participate and exercise a right to vote in the Conference of State Parties (art. 44(4)). In this context it is, however, necessary to stress that also EU Member States are parties to the Convention. This circumstance confronted with the nature and scope of Union's competence and the competence of its MS' makes it desirable to establish relevant procedures for coordination of EU and MS activities in the area of UNCRPD implementation. It is confirmed by the preamble to the Decision concerning the conclusion of the Convention by the Union, where it is stated that the EU and the Member States as Contracting Parties to the UNCRPD should be able to fulfil the obligations laid down by it and exercise the rights invested in them in a coherent manner. The issue of EU and Member States competence in the context of the Convention deserves therefore a brief comment.

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[8] CJEU Judgement of 18 March 2014 in case *Z. v A Government department and The Board of management of a community school,* C-363/12, paragraph 73. In general, see: K. Lenaerts, P. van Nuffel, European Union Law, London 2011, p. 861.

[9] K. Lenaerts, P. van Nuffel, *ibidem*. In the context of other international agreements see e.g.: E. Passivirta, The European Union and the United Nations Convention on the Law of the Sea, "Fordham International Law Journal", Volume 38, Issue 4, 2015, pp. 1062-1063.

[10] CJEU Judgement of 1 December 2016 in case *Mohamed Daouidi v Bootes Plus SL and Others*, C-395/15, paragraphs 40-42; see also: Commission Staff Working Document: *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities*, Brussels 05.06.2014, SWD (2014) 182 final, recital 14.

3. UNCRPD and EU's and Member States competence

Article 44(1) UNCRPD requires that regional integration organisations declared – in an instrument of formal confirmation – the extent of their competence with respect to matters governed by the Convention. The European Union fulfilled this obligation. In the Council Decision 2010/48/EC this issue is referred to in Annex II which includes the necessary Declaration of Competence. It is worth noting that this kind of declaration is essential from the point of view of relations between EU institutions and Member States and the way these relations are shaped in the context of UNCRPD implementation.

Annex II (*Declaration concerning the competence of the European Community with regard to matters governed by the United Nations Convention on the Rights of Persons with Disabilities*) lists competences transferred to the EU (primarily to the Community) by the Member States. It also points to the division into EU exclusive competence and competence shared with Member States which has been formally confirmed by the Treaty of Lisbon[11].

According to Annex II the exclusive competence of the EU in Convention-relevant matters covers: the compatibility of State aid with the common market and the Common Custom Tariff. What is more, to the extent that provisions of EU law are affected by the Convention, the EU has also an exclusive competence to accept such obligations with respect to its own public administration. Consequently, it is the Union who is responsible for regulating the recruitment, conditions of service, remuneration and training of non-elected officials. In Annex II there are also listed areas where the Union shares competence with Member States. These regard mainly: action to combat discrimination on the ground of disability, free movement of goods, persons, services and capital agriculture, transport, taxation, internal market, equal pay for male and female workers, trans-European network policy and statistics.

Obviously, the nature of the EU and MS competence should be evaluated in the light of relevant provisions of TFEU which define the essence of exclusive and shared competence[12]. In a nutshell – in the area of EU exclusive competence, in principle, only the Union may legislate. On the other hand, in the area of shared competence the EU and the Member States may legislate, however the Member States exercise their competence in that respect to the extent that the Union has not exercised its competence or has decided to cease exercising it. In the second case the limits for

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[11] *Treaty of Lisbon amending the Treaty on European Union and the Treaty establishing the European Community, signed in Lisbon*, 13 December 2007 (OJ C 306, 17.12.2007). Provisions referring to that issue are now included in art. 2 – 4 TFEU.

[12] For a broader study on EU and member States competence in the context of UNCRPD see: L. Waddington, The European Union and the United Nations Convention on the Rights of Persons with Disabilities: a Story of Exclusive and Shared Competences, "Maastricht Journal of European and Comparative Law", vol. 18, no. 4, 2011, pp. 431-453.

the Union's legislative activity are determined by the principle of subsidiarity (art. 5 TEU). At the same time competence not transferred to the Union remain by Member States. Thus, considering the substantial scope of the Convention it is clear that the range of EU and Member States competence in particular Convention matters differs. Some matters fall within the exclusive competence of the Union, some within the shared competence and some fall within competence of the Member States[13]. The extent of Union competence in that respect (exclusive and shared) is illustrated by the Appendix to Annex II which lists almost 50 Union acts referring to matters governed by the Convention[14].

At the same time the Convention itself (art. 33(1)) requires that the Parties (including RIOs) designate one or more focal points for matters relating to the implementation of the Convention and establish a proper coordination mechanism to facilitate the implementation thereof in different sectors and at different levels. From the perspective of the Union and its Member States and considering the nature of UNCRPD as a mixed agreement such a mechanism seems to be of crucial importance.

4. EU Code of Conduct setting out internal arrangements for the implementation of the UNCRPD – general remarks

Following art. 33(1) of the Convention, in 2010 the Code of Conduct between the Council, the Member States and the Commission (the Code) has been agreed[15].

The legal nature of the Code cannot of course be assessed in the light of art. 288 TFEU. It does also not seem to be a typical interinstitutional agreement as provided in art. 295 TFEU. Such agreements are concluded by the European Parliament (EP), the Council and the Commission and may – but do not have to – be of binding nature[16]. The Code of Conduct, on the other hand – has been concluded between Council, Commission and Member States[17]. And it does not include any arrangement

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[13] *Ibidem*, p. 438.

[14] Some of the acts originally included in the Appendix to Annex II were repealed, see: *Commission Staff Working Document: Progress Report on the implementation of the European Disability Strategy (2010 -2020)*, Brussels, 02.02.2017, SWD (2017) 29 final, Annex 1.

[15] *Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities* (OJ C 340, 15.12.2010).

[16] About interinstitutional agreements see e.g.: K. Lenaerts, P. van Nuffel, *op. cit.*, p. 925-927; C. Mik, Europejskie prawo wspólnotowe: zagadnienia teorii i praktyki, Warszawa 2000, p. 521-526; W. Hummer, From 'Interinstitutional Agreements' to 'Interinstitutional Agencies/Offices'?, "European Law Journal" 2007, nr 1, pp. 47-74.

[17] What is interesting the Code was adopted without involvement of the EP, which this institution finds regrettable, see*: European Parliament resolution of 20 May 2015 on the List of Issues adopted*

expressly defining its nature as binding. Does it mean that it is impossible to accept its binding character?

It is worth considering that the Code became a measure of the implementation of Council Decision (as a binding act). As such it appears to be a necessary instrument of a proper implementation of the Convention. What's more the signatories of the Code have expressly stated that provisions of the Code *which deal with matters of coordination between the Council, the Member States and the Commission are to be considered as part of the coordination mechanism mentioned in Article 33.1 of the Convention*. In this way the Code becomes a part of a binding international agreement concluded by the Union – a kind of extension of UNCRPD's binding provisions. Taking into consideration the binding force of the Convention the nature of the Code seems to go beyond a purely political declaration.

What would support the above argumentation might be the will of the parties to the Code. And they have expressly stated that it (the Code) "will apply" to particular Convention-related matters. The Code, at the same time, provides for certain reporting and monitoring obligations for the Union and Member States. It might therefore be assumed that the parties to the Code treat it as a binding instrument among them. In other words – their will makes the Code binding in their mutual relations. This way of reasoning could be strengthened by visible links between the Code and the principle of close (sincere) cooperation expressed in art. 4(3) TEU and mentioned in the Code in recital 1. Additionally, regarding the consistent embedment of the Code in the Treaty-based principle of sincere cooperation its binding nature finds considerably strong arguments.

The Code of Conduct may indeed be seen as an act executing the provisions of Council Decision 2010/48/EC, in particular art. 3 and 4 thereof. It should be reminded that these provisions refer basically to the problem of focal points foreseen by the UNCRPD and the representation of the EU and Member States in bodies created by the Convention (mainly Conference of Parties). In this respect the Decision includes basic solutions with regard to the scope of Union competence in matters governed by the Convention. The Code of Conduct provides these solutions with details.

It has to be underlined that also the Code of Conduct refers to the scope of EU and Member States competence in the context of division of implementing tasks. Areas falling within the competence of MS, within the EU exclusive competence and within the shared as well as coordinating, supporting and supplementing competence (art. 6 TFEU) have been distinguished. Pursuant to the type of competence in question the scope of EU and Member States implementing actions has been determined – in particular with regard to preparation to and participation in meetings of bodies created by the Convention.

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by the United Nations Committee on the Rights of Persons with Disabilities in relation to the initial report of the European Union, OJ C 353, 27.9.2016, p. 41-45.

It has been agreed in the Code that in matters falling within the Member States competence these states will be responsible for elaborating so-called coordinated positions. So, one could assume that in matters in which no competence had been transferred to the EU the implementation of the Convention belongs exclusively to Member States. It should be remembered however that the activity of MS must remain in accordance with the Treaty principle of sincere cooperation (art. 4(3) TEU). This is confirmed by the Code itself (point 2).

Matters falling within the Union's exclusive competence are subject to so-called Union positions. These are elaborated by the EU and refer to: the compatibility of State aid with the internal market, the common customs tariff and to the Union's own public administration. They may refer as well to other issues, but only to the extent the provisions of the Convention affect or alter common rules established already by the Union by means of international agreements concluded in accordance with art. 3(2) TFEU.

Finally, in matters falling within the shared competence the Union and the Member States remain responsible for elaborating so-called common positions. These refer in particular to Union's legislative acts listed in the Appendix to the Declaration of Competence mentioned previously in point 3 (covering such areas as: action to combat discrimination on the ground of disability, free movement of goods, persons, services and capital, agriculture, transport, taxation, etc.). The same rule applies to the area of Union's competence defined in art. 6 TFEU.

In result, while implementing the Convention, depending on the matter, the Union and Member States – in different configurations, but always in close cooperation – prepare and present coordinated positions (Member States competence), Union positions (EU exclusive competence) and common positions (shared competence and supporting, coordinating and supplementing Union's competence). This general framework for division of tasks deserves a rather positive assessment. It seems to correspond properly with the division (and essence) of EU and MS's competence as defined by the TFEU and to ensure a desired balance among them. It also induces active cooperation between the Union and its institutions and the Member States. At the level of more general assumptions the coordination mechanism created by the Code seems to provide required basis for the implementation of the Convention. The assessment of more detailed rules stemming from the Code and concerning the elaboration of the abovementioned positions will be presented in next items.

Apart from preparing the activities (establishing positions) of the Union and Member States the Code includes also rules for speaking and voting in Convention bodies in cases of particular type of position. It also refers to the question of nominations of experts to the Committee of the Rights of Persons with Disabilities (art. 34 of the Convention) and to the organisation of necessary focal points (art. 33 of the Convention). These issues also deserve a closer look and will be addressed in the subsequent paragraphs.

5. Rules for establishing of coordinated, Union's and common positions

A rule resulting from the Code of Conduct is that all the positions of the EU and Member States, regardless of their particular type, have to be duly coordinated, which – once again – deserves emphasis. It is also evident, that the process of establishing these positions is similar in case of coordinated, Union and common positions. This solution excludes the multiplication of procedures depending on the position in question. The Code simply establishes a harmonised (almost uniform) mechanism which – from a practical point of view – remains important and should be assessed positively.

The coordination process is based on coordination meetings of the Member States and the Commission. In case of coordinated positions (Member States competence) such a meeting might be convened by the Presidency acting on its own initiative or at the request of the Commission or a Member State. In urgent cases such a meeting may consist of an electronic coordination. In case of Union positions (EU's exclusive competence) and common positions (shared competence and competences from art. 6 TFEU) coordination meetings are convened on the initiative of the Presidency. They may also be convened at the request of the Commission or a Member State. It is also possible that in urgent cases these meetings consist of an electronic coordination. In all three cases meetings take place before and during each meeting of Convention bodies.

It is interesting that coordination meetings of the Commission and Member States are held within a relevant (competent) Council Working Group. This rule refers to establishing coordinated positions, Union positions and common positions as well. Which Working Group is competent in relation to the Convention-relevant issues being discussed is in principle determined by the Presidency. This mechanism means that the coordination process runs on the level of the Council as one of the Union's institutions with a visible role of the Presidency. At first sight it seems therefore that a certain dominance of the Member States (or institutions representing them) was accepted in this area. The nature of Union and Member States competence doesn't change much in this regard. On the other hand, however, it seems that the location of coordination meetings within the Council (competent Working Group) is treated as a proper means of securing efficiency of the coordination process and its compatibility with requirements of sincere cooperation. And from that perspective the presented solutions seem to be justified.

Technically the positions referred to in this paragraph are established after receiving the agenda of a meeting of the Convention body. On this basis the Commission sends to the Secretariat of the Council the indication of those agenda items which need a statement. The Commission also indicates by whom – Commission or Presidency – these statements should be made. The Secretariat circulates this indication to the Member States. Draft statements concerning issues covered by competence of Member States are prepared by the Presidency whereas draft statements relating to matters covered by exclusive Union competence and shared competence are prepared by the Commission. These drafts are forwarded to the Council's Secretariat which communicates them to the Member States and the Commission one week before the coordination meeting at latest. The Secretariat forwards immediately these drafts also to the competent Council Working Group. This is an organisational background for the coordination meetings aiming at establishing necessary positions of the EU and Member States.

There are also rules concerning representation of the EU and MSs in cases of already agreed positions. They are going to be presented in the next paragraph.

6. Presenting Union's and Member States positions (speaking and voting) in the Convention bodies

Establishment of coordinated positions, Union positions and common positions, might be treated as a first phase of the coordination process. These positions – prepared as it was described in the previous paragraph – are then presented on the level of bodies created by the Convention. The Code of Conduct includes necessary rules in that respect and it seems that these rules correspond with mechanisms designed for preparation of relevant positions. In this way the Code appears to be a sufficiently coherent, consistent instrument.

In principle Union positions are expressed by the Commission. This corresponds with the nature of the Commission as envisaged by Treaty provisions. According to art. 17(1) TEU the Commission is not only responsible for ensuring the application of the Treaties and acts adopted by the EU institution pursuant to them. It also ensures the external representation of the Union. Making the Commission the Union's voice in the context of the Convention and bodies created by it seems to be an obvious solution. This construct seems to remain in logical connexion with the nature of Union's powers and those of Member States.

Coordinated positions are on the other hand expressed by the Presidency or – if necessary – by a Member State appointed by it. This mechanism is quite understandable considering the fact that coordinated positions refer to matters covered by Member States competence. It is however interesting that such positions might be expressed by the Commission as well. In this case the agreement of all present Member States is required. This option might be technically comfortable and useful.

In case of common positions (shared competence, competence from art. 6 TFEU) it should be decided during a coordination meeting of the Commission and Member States who should express statements on their behalf. This rule refers to cases where particular competences are *inextricably linked* (point 6 c). In matters which are predominantly covered by Union competence it is the Commission who expresses common position. However, when the preponderance of the matter concerned falls within the competence of the Member States, common position will be expressed by the Presidency or by the Member State.

Rules for voting correspond with the above mechanisms. There are two cases when the Commission exercises Union's right to vote. First, the Commission votes on behalf of the EU on the basis of Union position. Second, the Commission exercises this right on the basis of common position but only when the issue concerned is predominantly covered by Union competence. In both cases the Commission should exercise the right to vote with regard to the results of the coordination process that clearly emphasises the significance of the coordination process. What also needs to be noted here is the significance of art. 44(4) of the Convention, according to which the EU (as RIO) exercises its right to vote in the Conference of States Parties with a number of votes equal to the number of its Member States that are Parties to the Convention. On the other hand, the Member States exercise their right to vote in issues covered by their competence (coordinated positions) and in matters covered by shared competence (common positions) when a matter concerned falls mostly within their competence.

It is also possible that during a coordination meeting within a competent Working Group the Commission and the Member States will fail to achieve a compromise. In effect no position is agreed. In such a case the Code of Conduct provides for a Commission's right to speak and vote but only in matters evidently belonging to Union's competence. What's more – the Commission may exercise this right only to the extent which is necessary to protect Union's *acquis*. In the same case of a lack of an agreement between Member States and the Commission these states may exercise their right to speak and vote in relation to issues covered clearly by their competence. An important condition in this respect is that Member States' position is coherent with Union's policies and in conformity with EU law which – once again – confirms the importance of the treaty-based principle of sincere cooperation.

7. Focal points and nominations

Two more issues concerning the Convention's implementation deserve a brief comment.

According to art. 33(1), Parties to the Convention are obliged to organise one or more focal points responsible for its implementation. Following that the Code of Conduct states (point 11) that in matters falling within Union competence (issues covered by EU exclusive competence and certain area of shared competence) the Commission is the focal point for matters related to implementation of the Convention. Member States on the other hand designate their own focal points and notify it to the Commission. It is also possible that coordination meeting take place on the level of Union and Member States focal points. Such meetings are convened by the Commission on its own initiative or at the request of a Members State's focal point.

At first sight these rules do not cause serious doubts. In case of the EU the Commission seems to be the proper body to fulfil the role of a focal point as an entity responsible for UNCRPD's implementation at different levels. On the other hand, the structure of art. 33 of the Convention suggests that focal points (area of implementation, art. 33(1)) should be "separated" from independent frameworks responsible for the promotion, protection and monitoring of the Convention's implementation (art. 33(2)). And the Commission seems to be located in both areas which may cause certain controversies. This issue will be addressed one of the subsequent items.

Finally, the EU has a right to nominate a candidate for an expert in the Committee on the Rights of Persons with Disabilities. The Committee is a Convention body consisting of maximum 18 members (art. 34(2) of the Convention). The Committee exercises mainly controlling and reporting functions. According to art. 35(1) of the Convention each State Party submits to the Committee a report on measures taken to implement the Convention and to fulfil its obligations in that respect. The Committee considers such reports and may forward appropriate suggestions and general recommendations to the State Party concerned (art. 36(1)). The Committee also reports every two years to the General Assembly of the UN and to the Economic and Social Council on its activities. Additionally, basing on the information received through States' reports, the Committee may make suggestions and recommendations in this regard (art. 39).

The Union has a right to nominate a candidate for an expert in the Committee, which is stated directly in the Code of Conduct (point 10). This right does not, of course, undermine the analogous right of the Member States. The Union nominates a candidate on the basis of the Commission's proposal. What is however interesting is the fact that this proposal has to be accepted by consensus of the Member States within a competent Council Working Group. In this way the Member States get a visible influence on the nomination of Union's candidate to the Committee.

8. Code of conduct for the implementation of UNCRPD and other EU codes of conduct referring to international agreements

The UNCRPD is said to be the first human rights convention to which the Union became a party[18]. In this sense the Convention and its location in the legal *acquis*

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[18] L. Waddington, *op. cit.*, p. 432.

of the EU is a certain novelty. Consequently – the Code as a kind of extension of the Convention's provisions becomes a novelty as well and the whole mechanism for UNCRPD's implementation, as designed by the Code, strictly corresponds with relevant requirements of implementation provided for by the Convention itself. In other words – the nature, construct, content of the Convention together with the shape of obligations imposed on parties thereto determines to a large extent the construct of the Code in question. It does not however mean that the Code analysed in this contribution is the only one instrument called "code of conduct" which appears in the EU legal order in the context of Union's participation in international agreements.

In the area of the implementation of agreements the EU has become a party to (or has accessed) it is possible to find other codes of conduct than the one analysed in this contribution. The *Revised Code of Conduct for the effective implementation of the Convention on the elimination of double taxation in connection with the adjustment of profits of associated enterprises*[19] could be an example in that respect. It is however necessary to emphasise that the nature, scope and internal structure of the Revised Code is considerably different to that of UNCRPD's implementation Code. And this seems to be caused by the aim, nature and scope of the so-called Arbitration Convention[20] which differs from UNCRPD in that respect. What's additionally interesting is the fact that in the Revised Code it is expressly stated that it has the character of a political declaration. It may be assumed therefore that – depending on the nature and scope of a particular agreement – arrangements for its implementation at Union's level may differ case by case.

There are also situations where relevant codes of conduct refer to areas other than pure implementation of an international agreement concluded by the Union. What might be an example in that respect is, inter alia, the Code of conduct between the Council, the Member States and the Commission on the UNESCO negotiations on the Draft Convention on the protection of the diversity of cultural contents and artistic expressions[21]. This Code refers to the process of negotiations of a particular agreement so to a different stage than the Code analysed in the context of the UNCRPD. Nevertheless, the Code from 2005 includes e.g. rules for negotiations which correspond with the division of powers between the Community (today the Union) and the Member States. And in this dimension these rules resemble those

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[19] Revised Code of Conduct for the effective implementation of the Convention on the elimination of double taxation in connection with the adjustment of profits of associated enterprises, *OJ C 322, 30.12.2009, p. 1-10.*

[20] Convention of 23 July 1990 on the elimination of double taxation in connection with the adjustment of profits of associated enterprises, *OJ L 225, 20.8.1990, p. 10-24.*

[21] Code of conduct between the Council, the Member States and the Commission on the UNESCO negotiations on the Draft Convention on the protection of the diversity of cultural contents and artistic expressions, Brussels, 31 January 2005 (02.02), 5768/05.

from the Code for implementation of the UNCRPD which refer to the division of tasks between the EU and Member States in the area of preparation of relevant positions and presentation thereof at the level of Convention bodies.

In light of the above considerations it is possible to assume that international agreements the Union becomes a party to or accesses may require an instrument of their implementation at the EU level. These instruments, which are often called codes of conduct, differ however depending on the nature of the agreement in question. In that context the Code for implementation of the UNCRPD becomes an instrument adjusted in its character to the specific nature of this Convention.

9. Evaluation of Union's implementation mechanism by the UNCRPD bodies

It is clear that the process of implementation of the UNCRPD, as an international agreement binding in its entirety on the Union's institutions, is subject to a kind of evaluation by Convention bodies. Due to art. 35 of the Convention, as mentioned in the previous item State Parties are obliged to submit a comprehensive report on measures taken to implement the UNCRPD. In 2014 the Commission had presented a relevant report including an extensive description of the Union's activities aimed at giving the effect to its obligation under the Convention[22].

The report was reviewed by the Committee on the Rights of Persons with Disabilities and the first recommendations were made. The Commission replied to them in June 2015[23] which started a dialogue between EU and the Committee on UNCRPD's implementation matters[24]. In October 2015, the Committee has published its concluding observations on the Union's initial report[25]. It referred, inter alia, to the institutional aspects of the implementation mechanism previously described.

One of the main concerns of the Committee in this regard was the shape of the Commission's involvement in the UNCRPD implementation process. The Committee stressed that Commission plays a double role here. On one hand it is designated as

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[22] Commission Staff Working Document: *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities*, Brussels 05.06.2014, SWD(2014) 182 final.

[23] Commission Staff Working Document *Reply of the European Union to the list of issues in relation to the initial report of the European Union on the implementation of the UN Convention on the Rights of Persons with Disabilities*, Brussels, 19.06.2015, SWD (2015) 127 final.

[24] For the summary of this dialogue see a document prepared by Inclusion Europe, which is available on the official webpage of the European Commission: http://ec.europa.eu/social/main.jsp?catId=1138&langId=en (access 29.08.2018).

[25] *Concluding observations on the initial report of the European Union*. Adopted by the Committee at its fourteenth session (17 August-4 September 2015), CRPD/C/EU/CO/1, source: https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/226/55/PDF/G1522655.pdf?OpenElement (access 28.08.2018).

a focal point, while on the other – it is a part of the mechanism for monitoring the implementation of the UNCRPD. Indeed, the Commission became a part of EU Framework on the Implementation of the UNCRPD[26] which existence should be seen in the light of art. 33(2) of the Convention. This provision requires that the State Parties establish a framework including one or more independent mechanisms for promotion, protection and monitoring of the implementation of the Convention[27]. Installing the Commission within implementing and monitoring mechanisms – according to the Committee's view – did not correspond with the so-called Paris Principles adopted at the beginning of the 1990s[28].

The Committee recommended the removal of the Commission from the independent EU monitoring Framework. This would allow to "decouple" the roles of the Commission in the implementation and the monitoring of UNCRPD's implementation and so assure compliance with the Principles aforementioned. The Commission referred to this recommendation in its document from February 2017[29] by confirming its withdrawal from the Framework. In other words – the Commission is not participating in the Framework's meetings which is a visible consequence of the Committee's recommendation.

In its observations the Committee also suggested that the EU considered the designation of focal points in each institution, agency and body. In the opinion of the Committee this would help enhance the interinstitutional coordination mechanism in relation to the UNCRPD implementation. In its report from 2017, however, the Commission did not refer to this suggestion[30].

10. Closing remarks

Considering the broad scope of the UNCRPD it becomes clear that the Convention is a field where competences of both – the European Union and its

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[26] The relevant arrangement was ready in October 2012. The Framework consisted of: European Parliament representatives, the European Ombudsman, the EU Agency for Fundamental Rights, the European Disability Forum and the Commission. The first meeting of the Framework took place in January 2013.

[27] See also: L. Waddington, Reflections on the Establishment of a Framework to Promote, Protect and Monitor Implementation of the UN Convention on the Rights of Persons with Disabilities (Article 33(2) CRPD) by the European Union, Maastricht Faculty of Law Working Paper no. 2011-3.

[28] See: UN General Assembly Resolution 48/134, *National institutions for the promotion and protection of human rights*, 20 December 1993, A/RES/48/134, http://www.un.org/documents/ga/res/48/a48r134.htm (access 28.08.2018).

[29] *Commission Staff Working Document: Progress Report on the implementation of the European Disability Strategy (2010 -2020)*, Brussels, 02.02.2017, SWD(2017) 29 final, p. 118, 148.

[30] For more comments on the implementation of the UNCRPD by the EU see: L. Waddington, The European Union …, *op. cit.*, pp. 449-452.

Member States – are exercised. Basing on the essence of exclusive, shared and supporting, coordinating and supplementing competences, which is defined in TFEU provisions, it has to be accepted that particular matters covered by the Convention fall – to a different extent – within the powers and activity of the EU and Member States as parties to the Convention bounded with its provisions. This circumstance affects the model of coordination of the UNCRPD implementation process in the EU law.

One of the key elements in that respect is the Code of Conduct governing the relations between the Council, the Commission and the Member States in the area of the Convention's implementation. The Code seems to reflect basic assumptions concerning the division of competence between the EU and MSs and respects the evident need for coordination of their actions. In the area of establishing the positions of the EU and Member States as well as in the area of presentation of such positions at the UNCRPD bodies, the Code visibly combines the nature of competence in question (e.g. exclusive and shared) with the mechanism assuring the coordination of steps taken by the EU and its members. Such a model should contribute towards an efficient implementation of the Convention in accordance with its provisions. And a correct and proper implementation is of crucial importance considering the place of the Convention in the hierarchy of EU law and its binding character for the EU and its Member States.

To sum up it should be said that the UNCRPD, as an integral element of EU legal order, has been endowed with a relevant mechanism for its implementation. From the legal-institutional point of view this mechanism seems to tie the respect for particular EU and Member States competence with the requirement of coordination of their actions. It may be hoped that it will contribute to an effective implementation of the UNCRPD as the first human rights treaty the EU has become a party to.

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Nazi Crimes on People with Disabilities in the Light of International Law – a Brief Review

Abstract: The cruelty of crimes committed by the Nazis during World War II is beyond belief. Ethnic cleansing focused mainly on the Jewish community and has been spoken of the loudest since the end of the war, but this was not the only course of eugenic thought. People who had been harmed by birth – the disabled and mentally ill, were not spared the torturers wearing German uniforms. This article presents the circumstances involved relating to the activities of AktionT4 in Germany and the territories under German occupation, and performs a legal analysis of these activities in the light of international law in the so-called Doctors' Trial, the first of the follow-up processes to The Nuremburgh Trial. The author introduces the legal bases of the sentences issued in the trial and highlights the process of shaping the responsibility of individuals in international law. The participation of Polish law enforcement agencies in prosecuting crimes against humanity committed on the patients of psychiatric hospitals and care centers in Poland, is also addressed. The proceedings in this case have been ongoing to this day, now conducted under the auspices of the Institute of National Remembrance.

Key words: Nazi crimes, World War II, crimes against humanity, international law, Nuremberg trial, Doctors' Trial, disability, Aktion T4.

The history of the world is marked by tragic events caused by military conflicts. For millennia people have waged wars and killed in order to achieve material and territorial gains, however, the *casus belli* of World War II lay in a different direction and the number of victims it consumed is unprecedented. Victims, who did not die on a battlefield bearing arms, but ordinary people who were brutally murdered in the name of Nazi ideology. The development of eugenic thought and desire in preserving the German race led to the mass murder of millions of innocent civilians. Unfortunately, people with disabilities and mental illnesses accounted for a notable percentage of these pointless deaths.[1] It is the phenomenon of elimination of imperfect individuals that is the authors focus of attention in the conducted research.

Central to this issue is Aktion T4, the T4 representing Tiergartenstasse 4,[2] the address of the Chancellery department set up early in 1940 to support the Aktion T4 programme. The purpose of the programme was the complete elimination of "life unworthy of life" (Ger. *Vernichtung von lebensunwertem Leben*), in other words, individuals with different kinds of defects and disabilities, developmental disorders and, above all, mental disorders.[3] People classified to this group were recognised as useless in society and as economic burden on the state which, in the face of intensive military operations underway, was unwarranted from the viewpoint of the Nazi government.

The beginnings of the intellectual trend called eugenics took root in Germany as early as in the 1920s. At that time two medical doctors, Alfred Hoche and Karl Binding, brutally interpreted Darwin's evolutionary theory in a booklet entitled "Permission for the destruction of a life deprived of value" (Ger. *Die Freigabe der Vernichtung lebensunwerten Lebens*).[4] According to their beliefs, humanitarianism manifested by saving every human life contradicts with natural law, where weak individuals die as a result of so-called natural selection. Therefore, it is justified to eliminate all disabled people by way of involuntary euthanasia, because the natural environment would in any event not provide them with the chance of survival.[5] Such ideas grew in German society, most of all among nationalists, and eugenics even became a scientific field. The Nazis began to realise the vision of societal "purgation" as soon as they took power in Germany. In 1933, on 14th of July, the Act on Preventing an Inheritably Burdened Progeny (Ger. *Gesetz zur Verhutung erbkranken Nachwuchsrt*) entered into force, under the power of which, individuals with inheritable diseased such as: mental retardation, schizophrenia, psychosis, epilepsy, and alcoholism, were involuntarily sterilised. The estimated number of people who fell victim to this procedure was in the region of 350,000.[6] A few years later, on 18 August 1939, the Reich Committee for the Scientific Registering of Hereditary and Congenital Illnesses was established, its

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[1] G. Aly, Die Belasteten. Euthanasie 1939-1945: eine Gesellschaftsgeschichte, Frankfurt am Mein 2013, pp. 9-22.

[2] D. Rubisia, Poligon doświadczalny Holocaustu, Portal edukacyjny IPN „pamięć.pl", http://pamiec.pl/pa/tylko-u-nas/14192,POLIGON-DOSWIADCZALNY-HOLOKAUSTU-artykul-Daniela-Rubisia.html (11.09.2018).

[3] E. Burdett, The Continent of Murder: Disability and the Nazi "Euthanasia Programme in the Euthanasia Debates of Britain and the United States, 1945-Present, Unpublished doctoral dissertation, London: University College London, p. 39.

[4] A. Hoche, K. Binding, Permission for the destruction of a life deprived of value, 1920.

[5] R.J. Lifton, The Nazi Doctors: Medical Killing and the Psychology of Genocide, New York 1986, pp. 45-47.

[6] Z. Jaroszewski, German Extermination of Psychiatric Patients in Occupied Poland 1939-1945, http://www.projectinposterum.org/docs/Jaroszewski1.htm (access 11.09.2018).

purpose being the registration and classification of newborns with unwanted health issues.[7]

Further, and far more drastic actions, were implemented by Hitler after the outbreak of World War II. In October 1939, the leader of the Reich signed an act (backdated to 1 September of that year), sanctioning the ultimate elimination of all disabled people from society. Initially, mass extermination in the territory of Germany concerned only children, mainly those staying in medical facilities. It is estimated that up to 1941, more than 5,000 German children were brutally murdered.[8] Doctors inspired by ideas propagated by eugenic thought did terrible things to implement their ideas. There were frequent cases in which the parents of hospitalised children received notification of the transfer of their child to a special center where they were to undergo diagnostic tests. After a few weeks, however, the parents would be informed that their child had died and typically pneumonia was given as the reason for death. In reality the children were injected with a lethal dose of toxic fluid, usually phenol.[9]

Exterminations were not just conducted on German territory but also in countries under occupation or otherwise annexed by Germany.[10] At the beginning of 1940, six official centers for the extermination of disabled adults were founded labelled “A”, “B”, “Be”, “C”, “D” and “E”. However, beyond these centres there were many unofficial sites that focused on the eradication of juveniles.[11] These clinics, as they were referred to, played a key role in the further development and evolution of extermination procedures during the Holocaust.[12] Patients of “special treatment centers” and psychiatric hospitals, were tested with different methods of killing – the most efficient and the least expensive. Initially patients were killed by lethal injection but later they were simply shot. As a progression and in the interests of efficiency, it was thought more efficient to kill people in number rather than one at a time,

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[7] R.N. Proctor, Racial Hygiene: Medicine under the Nazis. Cambridge 1988, pp. 8-10.

[8] C. Browning, The Origins of the Final Solution: The Evolution of Nazi Jewish Policy, September 1939 – March 1942, Jerusalem 2004.

[9] R.J. Lifton, The Nazi Doctors: Medical Killing and the Psychology of Genocide. New York 2000, p. 60.

[10] D. Rubisia, *op. cit.* As the first victim of “euthanasia” was Richard Kretschmar’s son. The father of the child wrote a letter to the Fuhrer himself, asking for the possibility of the legal murder of his child, which was born blind and physically deformed. Hitler sent to the family his personal physician, Dr. Karl Brandt, who supported the father’s request and on July 25, 1939, the boy was killed. As the official cause of death, however, a heart defect has been given. R. Stockton, Aktion T4, The Nazi Program That Slaughtered 300,000 Disabled People, https://allthatsinteresting.com/aktion-t4-program (access 15.09.2018)

[11] H. Friedlander, The Origins of Nazi Genocide: From Euthanasia to the Final Solution, Chapel Hill 1995.

[12] P.R. Breggin, Psychiatry’s role in the holocaust, “International Journal of Risk & Safety in Medicine” 1994, no. 4, p. 135.

experiments began using lethal gases such as: carbon monoxide, hydrogen oxide and hydrogen cyanide. The first experiments involving gas as a lethal agent were carried out in Poznań, where hundreds of prisoners were killed in an improvised gas chamber. The solutions used on a huge scale in Nazi concentration and extermination camps were mainly tested on people qualified for inclusion in the Aktion T4programme.[13] Frequently, the brains of the deceased were removed and used as samples for medical examination.[14]

Following a series of protests from German and Austrian society and church authorities, the programme was officially suspended on 24 August 1941, however, it continued to be carried out in secret.[15] On 30 October 1942, a new unofficial directive was released and issued to psychiatric hospitals, which ordered the introduction of a "special diet" for "hopelessly ill patients", a diet based on malnutrition and starvation slowly leading to their demise.

Due to the semiofficial character of the extermination programme for deficient persons, it is difficult to assess the number of victims involved with any degree of certainty. However, according to researchers, in Germany and Austria alone, the number exceeded 200,000 people,[16] while in the occupied European territories a further 100,000 individuals were believed to have been murdered.[17]. The last victim of the Aktion T4 programme, was a four-year-old boy, killed by lethal injection on 29 May 1945, in a hospital near Monachium, three weeks after the Third Reich's capitulation.[18]

Looking at the Aktion T4 programme from a legal perspective, we can see that the legal classification of mass murder on civilians is extremely simple in the light of contemporary international law. However, the question is how it appeared in the light of law at the time?

The aforementioned sterilisation procedure (at the initial stage) and the involuntary euthanasia of the mentally ill and disabled people which followed, had been sanctioned under the national law of the Third Reich. Hitler's decrees and decisions acquired that in the light of domestic law, all actions taken by the

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[13] C. Browning, *op. cit.,* pp. 185-189.

[14] Z. Jaroszewski (red.), Zagłada psychicznie chorych w Polsce 1939 -1945, Warszawa 1993.

[15] M. Burleigh, Between Enthusiasm, Compliance and Protest: The Churches, Eugenics and the Nazi 'Euthanasia' Programme, "Contemporary European History" 2008, no. 3, pp. 253-264.

[16] H. Jenner, Quellen zur Geschichte der "Euthanasie"- Verbrechen 1939-1945 in deutschen und österreichischen Archiven. Ein Inventar, https://www.bundesarchiv.de/geschichte_euthanasie/Inventar_euth_doe.pdf (15.09.2018)

[17] Euthanasie im Dritten Reich. Hinweise zu den Patientenakten aus dem Bestand R 179 Kanzlei des Führers, Hauptamt II b, https://www.bundesarchiv.de/DE/Content/Artikel/Ueber-uns/Aus-unserer-Arbeit/euthanasie-im-dritten-reich.html (access 15.09.2018)

[18] D. Stafford, Ostatni rozdział 1945, Warszawa 2009, s. 352-357. On October 2, 2014, the German authorities set out to commemorate the scientific victims of "euthanasia" in the form of a monument. https://www.t4-denkmal.de (15.09.2018)

Nazi authorities until August 1941, were theoretically legal. On the other hand, international law lacked a universal system for the protection of human rights both during World War II and before its outbreak. The League of Nations, created in 1919 as a response to the atrocities conducted in the First World War, was to ensure peace and respect for the inherent rights of the individual, but it did not establish universally binding norms, and its activity is now described as inept.[19] Only after the end of hostilities in Europe in 1945, did the actors on the international stage set out to take decisive steps in order to more effectively counteract cruelty and arbitrariness in the treatment of civilians by individual states. To this end, on 26 June 1945, at the conference in San Francisco, the United Nations (UN) was established.[20] The culmination of its activities was the adoption in 1948 of the Universal Declaration of Human Rights – an act binding the parties signing it, which many aspects of natural law made the law obligatory universally[21].

The world had no doubts that Nazi criminals should be punished, but there were no international rules at that time that would allow those amenable for the mass murders of civilians to be held responsible. What's more, there were also no institutions competent to deal with such cases, not to mention that there was not even a name for the crimes committed on such a large scale. The first act introducing the previously unknown responsibility of individuals for war crimes was the Moscow Declaration of 1943. It assumed the extradition of Nazi war criminals to the state in which they committed their deeds in order to bring them to justice in accordance with the national law in force therein.[22] It was an innovative solution, but in practice it turned out to be insufficient due to the territorial extent of the crimes committed by German commanders. Four world powers – the United States of America, Great Britain, France and Union of Soviet Socialist Republic – undertook to remedy this situation and on 8 August 1945, they signed the international agreement on the prosecution and punishment of major war criminals of the European Axis. Under this agreement, the International Military Tribunal (IMT) was set up to judge war criminals whose crimes could not be clearly classified territorially.[23] Although Berlin was designated as the permanent headquarters of the IMT, the first hearing took

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[19] N. Baranowska, T. Chłopecki, Kilka słów o kształtowaniu się praw człowieka w okresie XVIII-XX w., (w:) J. Mazurkiewicz (red.), Księga dla naszych kolegów, Wrocław 2013, p. 55.

[20] *Ibidem.*

[21] M. Gawlik, Krótkie dzieje praw człowieka, Wrocław 2006, p. 8.

[22] W. Góralczyk, S. Sawicki, Prawo międzynarodowe publiczne w zarysie, Warszawa 2009, p. 175.

[23] Agreement on the prosecution and punishment of major war criminals of the European Axis, art. 1, 8 August 1945, London, http://www.un.org/en/genocideprevention/documents/atrocity-crimes/Doc.2_Charter%20of%20IMT%201945.pdf (access 15.09.2018)

place in Nuremberg. Hence the colloquial name of the largest trial in history against Nazi war criminals – The Nuremberg Trial.[24]

The relevant text of the agreement was accompanied by the annex – Charter of the International Military Tribunal, which not only defined the system of IMT and the rules of its functioning, but also introduced to international law definitions of concepts that were hitherto unknown and which became permanent on the canvas of the international legal order. These concepts were: crimes against peace, war crimes and crimes against humanity. For the purpose of this study, the author will focus on the crimes referred to in the enumeration as the last – crimes against humanity.

From the Charter:

"*Crimes against humanity: namely, murder, extermination, enslavement, deportation, and other inhumane acts committed against any civilian population, before or during he war, or persecutions on political, racial or religious grounds in execution of or in connection with any crime within the jurisdiction of the Tribunal, whether or not in violation of the domestic law of the country where perpetrated.*"[25]

It is quite clear that the norm contained in this provision penalises all behaviours aimed at causing physical suffering to people, not only through murder or torture, but also by deprivation of liberty or forced relocation to a place of residence far away from their homeland. This standard is extremely important also for other reasons. This is the first legally sanctioned order to prosecute crimes committed, not only during the war but following it, against civilians. Until now, international agreements only referred to victims in the form of combatants (for example, the Geneva Conventions). It is also extremely important that sanctions dictated by the newly appointed tribunal were imposed irrespective of whether the internal law of the state in which the crime was committed recognised the behaviour as legal or not. In the light of the aforementioned legal acts adopted by the Nazis, this was a key provision.

It is also worth paying attention to the fact that the text of the agreement does not specify a minimum number of people who had to fall victim to behavioural conduct bearing the character of crimes against humanity. However, it is clearly emphasised that these activities were directed to people as a group, not as individuals. Moreover, all people involved in the planning of such activities and those who cooperated in their implementation were deemed to be responsible before the Tribunal. Acting under official or government orders did not exempt and individual from responsibility, but it could serve to alleviate the degree of punishment.[26]

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[24] TNA LCO 2/2980, Rough Notes, Meeting with Russians, 25 June 1945, (w:) B. Worden, Hugh Trevor-Roper: The Historian, London-New York 2016.

[25] *Ibidem*, Charter of the International Military Tribunal, art. 6.

[26] *Ibidem*, art. 7 and art. 8.

Defendants who had directly participated in the Aktion T4 programme were tried separately, the first of the so-called follow-up processes, after the trial of the most prominent Nazi criminals. In the literature, the first of these follow-up trials is commonly referred to as The Doctors' Trial or Euthanasia Trials. It was held before the American Military Tribunal No. 1 and bore the official title "United States of America v. Karl Brandt, et al.". Of the 23 accused of participation, or at least direct connection with the implementation of the Aktion T4's activities, 20 were doctors. They were charged with involvement in Nazi experiments on people and mass murder under the guise of euthanasia. On 20 August 1947, after a trial lasting 140 days, the hearing of 85 witnesses and the submission of some 1,500 documents, the American judges found 16 of the defendants guilty, seven of whom were sentenced to death with the remainder received prison sentences ranging from ten years to life. Those who had received death sentences were executed on 2nd June 1948.[27]

As mentioned above, actions aimed at the extermination of the disabled and the mentally ill were also carried out in countries under Nazi occupation, which included Poland. Importantly, it was in Poland that the first mass murders of disabled adults occurred, and this practice spread from Polish territories to others that had fallen to Germany.[28] Unfortunately, not everyone guilty of murdering almost 30,000 sick and disabled Poles were brought before the Nuremberg tribunal, which is why the prosecution of these crimes was taken up by Polish law enforcement agencies. On the basis of a decree of the Council of Ministers of 10 November 1945, the Main Commission for the Investigation of German Crimes in Poland was established and its branch commissions, spanned the country[29].

One of the first proceedings initiated in relation to the activities of Aktion T4 in Poland, was conducted in 1946-1947 by the Branch Commission in Krakow regarding the liquidation of patients in the hospital for the mentally ill in Kobierzyn. As a result of this atrocity around 1,000 helpless people lost their lives.[30] Despite the

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[27] As indicated by the title of the trial, Karl Brandt was the personal physician of Adolf Hitler. Through the Nuremberg Tribunal he was found guilty and hanged along with six other defendants condemned to death. Unfortunately, Joseph Mengele, arguably the cruelest and most morally depraved of the doctors involved, evaded capture. The Doctors Trial: The Medical Case of the Subsequent Nuremberg Proceedings, Holocaust Encyclopedia, https://encyclopedia.ushmm.org/content/en/article/the-doctors-trial-the-medical-case-of-the-subsequent-nuremberg-proceedings (access 15.09.208).

[28] B. Bojarska, Eksterminacja polskiej ludności powiatu tucholskiego w okresie działalności Selbstschutzu, „Biuletyn Głównej Komisji Badania Zbrodni Hitlerowskich w Polsce" 1968, vol. XIX, p. 7-14.

[29] Dekret z dnia 10 listopada 1945 r. o Głównej Komisji i Okręgowych Komisjach Badania Zbrodni Niemieckich w Polsce (Dz.U. 1945 No. 51 item. 293), http://prawo.sejm.gov.pl/isap.nsf/DocDetails.xsp?id=WDU19450510293 (access 15.09.2018)

[30] M. Szpytma, Z archiwów bezpieki – nieznane karty PRL, F. Musiał, J. Szarek (red.), Od Września do Norymbergi, Kraków 2012, vol. 18, p. 50-57.

fact that investigations lasted for over 30 years, they failed to bring those guilty of this particular crime to justice. However, it has not been forgotten and the Polish state has not ceased activities in this regard. Indeed, the role of the Chief Commission in 1998, was taken over by the Commission for the Prosecution of Crimes against the Polish Nation in the Institute of National Remembrance (IPN). Proceedings conducted by prosecutors of the IPN, cover crimes committed during and after the cessation of World War II and the pursuit of those responsible for such crimes continues to this day. Since the subject of their endeavours is largely crimes against humanity, they bear signs of internationality and do not undergo prescription. Moreover, their investigations involve accessing a vast range of data and the author intends to devote a separate study to the details of investigations into the extermination of people with disabilities, in line with the IPN's work in this field.

The fact that broadly understood human rights were developed only as a result of the devastating experiences of global armed conflicts brings a bitter conclusion to the state of humanity. World War II showed that international society was not prepared for the cruelty it suffered – both in its mental and strictly legal aspects. Today, having learned this difficult lesson, we have created a structure of regulations that severely sanction bestial behaviour of the type described herein, but let us hope that they will never have to be used. Especially for those as innocent and vulnerable as disabled people.

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Commentary on the Judgment of the Court of Appeal in Katowice of 11 September 2015, V Aca 109/15[1]

1. The interpretation of Article 13 § 1 of the Civil Code[2] has to be made in the spirit of Article 30 of the Constitution of the Republic of Poland stipulating that the inherent and inalienable dignity of the person shall constitute a source of freedoms and rights of persons and citizens. The provisions of the Constitution and international law on the subject of human rights protection are subject to violation in any case of adjudicating incapacitation, either full or partial, which does not significantly improve the legal or actual situation of the incapacitated person.
2. The adjudication on incapacitation cannot be based on potential risks and threats that may relate to health or even human life in the future.

1. Introductory comments

The legal regulations applicable in Poland regarding the institution of incapacitation are an example of substitute decision-making. This remark especially applies to full incapacitation, where the legal guardian appointed by the court obtains

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[1] The judgment published on the website of the Katowice Appellate Area, access: 1.06.2018. The judgment was issued as a result of an appeal against the judgment of the District Court in Gliwice of 21 November 2014 (Ref. no. II Ns 29/14); The Author's theses resulting from the justification of the judgment of the Court of Appeal.

[2] According to Article 13 § 1 of the Act of 23 April 1964 Civil Code, Dz. U. 2018, item 1025, as amended(hereinafter CC): "A person over thirteen years of age may be fully incapacitated if, due to mental illness, mental retardation or other mental disorder, in particular alcoholism or drug addiction, they are unable to manage their behaviour".

the right to make certain decisions for and on behalf of the incapacitated person.[3] The model is opposed to the concept of supported decision-making, the main advantage of which is the lack of the deprivation of legal capacity. This model assumes that the person is able to make decisions of legal significance provided they get the support which they need.[4]

The model of supported decision-making was best reflected in the regulations of the United Nations Convention on the rights of people with disabilities (the Convention) drafted in New York on 13 December 2006[5]. The Signatory States to the Convention committed to introduce in their national systems legal solutions enabling persons with a disability to make decisions on their own matters to the greatest extent possible and to be adequately supported in the process[6]. Although Poland ratified the Convention in 2012,[7] work on the amendment of the legal regulations regarding legal capacity was discontinued. The draft law strengthening the position of people with intellectual disabilities in Polish private law, including the provisions on continuing powers of attorney,[8] was even developed but to-date it has still to be passed through parliament.[9]

As the judgment of the Court of Appeal in Katowice commented on below demonstrates – regardless of the delays in the legislative work – the Convention's

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[3] More on incapacitation see: K. Lubiński, *Postępowanie o ubezwłasnowolnienie*, Warsaw 1979, passim; L. Kociucki, *Zdolność do czynności prawnych osób dorosłych i jej ograniczenia*, Warsaw 2011, pp. 171 et seq .; *Ubezwłasnowolnienie w polskim systemie prawnym*, Warszawa 2012, *passim;* M. Domański, *Ubezwłasnowolnienie w prawie polskim a wybrane standardy międzynarodowej ochrony praw człowieka,* Prawo w działaniu 2014, no. 17, pp. 7 et seq.

[4] See: M. Szeroczyńska, *Wprowadzenie* [in:] *Jeśli nie ubezwłasnowolnienie, to co? Prawne formy wsparcia osób z niepełnosprawnością,* K. Kędziora (ed.), Warsaw 2012, pp. 8 et seq.; K. Kurowski, *Niepełnosprawność i osoba niepełnosprawna – od medycznego do społecznego modelu niepełnosprawności* [in:] *Najważniejsze wyzwania po ratyfikacji przez Polskę Konwencji ONZ o Prawach Osób Niepełnosprawnych*, Biuletyn RPO. Źródła 2013, A. Błaszczak (ed.), no. 6, pp. 8 et seq.

[5] Dz. U. 2012, item 1169. hereinafter the Convention.

[6] See more on the obligations arising from the ratification of the Convention A. Błaszczak, *Zastrzeżenia i oświadczenia interpretacyjne Polski do Konwencji o prawach osób z niepełnosprawnościami* [in:] *Prawa osób z niepełnosprawnością intelektualną lub psychiczną w świetle międzynarodowych instrumentów ochrony praw człowieka*, D. Pudzianowska (ed.), Warsaw 2014, pp. 27 et seq.

[7] Based on the Act of 15 June 2012 on the ratification of the Convention on the Rights of Persons with Disabilities, adopted in New York on 13 December 2006 (Dz.U. item 882). The Convention entered into force in Poland on 25 October 2012.

[8] See more: P. Machnikowski, *Pełnomocnictwo opiekuńcze w pracach Komisji Kodyfikacyjnej Prawa Cywilnego w latach 2012-2015*, Rejent 2016, no. 5, pp. 50 et seq.; I. Kleniewska, M. Szeroczyńska, *Założenia uregulowania w polskim prawie instytucji asystenta prawnego osoby z niepełnosprawnością intelektualną lub psychospołeczną* [in:] *Jeśli nie ubezwłasnowolnienie, to co? Prawne formy wsparcia osób z niepełnosprawnością*, K. Kędziora (ed.), Warsaw 2012, pp. 116 et seq.

[9] See: M. Szeroczyńska, *Mozolna droga ku likwidacji instytucji ubezwłasnowolnienia* [in:] *Prawa osób z niepełnosprawnością intelektualną lub psychiczną w świetle międzynarodowych instrumentów ochrony praw człowieka*, D. Pudzianowska (ed.), Warsaw 2014, pp. 180 et seq.

ratification results in a change in the paradigm of perception of people with intellectual disabilities not only in the international but also in the national legal order. In this case, however, it is not about legislative changes, but about the modification of case law developed by common courts in incapacitation cases. The Court of Appeal in Katowice, examining the use of the institution of incapacitation *in casu*, considered the superior standard of human rights protection. Unlike the District Court in Gliwice, the Court of First Instance in the referenced case, it did not accept the existence of legal premises for incapacitation (in any form, full or partial), concluding that this would lead to excessive and irreversible interference by public authorities in the rights guaranteed by both the national and the international legal order. Article 13 of the Civil Code (hereinafter: CC) was interpreted in the spirit of Article 30 of the Constitution, indicating that the incapacitation of a given person with a disability may constitute a violation of their inherent dignity.

This way of perception deserves to be approved, but before the main arguments of the Court's justification are addressed, the diametrically opposed judgement of the Court of First Instance should be presented. In turn, this ruling reflects very well the model of standard adjudication in incapacitation cases being subject to criticism in the Polish legal doctrine.[10]

2. The facts in the case and the main justification for the Court of First Instance judgment

The person with a disability being the participant in the proceeding was affected by cerebral palsy with epilepsy and paresis accompanying this disease from birth. This young man was certified with multiple disabilities: an intellectual disability in a moderate form and motor retardation due to cerebral palsy. On the basis of a disability certificate issued on 22 May 2012, he is recognized as a person with severe disability, permanently incapable to work, requiring participation in occupational therapy, the provision of auxiliary care, rehabilitation and technical aids. Since he also requires the constant assistance of another person to compensate for a significant limitation in his ability to exist by himself on a daily basis, under the decision of the

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[10] See the research conducted by students of the Law Clinic at the Faculty of Law and Administration of the University of Warsaw in the years 2000-2001, collected and developed by A. Firkowska-Mankiewicz, M. Szeroczyńska, Praktyka ubezwłasnowolnienia osób z niepełnosprawnością intelektualną w polskich sądach. Raport z badań, Człowiek- Niepełnosprawność-Społeczeństwo 2005, no. 2, pp. 96 et seq .; as well as the research carried out by the Department of Common Courts of the Ministry of Justice in the years 2003-2004, see I. Kleniewska, *Postępowanie w sprawie o ubezwłasnowolnienie w praktyce sądowej* [in:] Prawo w akcji, vol. 1, E. Holewińska-Łapińska (ed.) Warsaw 2006, pp. 118-134.

Social Insurance Institution medical examiner of 8 June 2011, he was considered permanently incapable of independent existence.[11]

The proceedings on full incapacitation in this case were instituted not at the request of the immediate family[12] but by the prosecutor possessing the legitimacy on a general basis.[13] According to the justification of the judgement of the District Court in Gliwice, before the application for incapacitation was submitted, at the request of the Social Welfare Center, the verification procedure concerning the living conditions of the disabled person was opened in September 2013, largely in response to a "Blue Card" police procedure (the domestic violence police intervention protocol)[14] which had been conducted on the household where the participant in the proceedings stayed, and which had been ongoing since 30 June 2013. At the time, he lived in the apartment with his mother and her cohabitant who both had a tendency to abuse alcohol and while drunk they would quarrel and engage in acts of physical and psychological violence witnessed by the participant. In an environmental assessment conducted on 24 September 2013 by a probation officer at the place of residence, among others, the flat's poor hygienic condition, alcohol consumption by the participant's mother and her partner and related altercations were noted. There was also information on the previous criminality of the participant's mother and rehabilitation treatment. It is worth noting that the probation officer's assessment concluded with the suggestion of expediency in processing the participant's incapacitation. It was this conclusion that triggered the prosecutor to initiate proceedings.

In order to issue judgment, the District Court in Gliwice, as the Court of First Instance,[15] had to look at the personal and family situation of the participant in the

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[11] In Poland, there are two independent systems of disability certification. The first is implemented by municipal/district commissions for disability assessment (the guardianship allowance may be granted in connection with their decisions); the second is the Social Insurance Institution (Zakład Ubezpieczeń Społecznych, ZUS), which is connected with the award of disability benefits.

[12] According to Article 545 § 1 of the Act of November 17, 1964, the Code of Civil Procedure (consolidated text: Dz.U. 2018, item 15, as amended, hereinafter as CCP) the persons entitled to submit the application are: the spouse of the person whom the application for incapacitation concerns, its relatives in a straight line, siblings and its statutory representative. However, the rights of relatives in a straight line and siblings are excluded, if the person concerned by the application has a statutory representative (Article 545 § 2 of CCP). In particular, this situation occurs when the application for full incapacitation applies to a person over the age of 13.

[13] The prosecutor may submit the application for incapacitation if they find that there are no persons authorized to do so, or that these persons evade the application or are not able to report it themselves due to a mental illness, mental retardation, helplessness or other exceptional reasons. See § 359 of the Order of the Minister of Justice of April 7, 2016 – Rules of internal office of common organizational units of the prosecutor's office, Dz. U. item 508, as amended.

[14] The procedure of establishing the Blue Card is regulated in the Act of 29 July 2005 on preventing domestic violence (consolidated text: Dz.U. 2015, item 1390, as amended).

[15] According to Arr. 544 § 1 of the CCP cases of incapacitation belong to the jurisdiction of District Courts, recognizing them in the composition of three professional judges. The Court's local

proceedings. This procedure required to be conducted with great care since both the participant himself and his immediate family (the mother) opposed incapacitation. As stipulated in Article 554^1 § 1 of the Code of Civil Procedure (CCP), inquiries should first of all determine the state of health, personal, professional and property situation of the person the application refers to, the tasks the person needs to perform and the way the person satisfies his/her basic life needs.

In the course of the proceedings, it was established that the participant attended a job training school where he did very well. In the school's opinion, he was considered a friendly, smiling, kind and open student, willing to socialise both with his peers and with adults. While able to initiate and maintain verbal contact with an interlocutor, due to the occurrence of verbal stereotypes, he had problems with statement organisation. The opinion stressed that he could distinguish between good and evil but was very susceptible to the influence of others and often mimicked their behaviour. During the school year, considerable progress was observed in the participant in the area of socialisation and in becoming independent; he was very keen on joining in all kinds of practical activities and developing his independence, and he also attended revalidation classes.

In addition, the Court determined that the participant was independent in the area of basic hygiene activities, moved independently, took a minibus to school and for this purpose went by himself to a nearby bus stop. He could make a simple meal and do housework. He would not be able to take medications on his own but was able to communicate feelings of pain or discomfort. He did not understand the value of money but had his own bank account and, with the aid of his mother (who managed his money), he used a bank card. He could use a computer and an mp3 player.

Citing the information from the probation assessment of September 2013, the court undermined the credibility of the testimonies submitted by the participant's relatives (his mother and brother) who claimed that the participant had safe living conditions at his place of residence. On the basis of the documents attached to the application and described above, the court stated that the environment in which the participant lived was unfriendly toward him, mainly due to the presence of his mother's partner. It was also stressed that the participant's mother was being rehabilitated in a day-centre for alcohol abuse, which made it difficult for her to look after her son. This was also considered by the court to be a factor that posed a threat to the participant and one which in addition implied a need to place his finances under the control of a legal guardian.[16]

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jurisdiction specifies the place of residence (or stay) of the person to be incapacitated (Article 544 § 2 of the CCP).

[16] The legal guardian for the incapacitated person is appointed by the guardianship court in a separate proceeding.

The court's considerations on the need to regulate the legal status of the participant are worth analysing. In the court's opinion, the use of the institution of full legal incapacitation was justified in order to allow for quick decision-making in administrative cases regarding the participant and to protect his financial interests. It was pointed out that the participant was easily influenced and, as he independently rode a bicycle, went for walks and met other people, he was exposed to unfavourable dispositions of his property. Furthermore, by ruling on incapacitation, the court emphasised that it was concerned that he would not be able to express effective consent to a major medical procedure should such need arise and thus, this would serve to harm the participant's interests in protecting his health and his life. The expert witnesses in the case[17] indicated that the participant was not a mentally ill person in the sense of psychosis, he only showed symptoms of behavioural and emotional disorders. He was only partially oriented about his own person and situation, and the current date. He could not read or count. He could write his name with misspellings but beyond this he was unable to write. His ability to understand everyday social situations, socially acceptable behaviours and their causes, and the ability to issue valued judgments, was underdeveloped. As a result, the expert witnesses stated that he was unable to independently meet the fundamental needs of life or care for his health, property and personal safety issues. In these matters, he constantly used the help of other people, most often his mother. It was established that the psychological condition prevented him from independent existence, and cognitive disorders made it impossible for him to independently determine and satisfy basic life needs.

With regard to the foregoing, the court came to the conclusion that the conditions of incapacitation as referred to in Article 13 § 1 CC applied and fully incapacitated the participant, assuming that the application of this institution was in the interest of the participant and was in accordance with his wellbeing.

Referring to the ruling made by the court, it is worth emphasising the inconsistency of the conclusions resulting from the experts' opinions with the findings made on the basis of opinions on the participant collected from his school and home environment. The community interviews seemed to indicate that the participant only required assistance in conducting certain matters, while in some cases he managed particularly well on his own. Meanwhile, the experts' opinions directly indicated that his psychological condition made it entirely impossible for him to exist independently, and his cognitive disorders prevented independent determination and satisfaction of his basic life needs. At the same time, the experts did not make it clear what the specific life needs were that the participant was incapable of satisfying. Admittedly, the information collected indicated that the

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[17] The justification does not indicate in which specialty they were proficient. According to art. 553 § 1 of CCP a person subjected to the incapacitation procedure must be examined by a psychiatrist or neurologist, as well as a psychologist.

participant would probably not be able to take medications on his own and would not be able to prepare a complicated meal. Similarly, as a result of intellectual limitations, he required assistance with larger financial transactions from close relatives (he did not understand the value of money). One could also presume that due to his limited intellectual capacity, especially in the field of reading and writing, he could not be party to a civil law contract. At the same time, as the evidence collected also indicated, the participant was able to do all of these things given adequate support. He functioned properly both at school and in his home environment, and his needs were met thanks to the care of his mother and other people. Therefore, the question arises, what was the purpose of "full incapacitation" in this particular case?

The provisions of the Civil Code clearly indicate that the mental state of a natural person has legal significance, translating into two-fold protection: either by categorising circumstances causing this state as the reasons excluding or limiting legal capacity (incapacitation) or as the causes of a defect in the declaration of will namely lack of consciousness or freedom (Article 82 CC). In the latter case, the so-called abnormal psychological state of a given person is considered in the context of a specific factual situation in which the declaration of will was made and depending on the results of the examination it leads (or not) to a legal effect of the nullity of the legal transaction. In the case of incapacitation, the abnormal psychological state is considered in a longer term, the consequence of which is the indefinite deprivation of legal capacity. As a result, it becomes necessary to make decisions about the entire sphere of legal capacity.[18]

However, it should be noted, that if in this sphere the person does not participate or can only participate with help from others, then there is nothing to protect them from and no need to protect other transactions that may arise. Attention should also be given to the potentially "dangerous" behaviour of the participant stressed by the court. The Court indicated that the participant was easily influenced and that because he independently rode a bicycle, went for walks and met other people, he could make unfavorable dispositions with his property. At the same time, the Court of First Instance did not determine that such situations had ever taken place. Incapacitation in this case was simply being applied in a preventive sense.

The excerpt of the justification concerning the need of incapacitation due to the potential possibility of subjecting the participant to medical intervention deserves similar comment. Later the Court of Appeal rightly criticised this point of view, indicating that the ruling on incapacitation cannot be based on potential risks and threats that may arise in the future in relation to the person's health or even to their

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[18] The only exception is Article 14 § 2 of the Civil Code, according to which if a person incapable of concluding legal acts enters into a contract that is commonly concluded in minor current affairs of everyday life, the contract becomes valid at the time of execution, unless it causes serious harm to the incapable person.

life. At the time when the contested judgment was issued, there were no grounds to conclude that the participant required medical treatment of any kind or that such would be required in the near future. Moreover, in a case of emergency, a doctor can carry out necessary medical treatment without the consent of the patient, their legal representatives or guardianship court, if the delay caused by proceedings to obtain such consent would expose the patient to risk of loss of life, further injury or serious health disorder.[19]

Additionally, it can be supplemented with the provision of Article 32 para. 4 of the Act on the professions of doctor and dentist, which stipulates that if an incapacitated person is completely able to give an opinion on the medical examination, their consent is required along with the consent of their statutory representative. Therefore, the doctor has to take into account the opinion of the incapacitated patient if he/she has true discernment.[20] In turn, the case of partial incapacitation was treated in medical law in the same way as the case of an adult not being incapacitated and having so-called actual competence. In this case, such person can independently express consent to all medical interventions, including those that carry increased risk.[21]

To summarise the arguments presented up to this point, it is worth emphasising that the judgment of the Court of First Instance in this case, serves as a typical example of a judgment in which the court relies on experts' opinions in a quite unreflective way. Here, the experts focused on what the disabled person could not do, rather than on what their potential consists of. Despite the factual elements indicating that the participant managed well when receiving adequate support, attention was narrowed down to potential situations in which the participant would not be able to cope. The issue should also be seen in the premises of incapacitation provided in Article 13 § 1 CC. The court examines whether a person who is a participant in the proceedings affected by a mental illness, mental retardation or other type of mental disorder (in particular alcoholism or drug addiction) is, as a result of said conditions, unable to manage their behaviour. Therefore, *a contrario*, it asks experts whether the participant in the proceedings is able to manage their behaviour. This way of presenting the matter leads experts to give a negative answer. The so-called independent and exclusive competence test assessed *in abstracto* is not altogether

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[19] See Article 33 para. 1 and Article 34 paragraph 7 of the Act of 5 December 1996 on the professions of doctor and dentist, consolidated text: Dz. U. 2015, item 464, as amended.

[20] It concerns also the provisions of the Act of 6 November 2008 on patients' rights and the Patient's Rights Ombudsman, consolidated text: Dz. U. 2017, item 1318, item 1524, which refer to the Act on the professions of doctor and dentist. Similarly, under the provisions of the Act of 19 August 1994 on the Protection of Mental Health, Dz. U. 2018, item 138; see especially the provision of Article 22 para. 4 of this Act.

[21] See e.g. B. Janiszewska, *Zgoda na udzielenie świadczenia zdrowotnego. Ujęcie wewnątrzsystemowe*, Warsaw 2013, pp. 415 et seq.

impossible for people with intellectual disabilities to pass. I also dare to say that this same test might not be passed by some people who are within intellectual norms but suffering from various types of mental disorder. Everything depends on the task the person is expected to be able to cope with.

In this context, it is also worth noting that the Polish legislator clearly separates incapacitation into two types: full and partial. By meeting the same premises (mental illness, mental retardation, other mental disorder and in particular alcoholism or drug addiction), it differentiates the effects of an abnormal mental state as: that where the person is unable to manage their behaviour (Article 13 § 1 CC) and that where the person only requires assistance in managing their affairs (Article 16 § 1 CC). It seems that, taking into account the facts in the case, it was possible to apply Article 16 § 1 CC. However, in light of the additional factual findings made by the Court of Appeal in the case, even that ruling (partial incapacitation) would have been unjustified.

3. The main justification for the Court of Appeal judgment

The Court of Appeal in Katowice considered the appeal lodged by the participant himself (duly represented), as well as by the other participant in the proceedings (the mother). In the appeals, firstly the errors in factual findings were pointed out: the assumption that the participant did not have safe and peaceful living conditions and failure to adopt the state of affairs existing at the closure of the hearing as a basis for adjudication (Article 316 § 1 CCP with reference to Article 13 § 2 CC). It was also alleged that the District Court's judgment violated substantive law, i.e. Article 13 § 1 CC, and the Convention provisions.[22] A violation of Article 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms[23] was also stated. The claimants requested the court to amend the judgment by dismissing the application for incapacitation or to waive the judgment and to refer the case back to the District Court. It is also worth emphasising that one of the participants in the proceedings (the mother) requested the court to present a legal inquiry to the Constitutional

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[22] In particular, the claimants referred to Articles 3 and 19 of the Convention. Based on Article 3 lit. a) and c) of the Convention is an obligation to respect the inherent dignity, autonomy of a person with a disability, including freedom of choice and respect for their independence, as well as the obligation to ensure full and effective participation and inclusion of that person in society. According to Article 19 the aim is to recognize the right of persons with disabilities to live in society, including the right to make choices equally with other people, and to undertake effective and appropriate steps to facilitate the full enjoyment of the right to live in society by people with disabilities - its scope includes the right to participate in legal transactions.

[23] The provision of Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (hereinafter as ECHR) provides for respect of private and family life. The Court of Appeal found them irrelevant.

Tribunal on the compliance of Article 13 CC with the Constitution of the Republic of Poland and the international agreements ratified by Poland before mentioned.[24] The prosecutor demanded the appeal to be dismissed and the judgment to be upheld, or (possibly) partial incapacitation to be adjudicated.

The Court of Appeal considered both appeals justified, stressing that the Court of First Instance, relying on information obtained from the community assessment interviews of September 2013, being the basis of the application for incapacitation, did not deliberate findings on the current situation in the participant's household existing on the date the contested judgment was handed down. In this regard, the Court of Appeal carried out supplementary evidence proceedings. The psychiatrist under whose care the participant had been for several years testified that he had never found any negligence and irregularities in the way his mother cared for him. She assessed that the participant was always well-groomed and provided with proper care (the witness used the term "taken care of properly"). Also, in the community assessment prepared by a professional probation officer on 10 January 2014, it was stated that the participant lived only with his mother, that her cohabitant had moved out in November 2013 and that she herself had maintained abstinence from alcohol and attended therapy for addicts. In the assessment, the probation officer (the one who prepared the report of September 2013) included information that the participant's situation had improved and that the Blue Card procedure initiated on 30 June 2013 had been closed on 8 November 2013 (prior to the application for incapacitation being filed). On the basis of testimony submitted to the Court of Appeal by the participant's mother, it was also established that after the participant had come of age, in relation to medical treatment and dealing with administrative matters supported by his mother, the participant had never experienced any difficulties related to his condition that were of concern to doctors and administrative officers. In terms of the medical aspects of the participant's functioning, he was subject to constant treatment assisted by his mother. The fact that this assistance was properly provided was primarily demonstrated by the position of the psychiatrist attending the participant for many years, who had not found it to be flawed in any way. Also, the participant's functioning in the social sphere raised no objections. He attended school, had a bank account, used an ATM card and carried an ID card. The fact that this was implemented with help from his mother could not disqualify him as a participant in social life. Importantly, the

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[24] The Court of Appeal found them irrelevant. The Constitutional Tribunal in its judgment of 7 March 2007 (reference number K 28/05) did not assess incapacitation as an institution inconsistent with Article 30 and Article 31 of the Constitution of the Republic of Poland, but only described the procedural solution as inconsistent with the provisions of the Constitution, depriving an incapacitated person of the postulative capacity, i.e. the right to submit an application for instituting proceedings to waive or change legal incapacitation.

participant did not violate any social norms. On the contrary, he was perceived as a nice and friendly person.

Since, as demonstrated above, the participant's interests both personal and material were properly protected by the care exercised by his mother and other family members, the Court of Appeal changed the judgment of the Court of First Instance dismissing the application for incapacitation.

At the juridical level of the judgment, the Court stressed that incapacitation was a form of state aid for people who, due to specific disorders, are unable to function on their own. Incapacitation is to serve only the interests of that person and its aim is to help in dealing with personal and material matters.[25] Article 13 § 1 CC, ought to be interpreted in the spirit of Article 30 of the Constitution of the Republic of Poland, stipulating that the inherent and inalienable dignity of the person shall constitute a source of freedoms and rights of persons and citizens. It is inviolable, and its respect and protection constitute the responsibility of public authorities. Moreover, it should also consider the international legal order. In respect the latter, this includes the right to respect the inherent dignity and autonomy of a person with a disability, the right to an independent life and inclusion in society provided under the Convention, as well as that right resulting from Article 8 ECHR - the right to private life.

Regarding the legal consequences, the Court found that incapacitation involves deep interference with the rights guaranteed by both the Constitution and international agreements binding on Poland. In case of legal incapacitation, the whole sphere of decision-making is transferred into the hands of a guardian appointed by a court. The possibility then to participate in trade and make choices about every aspect of their functioning in social or personal life equal with all other people by persons with disabilities is significantly reduced. For this reason, incapacitation should be *ultima ratio*, i.e. a legal measure applied only if it is not possible to protect the interests of persons incapable of managing on their own in any other way. *A contrario*, it should be considered pointless whenever it is not absolutely necessary for the purpose it is to serve. Due to the conflict of values associated with legal incapacitation, the need to apply this measure has to be assessed on the circumstances of a particular case.

4. Summary

The institution of full incapacitation as a measure adjudicated for an indeterminate time and not restricted to specific ranges or types of cases, having

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[25] As stated by the Supreme Court in the provisions of October 27, 1976, II CR 387/76 and December 29, 1983, I CR 377/83, Legalis.

very serious legal consequences[26] should be applied exceptionally. The criterion of “inability to manage behaviour” used by the legislator should not be read in a clichéd way. The function of expert opinion is to help a court assess the life situation of the person who is to be incapacitated. In contrast to expert psychiatrists, neurologists and psychologists assessing the actual ability (competence) of a given person, the court is primarily to assess the person’s ability to participate in legal transactions and in social life. In this area, the most severe result of incapacitation takes place depriving the right to self-determination. In the decision of 5 January 1977,[27] the Supreme Court pointed out that if the patient’s life situation is stabilised, he or she is provided with sufficient factual care and there is no need to take any action requiring legal protection, the judgment on incapacitation would lead to disruption of the regulated actual situation. Therefore, the judgment of the District Court in Gliwice, referring only to potential threats in various aspects of the participant’s life, had to be assessed in a negative way, while the judgment of the Court of Appeal in Katowice deserved approval.

Undoubtedly, the provisions of the Convention requiring a change in the paradigm of perception of people with disabilities, especially those intellectually challenged, had a serious impact on the interpretation made by the Court of Appeal in Katowice. In place of the traditional state custody (in the form of social welfare), these provisions introduce the concept of assistance provided to a person with a disability, respecting their dignity, potential and will to exercise their own rights, i.e. the right to work, education, and electoral rights.[28] Although the factual situation made it clear that the premise of the need to provide “help in handling cases” was met, the court did not consider it appropriate to adjudicate partial incapacitation. It seems that it was due to the assumption that even the fulfillment of this criterion

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[26] The basic effect of legal incapacitation is the deprivation of legal capacity, which means that such acts are affected by absolute nullity (the exception is provided in Article 14 § 2 CC). In addition, on the basis of family and guardianship law (the Act of 25 February 1964, Family and Guardianship Code, Dz.U. 2017, item 628, Dz.U. 2018, item 950 with amendments, hereinafter FGC) incapacitation disqualifies from the possibility of being a guardian (Article 148 § 1 FGC), a probation officer (Article 178 § 2 of FGC in reference to Article 148 § 1 of FGC), a parenthood authority (Articles 94 § 1 FGC), a person adopting a child (Article 114^1 FGC). In addition, a fully incapacitated person cannot enter into a marriage, and the annulment of a marriage based on this reason may be demanded by each of the spouses (Article 11 FGC). From the civil law perspective, the prohibitions refer to a plenipotentiary (Article 100 CC) and a commercial proxy (Article 109^2 § 2 CC); such a person cannot make a will (Article 944 § 1 CC) or be an executor (Article 986 § 2 CC). In the field of labour law, full incapacitation results in the inadmissibility of taking up employment. Incapacitated persons do not have passive and active electoral rights, and also cannot perform certain professions.

[27] Ref. I CR 450/76, Legalis.

[28] See J. Lipowicz, *Wprowadzenie* [in:] *Najważniejsze wyzwania po ratyfikacji przez Polskę Konwencji ONZ o Prawach Osób Niepełnosprawnych*, A. Błaszczak (ed.), Biuletyn RPO. Źródła 2013, no. 6, p. 5.

does not reflect the actual need related to the functioning of this particular person. In this respect, the Court of Appeal rightly concluded that the use of the institution of incapacitation *in casu* should be considered in the context of the overriding constitutional principle of respect for the dignity of every human being, expressed in Article 30 of the Constitution of the Republic of Poland.

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Lisa Waddington, Anna Lawson (eds.)

The UN Convention on the Rights of Persons with Disabilities in Practice. A Comparative Analysis of the Role of Courts

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Introduced in 2008, the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) has existed for over a decade and in a considerable number of its State Parties the act has been in force long enough to demonstrate first issues with its adoption and effectiveness. Implementation of the CRPD should now be considered an overarching priority by organizations and individuals committed to improving the quality of life of people with disabilities. The CRPD is a potential catalyst for a radical reappraisal of policy and practice among governments and organizations concerning persons with disabilities, as well as by service planners and providers, members of professional and voluntary organizations, the research community, and by society at large. The 152 governments that have ratified the CRPD have entered into a commitment in international law to submit detailed reports to the CRPD Committee of the UN human rights commission. The Committee's criticisms of the nature and quality of government implementation highlight the need for sustained and informed advocacy by civil society to raise public awareness about the potential of the CRPD to benefit people with disabilities – here the crucial role belongs to academia.

The scholarly neglect regarding the rights of people with disabilities has just been filled by *The UN Convention on the Rights of Persons with Disabilities in Practice. A Comparative Analysis of the Role of Courts*, edited by Lisa Waddington and Anna Lawson examining the effectiveness of this CRPD implementation process in the context of courts' activity. The volume was published as part of the International Law in Domestic Legal Orders series of the Oxford University Press. This comprehensive study examines how courts in thirteen different jurisdictions use, interpret and make the act work. The first part of the book contains chapters specific to each jurisdiction (written by experts in both the CRPD and the particular jurisdiction in question), whereas the second part consists of four comparative chapters which draw on the rich analysis of the jurisdiction-specific chapters. The issues addressed by them include respectively the interpretation of CRPD provisions by domestic courts; the legal status of the CRPD in domestic law and its relevance to domestic case law; the uses made of the CRPD by domestic courts; and the judiciary's role and perception of its relationship with the CRPD. The book also includes reflections on the implications of this study, and previous comparative international law studies of CEDAW, for human rights theory.

The first chapter by Ana Laura Aiello provides an overview of how the CRPD is being applied by Argentinian courts. For this purpose, seventy-four judgments are analysed. There are two major findings: first, most relevant judgments involved legal actions against the social welfare system and legal capacity issues; second, most judgments tended to draw on the CRPD as an interpretive aid to domestic law or simply included generic references to the CRPD without putting it to any obvious use in the judgment.

The analysis of Australian jurisdiction provided by Lisa Waddington, shows that Australian courts have referenced the CRPD in their judgments to bolster or support their reasoning in a number of cases. On the other hand, Australian courts have also on occasions explicitly stated that they found the CRPD to be inapplicable or irrelevant. The Australian cases explored in this chapter therefore represent a wide diversity of judicial responses to the CRPD, and provide the basis for a fruitful discussion and analysis.

The chapter by Oliver Lewis presents an overview of the adjudicative bodies of the Council of Europe, i.e. the European Court of Human Rights and the European Committee of Social Rights, and outlines their mandates with regard to integrating UN human rights treaties. The relatively small dataset was forty-five cases dealt with by the Court and two collective complaints decided by the Committee that cite the CRPD up to 2016. The conclusions are that the Council of Europe system has yet to engage seriously in the CRPD's jurisprudential opportunities.

Lisa Waddington also examines implications of the EU's accession to the CRPD regarding the role for the Court of Justice of the European Union (CJEU). Given that the Court has the task of interpreting the CRPD as an instrument of EU law and, in particular, ensuring that EU secondary legislation is interpreted in a manner which is compatible with the Convention wherever possible, it is not surprising to find references to the CRPD in a number of judgments and opinions of its Advocate General rendered both before, and primarily after, the conclusion of the CRPD by the EU.

Valentin Aichele points to German courts' failure to be proactive in demonstrating "friendliness towards public international law" when dealing with international human rights norms. However, in quantitative terms, German courts have referred to the CRPD more often than any other UN international human rights instrument. Furthermore, in qualitative terms, federal courts have become more receptive towards the CRPD.

Another chapter by Shreya Atrey provides an account of Indian appellate courts' engagement with the CRPD and the developing caselaw on disability rights. The High Courts and the Supreme Court have resorted to the CRPD in diverse ways within "citation" and "interpretation".

An interesting view is presented by Eilionóir Flynn referring to Irish jurisdiction being in a specific position as a state which has not ratified the CRPD, but which is obliged to adhere to its provisions under EU law by virtue of the latter's conclusion of the CRPD in 2010. This chapter examines the extent of the impact that the CRPD can have on the judgments of domestic courts on disability rights in advance of the state's ratification of the CRPD.

Delia Ferri highlights how Italian lower and higher courts, including the Constitutional Court and the Court of Cassation, have attempted to overcome the gap between domestic law and the CRPD, by rethinking legal concepts in light of the CRPD, especially with regard to legal capacity and the domestic provisions of the civil code on the "administration of support", but also to non-discrimination legislation and reasonable accommodation.

Elizabeth Kamundia analyses fourteen cases in which Kenyan courts have made reference to the CRPD and finds that there is a steady increase in the usage of CRPD provisions by Kenyan courts, particularly since the coming into force of the Constitution of Kenya in 2010 which transformed Kenya into a monist state.

The Mexican practice is described by Matthew S. Smith and Michael Ashley Stein showing how Mexico's Supreme Court has applied the CRPD to decide cases involving persons with disabilities following its 2011 constitutional reform, frequently failing to do so in an even-handed manner. Civil society organisations that have advocated for progressive rulings have a responsibility for educating the Court to develop workable judicial tests for CRPD-based claims.

Dmitri Bartenev and Ekaterina Evdokimova's analyse on how Russian courts have approached principles and standards of the CRPD, shows that in the majority of cases the CRPD has been used only to reinforce the standards already provided by domestic laws. In a few cases, however, judges interpreted the CRPD provisions to establish new legal concepts or to apply progressively Russian laws concerning the human rights of people with disabilities.

Ignacio Campoy Cervera explores an uneven path to the application of CRPD by different Spanish courts focusing on the rights that have been most frequently referred to the courts: the rights to equality and non-discrimination; equal treatment as a person before the law; access to justice; personal liberty; honour, reputation and privacy; to education; an adequate standard of living; and participation in political and public life.

The chapter by Anna Lawson and Lucy Series examines courts in the United Kingdom using and interpreting the CRPD in seventy-five cases. The CRPD was used as an interpretive aid only in connection with understanding how ECHR and EU law should be understood in the domestic context, suggesting that, were ECHR and EU law no longer to be part of United Kingdom law, the CRPD would play a greatly diminished role in guiding case law in the United Kingdom.

The second part of the monograph starts with Anna Lawson and Lisa Waddington reflecting on the ways in which courts in the thirteen jurisdictions have interpreted the provisions of the CRPD. Firstly, it explores the interpretations which CRPD provisions (from the Preamble to Article 30) have been given by different courts in cases analysed in this study. Secondly, it considers various issues concerning the interpretations of the CRPD adopted in the thirteen jurisdictions.

The chapter which follows by Lisa Waddington on the domestic legal status of the CRPD and relevance for court judgments, explores four dimensions of the CRPD's legal status: direct effect; indirect interpretative effect (where the CRPD influences the interpretation given to domestic law); use of the CRPD because of commitments to another international treaty; and absence of domestic legal status.

On the basis of the previous chapters, Anna Lawson conducts a functional analysis, identifying and exploring seven ways in which the CRPD has been used in court judgments in the cases analysed in this book: first, its use to invalidate or declare unconstitutional national or regional legislation judged to be inconsistent with it; second, its use to overturn or radically reinterpret domestic jurisprudence or legal doctrine; third, its use to provide normative content to proactively fill gaps' in domestic law; fourth, its use to help resolve ambiguities in domestic law; fifth, its use to bolster or support decisions based on domestic or other international authorities; sixth, its use to affirm the importance of the human rights of disabled people; and, finally, its use as a check on executive or public body decision-making.

The chapter *The Role of the Judiciary and Its Relationship to the Convention on the Rights of Persons with Disabilities* by Lisa Waddington, examines the role of the judiciary with regard to the CRPD. It considers the relationship which the judiciary have or appear to perceive themselves as having with the CRPD and explores some of the factors seemingly prompting courts to refer to it. The first section reflects on: whether judges are able to choose to refer to the Convention or have a legal duty to do so; the significance of the fact that the CRPD is international law; and whether judges appear to see themselves merely as domestic actors, or as agents or trustees of the CRPD. The second section explores whether judges are referring to the CRPD in response to arguments raised before the court or doing so of their own volition.

Also considered are the relevance of *amicus curiae* interventions; reasons for referral related to the domestic legal system; and the role of particularly engaged individuals.

The monograph finds its meta-setting in the last chapter *Human Rights Theory and Comparative International Law Scholarship* prepared by Christopher McCrudden. An account of what we know about the use by domestic courts of international human rights law is identified, based on the findings in this volume and earlier work on the use of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). From that, three aspects of the domestic functions of international human rights treaties are tentatively identified as particularly significant: international human rights law is only partly internationally-directed; domestic courts very seldom appear to be acting as agents of international human rights law; and human dignity acts as an important meta-principle in the domestic use of international human rights law.

The book examines how the CRPD has been given effect and interpreted in different jurisdictions with two main interconnected aims. The first one is to investigate and compare the way in which the CRPD has been interpreted and applied by courts in different jurisdictions; the second is to investigate and deepen understanding of the CRPD's influence at the domestic level. The first of these aims situates it within the emerging field of comparative international law offering the first major contribution addressing an international human rights treaty other than the CEDAW. The second aim situates it within the field of disability law by offering the first sustained analysis of how the CRPD influences domestic court judgments.

This volume is a vital and thought-provoking addition to the literature on comparative international law and disability rights. It provides a critical insight into different ways of interpreting (or failing to interpret) CRPD provisions used by courts and it concludes that the impact of the CRPD on case law has so far been limited despite its implementation in legal systems. This groundbreaking text is the first sustained comparative international law analysis of the CRPD greatly contributing to the theory and practice of interdisciplinary disability studies. It focuses on the intersection between human rights law, disability law and international law through an examination of the role of courts, reflecting on the emerging patterns and trends in judicial usage and interpretation of the CRPD and on the wider implications for human rights theory and the nascent field of international comparative human rights law.

Specifically, it considers the transformative vision of the CRPD as a vehicle for fostering national-level disability law and policy changes. In doing so, it outlines challenges and opportunities in disability rights advocacy and human rights practice. The role of human rights in domestic law and process reflect important dimensions of international law and practice. Human rights advocates often fail to account for the potentially mutually constitutive nature of domestication processes and the transformative role that human rights treaties perform within societies. The monograph successfully proves that effective CRPD implementation must result in a human rights practice also including court-based advocacy.

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