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PROTECTION OF CHILDREN WITH DISABILITIES AS VIEWED FROM THE ASPECTS OF DIFFERENT MODELS OF DISABILITY

"States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community."
(United Nations Convention on the Rights of the Child, Article 23.1.)

Two distinct ways of conceptualising disability are the medical and social models of disability. The first one takes disability exclusively as a direct consequence of physical and mental impairment or as a problem that requires medical intervention. The second one sees disability as a socially conditioned phenomenon caused by environmental circumstances. The central theoretical assumption of this paper is that the different positions from which the relationship between impairment and disability is considered will inevitably reflect on the prevailing recognition of child protection. It is necessary to examine the protection process by evaluating several different approaches to disability because the way disability is understood affects the issues that must be addressed regarding the lives of children with disability, including finding the most appropriate way to resolve them. Following key literature, the author attempts to present previous theoretical discussions on the relationship between impairment and disability, as well as its repercussions on the child's position and protection. Starting from the former and contemporary definitions and models of disability on which they are based, the author considers differences between the disability concepts and illustrates the consequences that this could have on the position and protection of a child.

Keywords: *disability, impairment, child protection, theoretical models of disability.*

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Introduction

Contemporary international scientific discourse recognizes the multitude of active models or models in development as different approaches to the phenomenon of disability. Moreover, different conceptual models support the social perception of disability. As stated by Teodorović & Bratković (2001), there are three different models: the medical model, the deficit model and the social model. According to Mihanović (2011), these models still have a strong influence on parameter settings for persons with disabilities, including children. The models that made the greatest impact on the approaches to disability in the second half of the twentieth century are the medical and the social model (Radoman, 2004). The time period and the social circumstances of their construction and evolution were contrasting (Išpanović-Radojković, 2007; Radoman, 2004; Teodorović & Bratković, 2001).

The development of the theoretical concept of disability has its scientific, historical and socio-political dimension. Within these dimensions, over time, gradual changes have taken place. Within these changes, one can see how the theoretical concept of disability has gradually transitioned from the medical to the social model, recognizing the revolutionary transition at one point, as opposed to the medical definition and theoretical determination of the concept of disability. A critical analysis of each model, together with the abstraction of certain positive characteristics, has formulated the optimal variant of the so-called bio-psycho-social model of disability.

The central theoretical assumption of this paper is that the different positions from which the relationship between impairment and disability is considered will inevitably reflect on the prevailing recognition of child protection. It is necessary to examine the protection process by evaluating several different approaches to disability. This is important because the way disability is understood affects the issues that must be addressed regarding the lives of children with disability, including finding the most appropriate way to resolve them.

Development of theoretical models
of disability and terminology

In the nineteenth and twentieth centuries, the medical model arose from the bio-medical model of disability, which was primarily based around rehabilitation and restitution (Bury, 2001; Gough, 2005). Considered a "traditional", this model was dominant after the end of World War I, at a time when the world public was facing a large number of

war invalids. It was developed from the pragmatic needs of medical rehabilitation and retraining, and requalification of soldiers (Radoman, 2004). In this model, disability is treated as an individual's problem caused by illness, trauma or other health or physical condition that is intrinsic to that individual. In other words, a disability diagnosis is related to an individual's physical body (Fisher & Goodley, 2007). The focus is on medical treatment of the pathologized body function or organ and its normalization. The medical explanation of the dichotomy of normal and abnormal is in the centre of this model placed. Accordingly, the focus is on damage or impairment with the "defects" (impairments and/or difficulties) as the starting points, while the goals are achieved through protection, care and prevention.

However, insisting on the concept of "normal" in the non-disabled implies its opposition value in the disabled, characterizing them as "abnormal". Some critics of the medical model have commented on this issue. For example, Swain, French, Barnes, & Thomas (2013, p. 12) have noticed that when biomedicine sets reference points for what is "normal" or "acceptable" in society, then the cultural practises are directed towards the rejection and even despise of all that's "abnormal" in a given way. The authority introduces, constructs and establishes the category of "disabled" through their status of power and knowledge that their specialists have, such as doctors, state administrators and lawmakers. People with disabilities are recognized only as "different, abnormal, marked out as members of a minority group" (Hunt, 1966, as cited in Swain et al., 2013, p. 4). Therefore, the rehabilitation goal is to change that person to better fit into the social environment, that is, the established concept of "normality".

The person is the object of clinical intervention. The measures and procedures undertaken by the social services, or society, are aimed at "incapacity" and planned to reduce the consequences of the "damage" or impairment. The guiding principle used to motivate both professionals and persons with disabilities is based on the promotion of independence. If this could not be achieved, the person would be separated from the natural environment and all the opportunities that the environment could have provided and placed in the institution, most often permanently. The progress of science and medicine have made this model dominant for a long time.

During the 1970s and 1980s, the deficit model emerged as a transition between the medical and the social model. At its core, it originates from the philosophy of social integration and the normalization of persons with disabilities. This model emphasizes the importance of identifying and meeting the special needs of these individuals. It is believed that persons with disabilities have special needs. Moreover, the fulfilment of these needs

can be achieved by reducing or eliminating what hinders their social integration. Rehabilitation takes place in segregation or in the partial integration systems, aimed at reducing or eliminating difficulties in social integration.

The first indications of the social model occurred in the 1970s (Tregaskis, 2004), as the antipode to the then dominant, medical model. According to the "father" of the social model of disability, Michael Oliver, this model is an alternative interpretation to biomedical models that placed the problem in the individual with impairment (Moll & Cott, 2013). The origins of this model are based on a philosophy of inclusion that emphasizes that every person belongs to and contributes to their society. Persons with disabilities are viewed not through their limitations and difficulties, but their abilities, interests and needs, and above all, their human rights. The social model of disability explains that impairment does not restrict everyday life participation. Instead, society places physical, structural, and attitudinal barriers to full participation (Moll & Cott, 2013). Disability is seen as a socially conditioned phenomenon caused by environmental circumstances. These circumstances are disadvantageous, aggravating and put a person in a so-called handicap situation. Therefore, the basic assumption is that the position of these persons and their discrimination are socially conditioned, above all. The aim is no longer to "correct the deficit" but to completely equalize the rights of persons with disabilities with the rights of average, so-called "normal" populations. Persons with disabilities are included in all aspects of the life of the community to which they belong. In practice, this is achieved by removing all obstacles (physical barriers or prejudices) and creating conditions that equalize the opportunities for these persons to access all forms of participation in social life that any other citizen has (Teodorović & Bratković, 2001; Išpanović-Radojković, 2007). This model places each individual at the centre of the decision-making process, emphasizing an individual's rights. At the same time, the problem is placed outside that person, into society. Impairment does objectively exist and should not be ignored. Still, the impairment does not decrease the value of a person as a human being, and such an understanding is a product of the ignorance, prejudice and fears that prevail in a given environment (Mihanović, 2011).

As a result of years of consultation and field research conducted by the International Network on Disability Creation Process – INDCP (fr. Reseau International Sur le Processus de Production du Handicap – RIPPH), the conceptual framework for the Human Development Model – Disability Creation Process (HDM-DCP or DCP model) was created and developed. This model of disability is also known as the Quebec Model (Badley, 2008), the Handicap Creation Process (Whiteneck & Djikers, 2009) or the Quebec classification. Disability is here defined as the process created through the

association of risk factors, personal characteristics, environmental factors and life habits of a person. Here, life habits are introduced as a novelty. They represent activities of daily living or a role in a family or society, valued by a person or his or her sociocultural environment as significant for survival and sense of personal well-being. They are consistent with the person's age, gender and sociocultural identity, as well. Particular attention is paid to environmental factors, whether physical or social ones. In interaction with personal factors, environmental factors can significantly facilitate or hinder the fulfilment of life habits. These situations can occur in the range between complete social participation to complete non-participation or a handicap situation (Išpanović-Radojković, 2007).

According to Išpanović-Radojković (2007), the implementation of the Quebec classification in a population of children with cognitive, motor or multiple disabilities has certain advantages over the ICF classification. The main reason is its capacity to include the developmental dimension of a child. ICF, on the other hand, has proven to be applicable, reliable, and highly correlated with commonly used standard scales. Yet, the ICF classification fails to capture and consider the developmental nature of many abilities in children. On the other hand, the Quebec classification provides a more detailed elaboration of the bio-psycho-social model of disability meeting more effectively the human rights of persons with developmental disabilities. A key change in the ideology of evaluation and approach to persons with developmental disabilities is the shift from focusing on the pathology and diagnosis to the understanding of the perspective of persons with disabilities themselves and respecting their human rights (Išpanović-Radojković, 2007).

The DCP model or paradigm underlying the Quebec classification is designed to capture the dynamics of the interactive process between personal (internal) factors and environmental (external) factors. These two factors together determine the result of the performance of life habits according to a person's age, gender and socio-cultural identity. This theoretical orientation is in line with global, holistic, systematic, environmental and destigmatizing approaches to disability. Additionally, it underlines that it is important to promote optimal participation in society and to foster equality for persons with structural and/or functional differences. In that manner, this theoretical starting point is brought closer to the human rights ideology. The novelty brought by this model is the basic premise that the set of "personal factors" is larger and more comprehensive than the subsets "organ systems" (body) and "ability" (capacity). As presented, other variables of personal identity (age, gender, socio-cultural identity) need to be taken into account: first, in a situation when explaining performance on life habits, and secondly, in a situation

when considering the interaction between person and environment. The latter is especially important from a child protection perspective. The "interaction" seen as a continuous flow whose content cannot be defined is at the centre of this model, at the point of intersection of three major domains: personal factors, environmental factors and life habits. The goal of the Disability Creation Process model is to clarify those variables that determine this interactive process (Fougeyrollas, Cloutier, Bergeron, Côté, & St Michel, 1998).

The Quebec Classification is designed to be used as a whole when identifying a causal relationship or interaction between different determinants of a disability situation. Besides, it is possible to track changes and re-gather information at different points in time. Particularly, this opens up opportunities for measuring progress in achieving life habits in the rehabilitation process and for assessing long-term maintenance of acquired skills in the field of social participation. This approach allows the monitoring of the impact of changes in some of the personal factors (e.g., restoration of walking ability, improvement of behaviour) or environmental factors (e.g. a family change, availability of a new service). The changes are reflecting on the accomplishment of life habits and they are visible through the disability creation process (handicap situation). The changes can also be monitored at the level of social policies, for example, when assessing the eligibility to a program, social insurance scheme benefits, statutory protection against disability discrimination or belongingness to a target group (Fougeyrollas et al., 1998; Silvers, 2001). In other words, through this model, it is possible to observe the role of the family in the disability creation process of its disabled member in parallel to its protection because family members are an integral part of the environment or the social networks of that person.

One of the advantages of this model is the potentiality to follow the impact that the disability creation process has on the life habits of a whole family in which a child has impairments or disabilities. In this process, the protection of a child and a child's life habits cannot be implemented without affecting the life habits of the whole group, and vice versa. In such a way, the dimension of environmental factors is a key variable that enables the differentiation of personal capacities from the accomplishment in the domain of life habits. As defined, the accomplishment of life habits can be changed by personal factors, as well as by the environmental ones (Fougeyrollas et al., 1998).

The transitional period and the
international documents

The transition from the medical model to the social one, together with the influence of changes in social consciousness and the strengthening of the human rights movement after the World War II, has led to significant changes in the society's attitude towards persons with disabilities. Considerable progress in their rehabilitation can be observed in this period. Influenced by the social model and based on research conducted at the international level, the International Classification of Functioning, Disability and Health (ICF) was adopted in 2001 (WHO, 2001). One of the ideas and purposes when creating this model was to overcome the shortcomings of the previous one, the International Classification of Impairment, Disability and Handicap (ICIDH; WHO, 1980). More precisely, ICF was designed to overcome the narrow conception of ICIDH concerning the role of the environment in disability (De Kleijn-De Vrankrijker, 2003). In that way, a framework for describing and measuring health and disability was provided for this model. It is important to note that disability is viewed as a product of the interaction of a person's physical and mental state with the social and physical environment (Mihanović, 2011). Not only that the integrity of a person's bodily functions and structures is taken into account, but also a series of everyday life activities and situations is considered. Emphasis is placed on the context of a person's life and the impact of environmental factors on functioning, activities and participation, and not exclusively on the consequences of illness or impairment, as was the case in the previous version, that is, ICIDH. Still, the influence of personal factors is not specifically classified, thus representing the weakness of this classification at the same time (Išpanović-Radojković, 2007). However, since the introduction of ICF in 2001, participation has been the focus of numerous studies in the field of disability studies. Participation is considered to be evidence of changes that have been made by moving from a medical to a biopsychosocial model of disability, or various health conditions, and that it speaks in favour of the justification of the changes that began in the last decades of the twentieth century.

The adoption of the Universal Declaration of Human Rights (1948), the European Convention on Human Rights (1950), the Declaration on the Rights of Mentally Retarded Persons (1971), the Declaration on the Rights of Disabled Persons (1975) and other documents, set out the basic principle. This basic principle is the right of persons with disabilities to be involved in all aspects of the life of the community to which they belong. The consolidation and operationalization of this principle for its implementation are presented within the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Adopted by the United Nations General Assembly in 1993, it was one of the

major outcomes of the Decade of Disabled Persons at the time. According to the United Nations Convention on the Rights of the Child (1989), a disabled child has the right to a full and quality life in conditions that ensure dignity, enhance self-confidence and facilitate his or her active participation in the community. The state has a duty, following available resources, to take all necessary measures and allow each child with developmental disabilities to grow up and live with a family, which is a fundamental right of every child. The institutionalization of children is an exception to the rule and should only be applied in exceptional cases and for a limited time (Išpanović-Radojković, 2007). Further, the 2006 Convention on the Rights of Persons with Disabilities is based on the fact that despite the human rights that persons with disabilities all have theoretically, in practice they do not yet have those basic rights and fundamental freedoms of the majority of people. This need has been highlighted because persons with disabilities have long been considered "objects" of care or medical treatment rather than "holders" of all basic and guaranteed human rights (Mihanović, 2011).

Comparative considerations of child position in different models of disability

The main difference between these models is the question of causality. The medical model is based on an approach that emphasizes healing, particularly treatment, considering disability as individual pathology. On the other hand, the social model emphasizes the social cause of disability and focuses on functional consequences. The social model has evolved over the last 30 years and implies, above all, an approach based on environmental factors that shape participation in society. Furthermore, it implies a more human-centred, socio-political approach that directs awareness of discrimination against persons with disabilities. The relationship between the social and the medical model is usually presented as a contrast to one another. The medical model presents disability as an individual problem, directly caused by a disease, trauma or other compromising medical condition that can only be improved or reduced by medical intervention. However, the social model presents disability, not as an essential characteristic of the individual, but as a product of the social context and environment. This involves not only the physical structure of the environment but beliefs and prejudices that lead to discrimination against these persons, as well. By developing a social model, the goal is directed more towards the identification of situations in which persons with disabilities are, rather than at the person themselves. This conceptual approach allows the promotion of positive concepts and full recognition of different dimensions of disability. Experts of various profiles should be included. At the same time, interdisciplinary and individualized support to persons with disabilities should be based on the principles of

freedom of choice and decision making. Defining policies and strategies and including persons with disabilities are important steps in systematic actions taken to raise public awareness of disability issues. Bearing in mind that Serbia is a developing country, comprehensive research on the subject is necessary (Pešić, 2006).

As explained, the social model of disability is an environmentalist approach to disability (Radoman, 2004). It represents an expansion of disability perception towards the psychosocial factors. In addition, it leads to a better understanding of the interaction regarding persons with disabilities and persons without disabilities. As acknowledged, society is not sufficiently prepared to take the needs of people with impairments into account. When it comes to the change of society, the social model is potentially a more positive approach than the individual medical model approach. The focus shifts from isolated impairment to a social environment whose organization is not fully conducive to those persons with impairment (Tregaskis, 2004). At first, *impairment*, *disability* and *handicap* are three conceptual terms that may seem consistent and coherent. Regarding the two most influential classifications, that is, ICIDH (WHO, 1980) and ICF (WHO, 2001) three definitions can be summarized. First, an *impairment* can be defined as any loss or abnormality of a psychological, physiological, or anatomical structure or function. Next, a *disability* is defined as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Finally, a *handicap* is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual. However, seen from the perspectives of different disability models, they can be significant discrepancies among them. These differences inevitably affect the protection of children from this population. Regardless of the model considered dominant in a given scientific, professional and practical context, the fact that the first information pointing to the complex issues of disability appears in the sector of health care services, where the social aspect is often neglected (Jones, 2001). It is the social component or cultural determination of the impairment that may determine whether the impairment will undergo medical treatment. The decision on medical treatment depends on the type and level of severity of impairment, its distinctive characteristics and the cultural aspects with which that impairment might be associated (Jones, 2001).

When it comes to the importance of impairment in child protection, opinions vary in relation to the reference model of disability. Protection of a child with disabilities as viewed through the concept of impairment is, at first glance, fully sustainable and does not require re-examination. Nevertheless, three categories are debatable: constancy, a

constructive factor of disability, and exclusive medical context. In the case of the medical model, the focus on isolated impairment is its central problem, while supporters of the social model mostly consider socio-cultural factors.

Therefore, when speaking of the constancy of impairment, it implies some form of permanence and that impairment is undetachable over time (Tregaskis, 2004). The dimension of impairment in constituting a disability, however, is not viewed equally. Before-mentioned concepts may have diametrically opposite aspects. First, impairment can be understood as the cause of disability, and secondly, its importance in constituting a disability can be completely devaluated (Oliver, 1996 as cited in Tregaskis, 2004). Some authors have clarified that if an impairment is not the cause of disability, then it is the base element upon which disability is formed (Barnes, 2004). In the analysis of the child's position in the protection system, the question about the exact time of the onset of the impairment should be irrelevant. Similarly, this applies to whether the impairment is temporary or constant, as well. Both groups of impairment (temporary and permanent) should necessarily be equally represented and treated.

In summary, the visibly labelling and fatalistic nature of the medical approach to disability has led to a revolution in the perception of disability through developing a social model of disability. Representatives of the medical model of disability believe that the autonomy and self-sufficiency are the crucial elements in building a "normal" human condition and the standard by which the quality of life of the disabled is most often measured (Koch, 2001). They assume that persons with physical or cognitive impairments deal with limitations placed within themselves. As follows, restrictions occur when these persons try to engage in activities that are considered normal to the average person, further questioning both the quality and value of that life (Harris, 2000). On the other hand, some believe that independence and self-sufficiency are more a reflection of prejudice and discrimination than of reality (Nussbaum, 2011, as cited in Koch, 2001).

New tendencies in conceptualising disability

In recent decades, the family is increasingly encouraged to take an active role in health care, rehabilitation, education, social participation improving and vocational training for their child (Milićević & Klić, 2014). The idea to focus directly on barriers, which children were encountering, was introduced earlier by the social model of disability. Bearing in mind this social model thinking, the experience of "disability" occurs when a person encounters diminishing or oppressive attitudes, inaccessible environments or resource

limitations. Through such an exclusion, it can be concluded that society creates disablement, not impairment itself (Moore, 2011). Although parents and/or professionals usually identify and resolve the problems of children with disabilities, they give them little or no choice or a way for their voices to be heard. Additionally, there can be disagreement between children, their parents and different specialists. Many children are aware of the prevailing influence of biological, educational, social or cultural norms (Davis & Watson, 2000). Besides, self-reporting raises concerns that neurological or psychological dysfunctions may limit a child's ability to report accurately (Muldoon, Barger, Flory, & Manuck, 1998). On the other hand, some authors suggest that the ability of children to make choices remains unrecognised many times (Davis & Watson, 2000). Two key elements of the processes of empowerment of children with disability can be found in the literature. First, adults need to question the way they interpret the child's needs and behaviour. Secondly, children should have support to speak for themselves and the opportunity to express their views. The assumption that children with disabilities are competent to make choices about issues concerning their lives enables them to (self-) empower themselves (Davis & Watson, 2000).

Nowadays, the social model of disability is generally accepted. Yet, many authorities, state administrators, lawmakers and disability specialists still base their professional working on the conception of independence, as well as on a personal-deficit based representation of disability. A notable example is the independent living movement, which occurred during the 1970s (Swain et al., 2013). Given that "dependence" is considered "abnormal", protection of a child with disability here implies the effort invested in reducing the consequences of various functional deficits and achieving the greatest possible level of independence. Not surprisingly, as proposed in the medical model of disability, the problem lies within the person, and normality and independence in both personal and social functioning should be set as a golden standard for a child with a disability. In practical terms, functional abilities and performance are first evaluated using different assessment tools. The results are then compared with the norms or standards, usually related to gender and/or the age of that child. The previously mentioned method is sometimes referred to as "person-centred" or "personalized". The following step implies planning of treatment and providing interventions and services to reduce variations or deviations in certain areas of functioning. Thus, periodical evaluations are used to assess improvement, if or when required.

Conclusion

After the World War II, the effects of war and industrial injury slowly gave way to a growing interest in medicine in the field of health and social care disability issues, especially when it comes to the overall impact of chronic disease and impairment. This trend followed the development of specialized branches of medicine aimed at providing specialized services to chronically disabled patients, and medical research began to develop at a rapid pace (Bury, 1996). The dominant medical model of disability and the concept of normality determined the goals and orientations at the time. In the second half of the twentieth century, with the collaboration of medical professionals and sociologists, the medical and social dimensions of chronic illnesses and disabilities converged. The result was a community-oriented social-medical model. Now the focus was on the physical, psychological or anatomical impairments, as well as on the evaluation of the need for medical treatments and the current status of people with disabilities. Relying on the professional expertise of medical practitioners, prevention strategies began to be developed. During this period, the interpretative approach to an individuals' illness experiences also directed the protection of children.

However, the social model has been the dominant paradigm in scientific, theoretical, and practical considerations of disability in the past few decades. Contributions are multiple. Initially, there is a redefinition of disability concerning a disabling environment, followed by recognition of persons with disability as citizens with guaranteed human rights. The final step includes the structuralization of the environmental features focused on overcoming disabling conditions (Barnes, 2013). Undoubtedly, the main feature of this period in disability research was the social inclusion of children with disabilities and their protection in such a process. A major segment of this effort is the development and production of barrier-free infrastructures and cultures at the local, national and international levels (Barnes, 2011).

In conclusion, the medical and social models of disability are two influencing ways of conceptualising disability. View in this way, the position and protection of the child with a disability could be significantly different depending on the prevailing approach to disability. As presented, the way disability is understood affects the prevailing perception of child protection. This leaves consequences at the level of health care, protection and prevention, as well as at creating policies and strategies, day-to-day organisation of the family resources and support in children's life. The social model of disability is generally accepted. However, many authorities, state administrators, lawmakers and disability specialists still base their professional working on the conception of independence, as

well as on a personal-deficit based representation of disability. Furthermore, the empowerment movement is one of the ways found regarding foregrounding the voices of children with disability so that their aspirations to make choices about issues concerning their lives are not overlooked.

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