LEGAL PROTECTION OF CHILDREN WITH DISABILITIES

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edited by Katarzyna Roszewska

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List of Abbreviations

AAC – assistive and alternative communication

Act on the Rights of Persons with Disabilities – Act of XXVI of 1998 on the Rights of Disabled Persons and Ensuring Their Equal Opportunities

Child Protection Act – Act XXXI of 1997 on the Protection of Children

Civil Code – Act V of 2013 on the Civil Code

Civil Procedure Code – Act CXXX of 2016 on Code of Civil Procedure

CRC – UN Convention on the Rights of the Child

CRPD – Convention on the Rights of Persons with Disabilities adopted by the UN General Assembly on 13 December 2006

ETR – text easy-to-read

GenCom21 – United Nations Committee on Economic, Social and Cultural Rights, General Comment No. 21, GE.09-46922 (E) 070110

ICESCR – The International Covenant on Economic, Social and Cultural Rights

ILO – International Labour Organization

Parental Responsibility Act – Act LXII of 2021 on International Judicial Cooperation Related to Parental Responsibility

Report – Report on access to justice for children with mental disabilities – International standards and research results in ten European countries (A mentális fogyatékossággal élő gyermekek hozzáférése az igazságszolgáltatáshoz – Nemzetközi sztenderdek és kutatási eredmények tíz európai országban), MDAC Mental Disability Advocacy Center 2015. European Commission

SDGs – Sustainable Development Goals

UNICEF – the United Nations Children's Fund

Preface

According to a 2021 UNICEF report, the number of children with disabilities globally is estimated at almost 240 million. This means that every tenth person under the age of 18 has been determined to some extent to have to cope with an impairment in his or her body structure or function, or mental functioning; activity limitations and participation restrictions in normal daily activity.

Nowadays, there is no doubt that children with disabilities are human rights holders on an equal footing with others, including other children. However, children with disabilities continue to be at a disadvantage compared to children without disabilities on most measures of child well-being, the report says.

More than 80% of children with disabilities worldwide (according to UNICEF) live in developing countries with little or no access to services, not to mention that disability in these countries is caused chiefly by war, poverty, and lack of access to running water and vaccinations. Children with disability are more likely to experience abuse and multidimensional poverty than their healthy peers, and face significantly poorer health and education outcomes. Their institutionalization instead of decreasing shows continuity.

Understandably, the lack of access to goods and services as well as their possible extent or quality looks very different in developed, including EU, countries. Due to its subject and research objectives, the almost year-long Legal Protection of Children with Disabilities research within the Polish-Hungarian Research Platform project organized by the Institute of Justice in Warsaw does not consider the full context of children's disabilities worldwide or provide a general overview of their rights. From the perspective of our region, the research focused on the rights, which are particularly important to the developmental stage of a child, such as: education, family life and peer activity health and social security, access to protection institutions and the justice system in family matters.

The implementation of these rights is the responsibility of the whole society, as disability is more a result of a social interaction rather than the actual condition of the person with disability. Unfortunately, the coping mechanisms of the societies need further improvement.

The research results were presented at the International Scientific Conference: Polish-Hungarian Research Platform and Comparative Research Platform, on November 15–17, 2023, in Warsaw, in submitted articles and in this monograph.

The monograph has been divided into six independent chapters prepared by researchers from Hungary and Poland on the following topics:

I. The Rights of a Child with Disability: Principles of the United Nations Convention on the Rights of the Child.
II. The principle of accessibility in the implementation of the rights of children with disabilities.
III. Disabled Children's Right to Social Security.
IV. Social security of children with disabilities as part of the state security system of the Republic of Poland.
V. Access to health services for children with disabilities.
VI. The rights of participation of children with disabilities in cross-border family matters.

Each chapter ends with *de lege ferenda* conclusions.

We believe that the monograph will contribute to better understanding and strengthening of the rights of children with disabilities.

Katarzyna Roszewska

DR. MÁRTA BENYUSZ

Ferenc Mádl Institute of Comparative Law | DOI: 10.32041/9788367149723/1

Chapter 1. A Child-Rights Based Approach Towards Children with Disabilities. The Role of National Human Rights Institutions[1]

1.1. Introduction

In my paper *The Rights of the Child with Disability: Principles of the United Nations Convention on the Rights of the Child*[2] I wrote about the child-rights based approach towards children with disabilities and its reflections in Hungarian law. I introduced the currently available human rights protection i.e the provisions of the United Nations Convention on the Rights of the Child (hereinafter referred to as UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (hereinafter referred to as UNCRPD). I examined the four plus one principle of the UNCRC as a core element of the child rights-based approach: (i) non-discrimination, (ii) the viewpoint of the child, (iii) the best interest of the child, (iv) the right to life, survival and development, in a caring and loving family environment (as a plus one). I also went through the approach of the Committee on the Rights of the Child (hereinafter referred to as CRC Committee) to the Committee on the Rights of Persons with Disabilities (hereinafter referred to as CRPD Committee). Nevertheless, I noted and I would like to once again underline,

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[1] The research is the second part of the reasearch conducted under Polish-Hungarian Research.

[2] The paper was submitted as the first part of the reasearch conducted within the frame of the Polish-Hungarian Research Platform.

as a starting point to this paper, that the child-rights based approach is not necessarily identical with the approach of the CRC Committee or – in terms of children with disabilities – the approach of the CRC Committee read together with the remarks of the CRPD Committee. Such an approach is of course based on the widely agreed[3] and legally binding text of the UNCRC – in terms of children with disabilities read together with the UNCRPD – and also takes into account and monitors the interpretative work of the Committees and applies if it can be integrated and pasted into national measures. But the child-rights based approach on a national level may still be adequate and taking into paramount consideration the best interest of the child if it does not echo or even directly conflict with the opinion of the CRC Committee. However, in order for the approach to stay genuinely child-rights based it should never conflict with the UNCRC provisions. Besides covering the subject of the child-rights based approach, my paper highlighted the importance that lays in the national implementation of the UNCRC. This paper will pick up the thread at this point and raise the question of how the national implementation of the UNCRC and the formation of the child rights-based approach may be effectively enhanced for the benefit of children, especially children on the periphery,[4] such as children with disabilities. What is the institutional background that – in a good enough legislative environment – has the mandate and adequate power and trust of the society which provides a real chance in forming the child rights-based approach to be a standard also towards those children who suffer from some kind of disability or who are pushed onto the periphery from any other reason. I argue that specialised national human rights institutions (hereinafter referred to as NHRIs) have the chance to complete this interdisciplinary task and act as national shapers of the child rights-based approach. Nevertheless, one size does not fit all. In order to find

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[3] Except for the US, all States of the UN have ratified the UNCRC.

[4] In this context I use the expression children on the periphery for children who are in a particularly disadvantaged situation and thus need specific attention such as for instance: minority children, children in alternative care; children affected by migration/asylum seeking children; children in psychiatric care; children with disabilities; children in poverty; children with incarcerated parents.

a solution that will truly be child-friendly, it needs to be adjusted and pasted into the national legal system carefully.

1.2. NHRIs – general remarks

NHRIs are state-mandated bodies, independent of government, with a broad constitutional or legal mandate to protect and promote all human rights at the national level. As a general rule, NHRIs address the full range of human rights, including civil, political, economic, social and cultural rights. NHRIs can take various forms, such as ombudsman offices, commissions, or councils, and they operate independently of the government while being accountable to the public.

On an international level, the possible necessity of NHRIs was first raised two years before the Universal Declaration of Human Rights (hereinafter referred to as UNDHR).[5] Three decades later, in 1978, under the supervision of the Commission on Human Rights, draft guidelines were adopted on the possible role and functioning of NHRIs. In 1991, an international workshop was organised which resulted in the Paris Principles,[6] which are widely accepted to be a guiding threshold for the credibility and legitimacy of these institutions.[7] In 2005, the Commission on Human Rights strengthened[8] the importance of establishing NHRIs which are designed in line with the requirements of the Paris Principles. The Paris Principles call for the establishment of NHRIs which correspond to the requirement of a broad mandate, broad function, pluralism, independence

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[5] In 1945, the Economic and Social Council considered the issue of national institutions.

[6] Principles Relating to the Status of National Institutions. These were endorsed by the Vienna World Conference on Human Rights and the UN General Assembly in 1993, by General Assembly resolution 48/134, https://www.ohchr.org/en/instruments-mechanisms/instruments/principles-relating-status-national-institutions-paris (accessed on: 14.10.2023).

[7] National Human Rights Institutions; History; Principles; Roles and Responsibilities, p. 7.

[8] National institutions for the promotion and protection of human rights, Human Rights Resolution 2005/74.

from the government, adequate power, recourse, cooperative work and international engagement. According to the Paris Principles, the NHRIs should have a quasi-jurisdictional competence in order to play a vital role in safeguarding human rights and foster a more inclusive and just society. They serve as bridges between governments, civil society, and international human rights mechanisms, working to ensure that the principles enshrined in binding international human rights instruments are upheld at the national level. While the structure and effectiveness of NHRIs can vary from one country to another, the core principle of promoting and protecting human rights remains consistent. As a crucial component of the human rights framework, NHRIs contribute to the ongoing global effort to protect and promote the dignity and rights of all individuals. It is not necessarily enough that human rights are recognised in international and regional human rights instruments; they also need concrete responses within domestic systems to allow the treaties to function and be implemented in a local level.[9]

It is evident that children's rights are human rights and therefore are somehow protected by an NHRI of a broad mandate. Some argue that such institutions – due to their integrated nature – might more effectively protect the rights of the child. The main argument for an integrated institution is that it is needed to build on the interdependence and indivisibility of all human rights and to mainstream children's rights across all areas. A single institution is likely to foster greater communication, which can enhance the cross-fertilization of ideas and sharing of good practices, and to favour a unified approach to issues affecting all children's rights. This can also mitigate potential jurisdiction issues, where a particular problem (e.g., discrimination against a child with a disability or an indigenous individual) could fall under the scope of various specialised institutions. Yet an integrated structure alone does not guarantee a highly unified approach to human rights; there must also be

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[9] G. de Beco, *National Human Rights Institutionsin Europe*, "Human Rights Law Review" 2007, Vol. 7, No. 2, p. 331.

a willingness within the institution to undertake cross-disciplinary work.[10] However, it is not a coincidence that the UNCRC is one of the most widely accepted human rights treaties in the world targeting one particular period of a human's life. Children's rights are needed for a fruitful childhood. The vulnerability and outstanding importance of childhood in one's life justifies a specified approach and the fact that there shall be a child rights-based approach formed towards children, rights that are thoroughly and consequently applied towards all children, calls for the establishment of an institution where the specified knowledge and the resources to be active in the formation and realisation of this child rights-based approach are guaranteed. Nevertheless, if one opted for an integrated institution, it is still a necessity to appoint a deputy that would focus on the above-mentioned child rights-based approach.

1.3. The necessity of specialised NHRIs for a more effective formation of a child rights-based approach

1.3.1. INTERNATIONAL LEVEL

There is no direct reference in the UNCRC to establish NHRIs for enhancing a better and more effective implementation or monitoring of the implementation of children's rights. Article 45[11] of the UNCRC strengthens very much the role of the United Nations

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[10] UNICEF, Office of Research: Championing Children's Rights: A global study of independent human rights institutions for children – summary report, October 2012, p. 15 [hereinafter: UNICEF].

[11] a) The specialized agencies, the United Nations Children's Fund, and other United Nations organs shall be entitled to be represented at the consideration of the implementation of such provisions of the present Convention as fall within the scope of their mandate. The Committee may invite the specialised agencies, the United Nations Children's Fund and other competent bodies as it may consider appropriate to provide expert advice on the implementation of the Convention in areas falling within the scope of their respective mandates. The Committee may invite the specialised agencies, the United Nations Children's Fund, and other United Nations organs to submit reports on the implementation of the Convention in areas falling within the scope of their activities.

Children's Fund (hereinafter referred to as UNICEF) and so-called specialised agencies. Article 33[12] of the UNCRPD already mentions the important role national human rights institutions have in national implementation and obliges State Parties to "maintain. strengthen, designate or establish, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention". Nevertheless, the lack of NHRIs in the text of the UNCRC and their presence in the UNCRPD might be purely due to historical reasons. The UNCRC was adopted in 1989, and the importance of NHRIs was strengthened in the Vienna Declaration, and the Paris Principles were adopted in 1993 by the General Assembly. The necessity of a specified monitoring appears in other documents of international law[13] as well, both regarding children's rights and other human rights aspects. UN Guidelines on Alternative Care call

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b) The Committee shall transmit, as it may consider appropriate, to the specialised agencies, the United Nations Children's Fund and other competent bodies, any reports from States Parties that contain a request, or indicate a need, for technical advice or assistance, along with the Committee's observations and suggestions, if any, on these requests of indications.

c) The Committee may recommend to the General Assembly to request the Secretary-General to undertake on its behalf studies on specific issues relating to the rights of the child.

d) The Committee may make suggestions and general recommendations based on information received pursuant to Articles 44 and 45 of the present Convention. Such suggestions and general recommendations shall be transmitted."

[12] 1. States Parties, in accordance with their system of organisation, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for the protection and promotion of human rights'.

3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

[13] UNICEF, p. 8.

on States to "ensure that an independent monitoring mechanism is in place, with due consideration for the principles relating to the status of national institutions for the promotion and protection of human rights (Paris Principles). The monitoring mechanism should be easily accessible to children, parents and those responsible for children without parental care".[14] The Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment aims to "establish a system of regular visits undertaken by independent international and national bodies to places where people are deprived of their liberty, in order to prevent torture and other cruel, inhumane or degrading treatment or punishment".[15] It requires States Parties to establish one or several independent national mechanisms to prevent torture in the country and in so doing to give due consideration to the principles related to the status of national institutions mandated to promote and protect human rights.[16] UN Rules for the Protection of Juveniles Deprived of their Liberty (so-called Havana Rules) call for the appointment of independent inspectors with the power to conduct unannounced and regular inspections of facilities with unrestricted access to employees, juveniles and records, and with full guarantees of independence in the exercise of this function. They also specify that an independent office should receive and investigate complaints made by juveniles deprived of their liberty.[17] A strong and specific legal basis for establishing specialised NHRIs is Article 10[18] of the Lanzarote Convention.

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[14] UN Guidlines on Alternative Care, para. 130.

[15] Article 1 of the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.

[16] Article 17 and Article 18 of the Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment.

[17] United Nations Rules for the Protection of Juveniles Deprived of Their Liberty (Havana Rules), Adopted by General Assembly Resolution 45/113 of 14 December 1990, paras. 72 and 77.

[18] "1. Each Party shall take the necessary measures to ensure the co-ordination on a national or local level between the different agencies in charge of the protection from, the prevention of and the fight against sexual exploitation and sexual abuse of children, notably the education sector, the health sector, the social services and the law-enforcement and judicial authorities.

The CRC Committee deducts the alleged obligation of the States to establish specialised national human rights institutions from Article 4 of the UNCRC, which says that "*the state parties undertake all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention*". According to the UNCRC Committee, a comprehensive review of all domestic legislation and related administrative guidance to ensure full compliance with the UNCRC is an obligation under the Convention. The review needs to consider the Convention not only article by article, but also holistically, recognising the interdependence and indivisibility of human rights. The review needs to be continuous rather than one-off, reviewing proposed as well as existing legislation. And while it is important that this review process should be built into the machinery of all relevant government departments, it is also advantageous to have independent reviews by, for example, parliamentary committees and hearings, national human rights institutions, NGOs, academics, affected children and young people and other stakeholders.[19] The review needs to be supplemented by monitoring. Self-monitoring and evaluation is an obligation for governments, according to the UNCRC Committee, but it also regards as essential the independent monitoring of progress towards implementation by, for example, parliamentary committees, NGOs,

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2. Each Party shall take the necessary legislative or other measures to set up or designate: independent competent national or local institutions for the promotion and protection of the rights of the child, ensuring that they are provided with specific resources and responsibilities; b mechanisms for data collection or focal points, at the national or local levels and in collaboration with civil society, for the purpose of observing and evaluating the phenomenon of the sexual exploitation and sexual abuse of children, with due respect for the requirements of personal data protection.

3. Each Party shall encourage co-operation between the competent state authorities, civil society and the private sector, in order to better prevent and combat sexual exploitation and sexual abuse of children."

[19] Committee on the Rights of the Child, General Comment No. 5, General measures of the implementation of the Convention on the Rights of the Child (Art. 4, 42 and 44, para. 6), CRC/GC/2003/5 (2003), para. 18 [hereinafter: CRC/GC/2003/5].

academic institutions, professional associations, youth groups and independent human rights institutions.[20]

The CRC Committee issued a specific general comment (hereinafter referred to as NHRI's GC)[21] to direct states in establishing these institutions.

Firstly and foremostly, the NHRI's GC states that while adults and children alike need NHRIs to protect their human rights, additional justification exists for ensuring that children's human rights are given special attention.[22] The stress here also needs to be put on all children, also those children who do not only need special attention because they are children, but also because they have a condition that tends to push them to the periphery, such as their disability. The justifying reasons include the *vulnerability stemming from the developmental state*, which needs particular sensitivity in terms of children with disabilities, the fact that *their opinion is rarely taken into account*, which in terms of children with disabilities also stands out even more, and the *difficulty that they face when meeting* the judicial system; in general, their access to their rights is limited. Therefore, there should be a national human rights institution designed to protect children's rights that is constitutionally entrenched and must at least be legislatively mandated.[23] NHRIs should be accorded such powers as are necessary to enable them to discharge their mandate effectively, including the power to hear any person and obtain any information and documentation necessary for assessing the situations falling within their competence. These powers should include the promotion and protection of the rights of all children under the jurisdiction of the State party in relation not only to the State but to all relevant public and private entities. The NHRI establishment process should be consultative, inclusive and transparent, initiated and supported at the highest levels

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[20] CRC/GC/2003/5, para. 46. (See as well para. 65).

[21] Committee on the Rights of the Child, General Comment No. 2, The role of independent national human rights institutions in the promotion and protection of the rights of the child, CRC/GC/2002/2 (2002) [hereinafter: CRC/GC/2002/2].

[22] CRC/GC/2002/2, para. 5.

[23] CRC/GC/2022/2, para. 7.

of government and inclusive of all relevant elements of the State, the legislature and civil society. In order to ensure their independence and effective functioning, NHRIs must have an adequate infrastructure, funding (including specifically for children's rights, within broad-based institutions), staff, premises, and freedom from forms of financial control that might affect their independence.[24] While the CRC Committee acknowledges that this is a very sensitive issue and that State parties function with varying levels of economic resources, the Committee believes that it is the duty of States to make reasonable financial provision for the operation of national human rights institutions in light of Article 4 of the UNCRC.[25]

NHRIs must have the power to consider individual complaints and petitions and carry out investigations, including those submitted on behalf of or directly by children.[26] In order to be able to effectively carry out such investigations, they must have the powers to compel and question witnesses, access relevant documentary evidence and access places of detention. They also have a duty to seek to ensure that children have effective remedies – independent advice, advocacy and complaints procedures – for any breaches of their rights. Where appropriate, NHRIs should undertake mediation and the conciliation of complaints.[27] NHRIs should have the power to support children taking cases to court, including the power (i) to take cases concerning children's issues in the name of the NHRI and (ii) to intervene in court cases to inform the court about the human rights issues involved in the case.[28] NHRIs should be geographically and physically accessible to all children. In the spirit of Article 2 of the Convention, they should proactively reach out to all groups of children, in particular the most vulnerable and disadvantaged, such as (but not limited to) children in care or detention,

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[24] CRC/GC/2022/2, para. 10.

[25] CRC/GC/2022/2, para. 11. *In addition, the mandate and powers of national institutions may be meaningless, or the exercise of their powers limited, if the national institution does not have the means to operate effectively to discharge its powers.*

[26] CRC/GC/2022/2, para. 13.

[27] CRC/GC/2022/2, para. 13.

[28] CRC/GC/2022/2, para. 14.

children from minority and indigenous groups, *children with disabilities*, children living in poverty, refugee and migrant children, street children and children with special needs in areas such as culture, language, health and education.[29] NHRI legislation should include the right of the institution to have access in conditions of privacy to children in all forms of alternative care and to all institutions that include children. Specialised NHRIs have the capacity to make children, their rights and their best interests, more visible. Standalone institutions, focusing on children's rights, have a chance to make the recognition of children as rights-holders more tangible and make a step forward towards accessibility and genuine participation. If human, material and financial resources are guaranteed adequately, specialised NHRIs have the biggest chance to reach children and involve them in their work, so that their needs can be addressed directly. This opens also a possibility to design these institutions as being accessible to all children, also to those who live with some kind of disability, which is a very accurate and key question in terms of the realisation of their rights. Nevertheless, research shows that children are many times unaware of the existence of the institution[30] and of the possibility to file a complaint or raise their voices. How accessibility can be enhanced should be also a question on the national level, as it needs to take into account the specificities of the local circumstances[31] and the group of children concerned. However, there are indeed some characteristics that may be considered when working on the accessibility of these institutions such as proactivity, age-appropriate outreach, and child (for children with disability as well)- accessible mechanisms that enable children to reach the institution using their own initiative. *Awareness raising* is also an important element of the accessibility, which is interconnected with Article 42 of the UNCRC that underlines the role of the state to make the principles and provisions

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[29] CRC/GC/2022/2, para. 15.

[30] UNICEF, Office of Research: Championing Children's Rights: A global study of independent human rights institutions for children – summary report, October 2012, p. 15.

[31] It is more than the issue of location, although this is part of it.

of the UNCRC widely known, by appropriate and active means, to adults and children alike. *Geographical accessibility* is also essential, which can be enhanced by establishing branches. Being accessible to children with disabilities makes an institution's advocacy efforts on behalf of children with disabilities credible and legitimate. Information relating to the physical accessibility of institutions to children with disabilities is generally lacking. The ability of independent human rights institutions for children to communicate with those who have cognitive disabilities remains, however, little explored.[32]

Independent human rights institutions for children have an opportunity to take an important role in advocating policies that aim to correct the disadvantages experienced by some children (e.g. as a result of disability) and address the matter of exclusion.[33]

1.3.2. NATIONAL LEVEL

Some countries (e.g. Norway, Italy (Veneto region), Costa Rica) had an NHRI specified in the protection of children before the adoption of the UNCRC. Nevertheless, the adoption of the convention as well as the NHRIs GC and the general comment on the measures of implementation accelerated the process of the establishment of further such institutions.[34] In the beginning the Norwegian example served as a role model. However, for today there are NHRIs that have much wider competences (e.g. Poland, Germany). Currently, among the Member States of the European Union Belgium, Croatia, Cyprus, Denmark, Estonia, Finland, France, Greece, Italy, Ireland, Lithuania, Luxembourg, Malta, Norway, Poland, Slovakia, Slovenia, Spain, Sweden and the Netherlands have a specialised NHRI in children's rights.[35]

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[32] UNICEF, p. 22.

[33] Ibidem, p. 11.

[34] Ibidem, p. 8.

[35] Some of them working as a deputy ombudsperson of an integrated institution.

1.3.3. NATIONAL LEVEL – HUNGARY

The role of NHRIs, that is established and is operating in line with the Paris Principles, is taken by the Office of the Commissioner for Fundamental Rights (*Alapvető Jogok Biztosának Hivatala*) in Hungary. There is no specialised NHRI or any other type of authority that would have the competence to deal with the rights of the child. If we look at the organisational map of the Office, we see that there is one Department that deals with equality issues and children's rights together, and a sub-department that concentrates on children's rights. This is a small department which only from a human resources perspective has no competence to deal with breaches of children's rights in the whole country.

In order to make it visible how a specialised NHRI differs from an NHRI that has a broad competence as regards protecting human rights (incl. children's rights), I made a comparison between the Hungarian NHRI, i.e. the Commissioner for Fundamental Rights (hereinafter for the sake of comparison referred to as HU NHRI) and the Polish NHRI specialised in children's rights (*Rzecznik Praw Dziecka*) (hereinafter for the sake of comparison referred to as PL NHRI). The scope of this comparison is purely based on the regulatory background and did not go into investigating the actual practise of these two institutions. Nevertheless, if one solely examines the legislative provisions, one may already draw conclusions and argue:

> that a specialised NHRI has a bigger chance to protect and represent the rights of children and to make children on the periphery such as children with disabilities more visible.

The biggest difference between the two institutions – as already mentioned – is that while the Polish NHRI was designed especially to protect the rights of the child, the HU NHRI is a general human rights institution which has an equivalent in the Polish legal system (*Rzecznik Praw Obywatelskich*).

Both institutions have a mandate given by the constitution. The legal basis of the HU NHRI may be found in Article 30. of the Fundamental Law. The provisions of the Fundamental Law are purely general provisions as Article 30 says that:

> (1) The Commissioner for Fundamental Rights shall perform fundamental rights protection activities; his or her procedures may be initiated by anyone.
>
> (2) The Commissioner for Fundamental Rights shall investigate any violations related to fundamental rights that come to his or her knowledge, or have such violations investigated, and shall initiate general or specific measures to remedy them.
>
> (3) The Commissioner for Fundamental Rights and his or her deputies shall be elected for six years with the votes of two thirds of the Members of the National Assembly. The deputies shall protect the interests of future generations and the rights of national minorities living in Hungary. The Commissioner for Fundamental Rights and his or her deputies may not be members of political parties or engage in political activities.
>
> (4) The Commissioner for Fundamental Rights shall give an account annually to the National Assembly of his or her activities.
>
> (5) The detailed rules for the Commissioner for Fundamental Rights and his or her deputies shall be laid down in an Act.

One might see that these are general provisions, and that on the constitutional level there is no reference to children's rights or disability rights in connection with the HU NHRI.

The provisions determining the rights of the child and the protection of children are in Article XV[36] and XVI[37] of the Fundamental Law. There is no direct reference to the views of children, so on the constitutional level there is a caring-model in place towards children rather than a rights-based approach.

The legal basis of the PL NHRI is laid down in Article 72 of the Polish Constitution. It declares the constitutional framework of the protection of the rights of the child as well and says that:

> (1) The Republic of Poland shall ensure the protection of children's rights. Everyone has the right to demand that public authorities protect children against violence, cruelty, exploitation and demoralisation.
>
> (2) A child deprived of parental care has the right to the care and assistance of public authorities.
>
> (3) In the course of determining the rights of the child, public authorities and persons responsible for the child are obliged to listen to and, if possible, take into account the child's opinion.
>
> (4) The Act specifies the competences and method of appointing the Ombudsman for Children.

Besides a clear legal basis on establishing an "Ombudsman for Children", the constitution also encompasses a direct reference to

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[36] "*(5) Hungary protects families, children, women, the elderly and the disabled with special measures.*"

[37] "*(1) All children have the right to the protection and care necessary for their proper physical, mental and moral development. Hungary protects children's right to self-identity according to their birth sex, and ensures education according to the value system based on our country's constitutional self-identity and Christian culture.*

(2) Parents have the right to choose their child's education.

(3) Parents are obliged to take care of their minor children. This obligation includes teaching their child.

(4) Adult children are obliged to take care of their parents in need."

the child's view, clearly stipulating that the child is a subject and not an object of the protection and is indeed a rights bearer.

The detailed legislative background of the HU NHRI is laid down in Act CXI of 2011 on the Commissioner of Fundamental Rights. Article 1 of the Office of the Commissioner for Fundamental Rights says that the rights of the child should have special attention. Besides this provision, there is no reference to children's rights.

The detailed legislative background of the PL NHRI is laid down in the Act of 6 January 2000 on the Ombudsman for the Rights of the Child.[38] It is an act of 21 articles and lays down the task and competences of the PL NHRIs.

Further on in my comparison I investigated (i) the subject scope of each NHRI, i.e. what is the definition of children whose rights are protected, (ii) is there any special provision that refers to children with disabilities, (iii) what kind of membership does the institution have in the European Network of Ombudspersons for Children (hereinafter referred to as ENOC),[39] (iv) does it participate in international monitoring actively, (v) what are the tasks and competences of the given institution, with special attention on the accessibility to children, and (vi) whether there are public campaigns initiated by the institution.

(i) *Definition of the child*

Article 2 of the Act on PL NHRI defines the child as every human being from their conception till their age of majority. Majority is attained either on the 18th birthday, or earlier at the age of 16 by marriage. The Act on the HU NHRI has no definition. The Hungarian legal system protects the foetus, but it does not give the status of the child to it in any piece of legislation.[40] Legal capacity is obtained by being

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[38] Act of 6 January 2000 on the Ombudsman for the Rights of the Children, Journal of Laws of 2023, item 296, consolidated text.

[39] https://enoc.eu/ (accessed on: 14.10.2023).

[40] As mentioned in my previous paper, the Act on Healthcare in Article 185 provides a possibility to terminate the pregnancy until the 24th week on potential disability grounds which – among other reasons – is stemming from this different definition of the child.

born alive from the moment of conception, the foetus has a conditional legal capacity. The end of the period of childhood,[41] in line with the UNCRC is in general on the 18th birthday of the child, or similarly to the Polish law at the age of 16 by marriage.

(ii) *Special reference to children with disabilities*

Article 3 paragraph 4 of the Act on PL NHRI makes special reference to children with disabilities and declares that the PL NHRI operates with a special care and aid to children with disabilities. There is no reference to children with disabilities in the Act on HU NHRI. The CRPD is separately mentioned, and the HU NHRI is appointed as the institution being responsible to accomplish the task given by Article 33 paragraph 2 of the UNCRPD. This task is detailed in chapter III/D.

(iii) *Membership of ENOC*

The PL NHRI has a full membership with the ENOC, while the HU NHRI has an associate membership. The PL NHRI is part of the European Network of Young Advisors (hereinafter referred to as ENYA)[42] while the HU NHRI is not.

(iv) *Participation in international monitoring*

The PL NHRI is actively involved in international monitoring and in the dialogue with the UNCRC Committee, while the HU NHRI does not undertake this task.

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[41] The UNCRC does not define the beginning of childhood. It is up to each state party to determine it.

[42] The purpose of the ENYA project is to actively involve children and young people in ENOC's annual work and to give them the opportunity to be heard at a level that exceeds their country's boundaries, at a European level. ENYA aims to ensure a meaningful and effective participation of young people by giving them a say on specific topics.

(v) *Tasks and competences of the NHRIs*

The Act on PL NHRIs in Article 3 defines the tasks of the institution as follows. The PL NHRI takes action to ensure the child's full and harmonious development, respecting his or her dignity and subjectivity. It works to protect children's rights, in particular (i) the right to protection of life and health; (ii) the right to be raised in the family; (iii) the right to decent social conditions; (iv) the right to education. The PL NHRI takes action to protect the child against violence, cruelty, exploitation, demoralisation, neglect and other ill-treatment. It provides special care and assistance to disabled children – as already referred to above – and promotes children's rights and methods of their protection.

The HU NHRI has no specific tasks as to the rights of the child. Article 1 paragraph 2 underlines that the HU NHRI pays special attention in the course of its activities, especially when conducting *ex officio* proceedings to (i) children's rights and (ii) the most endangered groups of the society.

As to the competences, both the PL NHRI and the HU NHRI has the competence to handle individual complaints, to initiate an inquiry *ex officio*, to turn to the constitutional court, and to review draft laws. The PL NHRI has the competence to intervene in judicial proceedings, and morever it can request the annulment of a final judgment.

(vi) *Involvement in public campaign*

If we browse on the site of the HU NHRI, we find almost no documents that would deal with the rights of children on the periphery. The website of the PL NHRI is child-friendly; nevertheless, the website of the HU NHRI is not truly accessible for a child, not mentioning children on the periphery. There are no such questions taken into account as whether the setting is accessible to children with disabilities, whether there are specific measures in place for children with communication difficulties (children with disabilities, young children, children who do not speak the national language, children who have suffered trauma, among others) to be heard? Due to the fact that disability is rather a social concept than a real "problem" stemming merely from the impairment of the given individual,[43] missing out on public campaigns is a missed opportunity to mitigate social barriers between healthy children and children with disabilities.

1.4. Closing remarks and *de lege ferenda* proposals

Local organisations are responsive to community interests and values, while still remaining open, inclusive and sensitive.[44] They have a real chance in the formation of a child rights-based approach towards all children. Nevertheless, in Hungary there is clearly a lack of the capacity for such a shaping activity to be performed. The same problem arises with the actual child rights' protection or monitoring activity.

Therefore, there is a need for establishing a specialised national human rights institution which is clearly authorised to protect children in accordance with Articles L), II., XV., XVI., XVIII. of the Fundamental Law, as well as in accordance with the effective child protection and child rights regulations, and for adopting a separate law that would provide appropriate mandates and competences for this to be performed. The children's rights ombudsman created independently would be elected by the parliament, and filled with a human resource that has an outstanding expertise in the field of children's rights. Each group of children would need and have

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[43] The social model of disability recognises that disability is rather a social construct and therefore the discrimination against persons with disability stemms not from the impairment but from the attitude of the society. This is backed up by the CRPD Commission in its General Comment No. 6 (2018) on equality and nondiscrimination in para. 7: "*The human rights model of disability recognises that disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights. It acknowledges that disability is one of several layers of identity. Hence, disability laws and policies must take the diversity of persons with disabilities into account.*"

[44] S. Swimelar, *Human Rights Matters: Local Politics and National Human Rights Institutions*, "Human Rights Quarterly" 2009, Vol. 31, No. 3, p. 830.

separate attention. The separate law on the ombudsman would, among other things:

- strengthen the international role of the children's rights commissioner, especially during the preparation of the report to the UN Committee on the Rights of the Child,
- it would lead an active legal clinic to help remedy violations of children's rights,
- it would be authorised to work together with state and with church-run public education institutions in the field of child protection,
- it would also be authorised to take action against institutions and private entities if they carry out activities contrary to the Fundamental Law or the UNCRC,
- it would have a competence to interfere in judicial proceedings, even to challenge a final judgement,
- it would have a clear mandate to pay special attention to children with disabilities,
- it would have a clear mandate to engage in public campaigns.

As to the concrete textual changes, the recommendation goes for changing the text of Article XVI of the Fundamental Law, which is a fundamental legal base for the protection of children's rights in national law. The recommended changes would strengthen the protection of the rights of the child as well as provide a legal basis for the establishment of an NHRI in a form of a child rights commissioner. As argued before, the establishment of such an institution would provide a greatly added value to the institutional protection of the rights of the child.

The text of Article XVI of the Fundamental Law is currently the following:

1. Every child shall have the right to the protection and care necessary for his or her proper physical, mental and moral development. Hungary shall protect the right of children to a self identity corresponding to their sex at birth and shall ensure an upbringing for them that is in accordance with the values based on the constitutional identity and Christian culture of our country.

2. Parents shall have the right to choose the upbringing to be given to their children.
3. Parents shall be obliged to take care of their minor children. This obligation shall include the provision of schooling for their children.
4. Adult children shall be obliged to take care of their parents if they are in need.

The recommendation is to complete Article XVI as follows:

1. Hungary protects the best interests of the child. All children have the right to the protection and care necessary for their proper physical, mental and moral development. Hungary protects children's right to self-identity according to their birth sex, and ensures education according to the value system based on our country's constitutional self-identity and Christian culture.
2. Parents shall have the right to choose the upbringing to be given to their children.
3. Parents are obliged to take care of their minor children. This obligation includes teaching their child. In the absence of parental care, children have the right to substitute protection from the state.
4. When determining the rights of a child, public authorities and persons responsible for the child are obliged to listen to the child's opinion and, if possible, take it into account.
5. Adult children are obliged to take care of their parents in need.
6. The Children's Rights Commissioner is elected by the votes of two thirds of the Members of the National Assembly present and is responsible for the protection of children's rights within the framework of the Fundamental Law of Hungary and its obligations under international law. The activities of the Children's Rights Commissioner are regulated by Articles L), II., XV., XVI., XVIII. of the Fundamental Law.
7. The activities of the Children's Rights Commissioner are established by a separate law.

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Chapter 2. Access to Education for Children with Disabilities – Analysis of the Legal Basis

2.1. Introduction

Education is a value in its own right and an instrument of social change, understanding the world, self-direction, and participation in the life of human communities. It serves the achievement of social goals and the realisation of society's needs.[1] School, on the other hand, is the place where a child not only acquires knowledge, but also socialises, learns attitudes and social competences, and establishes peer relationships. Therefore, the educational process cannot take place in isolation.[2] Inclusive education is not only a desirable goal, but also a legal requirement. The present publication undertakes an analysis of the legal regulations that make this goal a reality or those that hinder its realisation. Due to the limitations of the study, the considerations focus on Polish law and only refer to the international standard by which Poland is bound to a narrow extent.

The right to education in Polish law has a solid legal basis in the Constitution of the Republic of Poland of 2nd April 1997[3] by itself; which distinguishes it from the other provisions of Chapter II of the act.

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[1] R. Raszewska-Skałecka, *Edukacja osób niepełnosprawnych jako dobro wspólne na tle rozważań administracyjnoprawnych*, "Acta Universitatis Wratislaviensis" 2016, nr 3725, pp. 124–125.

[2] Government Programme Accessibility Plus 2018–2025, adopted by Resolution of the Council of Ministers No. 102/2018 of 17 July 2018, p. 30.

[3] Journal of Laws of 1997, No. 78, item 483, as amended.

Article 70 of the Constitution establishes successively the right to education, the compulsory education of children, free education in public schools, with the exception of higher education, the absence of a monopoly of public schools, parental freedom in the choice of school, as well as the universal and equal access to education and, finally, the autonomy of higher education institutions. Furthermore, the provision stipulates certain guarantees for the exercise of this right. A separate regulation is devoted to freedom of scientific research (Article 73 of the Constitution).

The Constitution uses the expression "right to learn" (Pl. *prawo do nauki*), which linguistically appears to be a narrower concept than the right to education in international regulations. UNESCO defines the term "education" as the entire process of social life by means of which individuals and social groups learn to develop consciously within, and for the benefit of, the national and international communities, the whole of their personal capacities, attitudes, aptitudes, and knowledge. This process is not limited to any specific activities.[4] Yet the English version of the Constitution available on the Sejm website contains the term "right to education".[5] And the scope of the Polish Constitution, in principle, covers the elements that make up the international standard of the right to education arising from the International Covenant on Economic, Social and Cultural Rights (1966)[6] and the Convention on the Rights of the Child (1989)[7], hereinafter referred to as CRC.

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[4] Recommendation concerning Education for International Understanding, Co-operation and Peace and Education relating to Human Rights and Fundamental Freedoms, UNESCO General Conference, 19th November 1974, https://www.refworld.org/legal/resolution/unesco/1974/en/18786 (accessed on: 12.10.2023).

[5] https://www.sejm.gov.pl/prawo/konst/angielski/kon1.htm (accessed on: 11.10.2023).

[6] Journal of Laws of 1977, No. 38, item 169.

[7] Journal of Laws of 1991, No. 120, item 526.

2.2. The Nature of the Right to Education

The right to education belongs to the second generation of human rights. However, there is no consensus as to the category of broad social rights to which it belongs.[8] It has been pointed out in Polish subject literature that it is a central cultural right, as cultural rights are considered to give rise to the rights of the individual that enable them to achieve adequate intellectual development.[9] Indeed, international law broadly defines the aims of education as not so much the mere acquisition of knowledge as the full development of personality. This does not mean, however, that it equates the right to education with the right to culture. At other times, the right to education is combined with economic[10] or social[11] rights. Finally, it is argued that the category of economic, social, and cultural rights and freedoms is often treated as a whole and referred to as social or societal rights, albeit understood not so much as rights to benefits, but as rights related to the whole of the human social condition.[12] The right to education therefore appears to have economic, cultural, and social dimensions at the same time.

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[8] B. Zawadzka, *Prawa ekonomiczne, socjalne i kulturalne*, Warszawa 1996, p. 8.

[9] J. Mikosz, *Prawo do nauki*, [in:] R. Wieruszewski (red.), *Prawa człowieka. Model prawny*, Wrocław–Kraków–Warszawa, 1991, p. 979; B. Banaszak, *Konstytucja Rzeczypospolitej Polskiej. Komentarz*, Warszawa 2012, p. 415; M. Jabłoński, S. Jarosz-Żukowska, *Prawa człowieka i systemy ich ochrony. Zarys wykładu*, Wrocław 2004, pp. 54, 114; M. Drejs, *Prawo do nauki*, [in:] T. Jasudowicz (red.), *Polska wobec europejskich standardów praw człowieka*, Toruń 2001, p. 194; S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki i jego gwarancje*, [in:] A. Bisztyga, M. Jabłoński (red.), *Realizacja i ochrona konstytucyjnych wolności i praw jednostki w polskim porządku prawnym*, Wrocław 2014, p. 637.

[10] M. Jabłoński, S. Jarosz-Żukowska, *Prawo konstytucyjne w formie pytań i odpowiedzi*, Wrocław 2003, p. 227; A. Grzejdziak-Przybyłowicz, *Prawo do nauki. Prawa dziecka-ucznia*, "Studia Prawa Publicznego" 2017, nr 4(20), p. 106.

[11] L. Garlicki, *Prawa socjalne w orzecznictwie TK*, "Przegląd Sejmowy" 1995, nr 2, p. 56 on the basis of the provisions of the Constitution of the Polish People's Republic that remained in force; J. Oniszczuk, *Problemy realizacji wolności i praw socjalnych gwarantowanych Konstytucji RP*, [in:] L. Wiśniewski (red.), *Wolności i prawa jednostki oraz ich gwarancje w praktyce*, Warszawa 2006, pp. 199–201.

[12] B. Zawadzka, *Prawa ekonomiczne...*, *op. cit.*, p. 8.

Moreover, the status of Article 70 is analysed in terms of a subjective right and a programmatic norm. The problem with determining the nature of the rules arising from the expansive content of Article 70 of the Constitution has been faced by the Constitutional Tribunal (TK) itself. For example, it has taken contradictory positions as to the nature of the content of Article 70(4). On one occasion, it ruled that no subjective right was granted, and treated the provision as addressed to the ordinary legislature, ordering it to pass a specific law.[13] At another time, it did derive a subjective right from the provision, which it identified as the right to obtain financial assistance from the public authorities to the extent that universal and equal access to education is guaranteed.[14] However, even in this interpretation, the TK pointed to the complex normative character of Article 70, which in fact contains both a subjective right – universal and equal access to education (Article 70(4) sentence 1) – as well as the state's numerous tasks in the field of education, which however give the individual no claim to their enforcement.[15] This view is similar to the position that Article 70(4) is a programmatic or guarantee provision *vis-à-vis* the general right to education (Article 70(1)), but also a source of a more specific subjective right – the right to equal access to mechanisms for the state to equalise educational opportunities. Also worth noting is the view expressed in the dissenting opinion to the judgment of 02/07/2002 (U 7/01) by Justice M. Mazurkiewicz, who argued that the content of Article 70(4) precludes the possibility of treating it solely as a competence rule. The provision should be regarded as a normative basis for decoding the rights of the subjects mentioned therein in terms of state aid. In its light, it is also legitimate to assess the provisions of the laws

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[13] Judgment of the Constitutional Tribunal of 02 July 2002, U 7/01, OTK-A 2002, No. 4, item 48, with six dissenting opinions. See also judgment of the Constitutional Tribunal of 13 November 2007, P 42/06, OTK-A 2007, No. 10, item 123.

[14] Judgments of the Constitutional Tribunal of 26 April 2004, K 50/02, OTK-A 2004, No. 4, item 32, and of 16/01/2007, U 5/06, OTK-A 2007, No. 1, item 3. See also B. Banaszak, *Konstytucja…*, *op. cit.*, p. 421.

[15] Judgment of the Constitutional Tribunal of 16 January 2007, U 5/06, OTK-A 2007, No. 1, item 3.

and executive acts that concern the sphere of these rights as well as the scope and completeness of the statutory regulation.[16]

The provision is undoubtedly extensive. In the process of its interpretation, it is necessary not so much to look for the uniform character of the entire normative content of Article 70, but rather to determine which of its provisions give rise to freedom of education, which create a subjective right of an individual (citizen), and which establish certain obligations on the part of the public authority.[17] It is generally agreed that we can derive a subjective right to education,[18] sometimes also referred to as a "subjective positive right from which arises the right to demand a benefit from the state, i.e. free access to education",[19] including constitutional guarantees of its realisation, under Article 70 of the Constitution. It is accompanied by other provisions in the nature of civic duty and civic liberty, and even certain elements of the political system (in this case, Poland's educational system).[20] Alternatively, it may be understood in broad terms together with the guarantees which serve its realisation. Then, the universal and equal access to education is treated as a necessary element of the "right to education". [...], which means that their realisation may be claimed also by means of a constitutional complaint.[21]

For pupils with disabilities, the strong argumentation in favour of an extended subjective right with specific positive obligations on the part of the public authorities is good news. It strengthens their

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[16] Dissenting opinion of TK Justice M. Mazurkiewicz on judgment of the Constitutional Tribunal of 02 July 2002, U 7/01, OTK-A 2002, No. 4, item 48.

[17] Cf. S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki...*, *op. cit.*, p. 639.

[18] A. Grzejdziak-Przybyłowicz, *Prawo do nauki. Prawa dziecka-ucznia*, "Studia Prawa Publicznego" 2017, nr 4(20), p. 106; L. Garlicki, M. Derlatka, [in:] L. Garlicki, M. Zubik (red.), *Konstytucja Rzeczypospolitej Polskiej. Komentarz II, Art. 30–86*, Warszawa 2016, p. 748; H. Zięba-Załucka, [in:] W. Skrzydło, S. Grabowska, R. Grabowski (red.), *Konstytucja Rzeczypospolitej Polskiej. Komentarz encyklopedyczny*, Warszawa 2009, entry "Prawo do Nauki", p. 390.

[19] H. Zięba-Załucka, [in:] W. Skrzydło, S. Grabowska, R. Grabowski (red.), *Konstytucja...*, *op. cit.*, p. 390; P. Bała, *Konstytucyjne prawo do nauki do nauki a polski system oświaty*, Warszawa 2009, p. 233.

[20] L. Garlicki, M. Derlatka, [in:] *Konstytucja...*, *op. cit.*, pp. 748 and 762.

[21] Ibidem, pp. 751 and 755.

position as subjects to the right to education. However, it should be noted at this point that the Constitution lists the duties of the public authorities without dividing the competences between the central and the local government, resulting in disputes about the scope of the tasks of the latter (discussed further on).

Finally, the right to education "must be seen both in terms of an individual good and value as well as an important fundamental social good. The realisation of the right to education is not so much some special privilege of the modern human as it is an indispensable condition for the development of society and, at the same time, for the full participation of the individual in society".[22] The power of the constitutional right to education to affect the rights of pupils with disabilities has its limitations due to the historical period in which the Constitution was adopted. Having stated that, not Nevertheless, not even the reticence of the authors of the Constitution to make social commitments without coverage impacted on it. Unlike many other provisions in Chapter II of the Constitution, Article 70 guarantees an extensive right to education to the public at large. This is probably because the right to education at the drafting stage of the Constitution was treated more as a freedom and personal right than as a social right.[23] In contrast, the human rights model of the time in the field of the rights of persons with disabilities was at a completely different developmental stage. Back in the 1990s, the new paradigm of the rights of persons with disabilities was just evolving from the medical model.

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[22] Judgment of the Constitutional Tribunal of 08 November 2000, SK 18/99, OTK-A 2000, No. 7, item 258.

[23] W. Borysiak, M. Królikowski, K. Szczucki, *Comment to Article 70, section II*, [in:] M. Safjan, L. Bosek (red.), *Konstytucja RP. Komentarz. Art. 1–86*, t. 1, Warszawa 2016, an electronic edition.

2.3. The Place of the Right to Education in Polish Law

The Constitution did not adopt the model of treating human rights collectively – as the Vienna Declaration (1993)[24] proclaimed – and instead divided them into lists of personal, political, as well as economic, social and cultural rights and freedoms. Yet they are all included in Chapter II of the Constitution entitled "The Freedoms, Rights, and Obligations of Persons and Citizens". The right to education is included in the list of economic, social, and cultural rights and freedoms. When interpreting it on the basis of the Polish basic law, it is suggested to read it in conjunction with other rights, in particular: Article 25(2) (impartiality of the authorities, including the public school, in religious and philosophical matters); Article 53(3) (the right of parents to ensure their children's moral and religious upbringing and teaching in accordance with their beliefs); Article 53(4) (permissibility of religion in public schools); Article 73 (freedom of education, enjoyment of cultural goods); Article 33 (ensuring access to education regardless of gender); Article 35(2) (right to education exercised by national and ethnic minorities); Article 73 (freedom of teaching and scientific research); Article 32 (implementation of the general principle of equality); and Article 48 (right to education in conformity with convictions).[25]

At the same time, this right is regulated in the Constitution more broadly and precisely than other social rights, and so the substantive freedom to set restrictions is narrowed down.[26]

In the context of the place of regulation of the right to education, it is also worth pointing out that the education of children

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[24] Adopted by the World Conference on Human Rights in Vienna of 25 June 1993, A/CONF.157/23.

[25] L. Garlicki, M. Derlatka, *Art. 70*, [in:] *Konstytucja..., op. cit.*, p. 748; W. Borysiak, M. Królikowski, K. Szczucki, *Comment to Article 70, section IV*, [in:] *Konstytucja RP..., op. cit.*; M. Florczak-Wątor, *Comment to Article 72, remark 2*, [in:] P. Tuleja (red.), *Konstytucja Rzeczypospolitej Polskiej. Komentarz*, Warszawa 2019; the same opinion is presented by M. Zaborniak-Sobczak, *Konstytucyjne prawo do nauki uczniów z niepełnosprawnością i jego realizacja w systemie szkolnictwa ogólnodostępnego*, "Przegląd Prawa Konstytucyjnego" 2022, nr 5(69), pp. 304–305.

[26] L. Garlicki, M. Derlatka, [in:] *Konstytucja..., op. cit.*, pp. 749–750.

with disabilities is regulated by statutory provisions concerning the general education system, in contrast to the employment of persons with disabilities, which is not covered in the Labour Code (1974).[27] It is only at the level of implementing provisions that regulations dedicated to pupils with special educational needs appear. The mainstream positioning of the education of pupils with disabilities is a value in itself. It contributes to the legal awareness of the rights of these pupils. It influences the awareness of their special needs among organisers, professionals, and participants in the education system.

2.4. The Content of the Right to Education

The **right to education** is a universal right, granted to everyone without exception, understood as the possibility to acquire knowledge (education) carried out in organised forms, on a regular and continuous basis, covering specific areas of knowledge (basic knowledge enabling the acquisition of specialised knowledge leading to a diploma, as well as the continuation and deepening of education)[28] in all its forms.[29] As a right, it involves the state providing unrestricted access to education,[30] consisting in the use of the educational services of educational institutions.[31] It is also defined in a strict sense – as the right to learn (to receive education) – and in a broader sense – as the right to benefit from educational

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[27] Act of 26 June 1974 Labour Code, Journal of Laws of 2023, item 1465, as amended, consolidated text. See on this subject K. Roszewska, *Aksjologiczne podstawy unormowania zatrudnienia pracowniczego osób z niepełnosprawnościami w kodeksie pracy*, "Praca i Zabezpieczenie Społeczne" 2014, nr 12, pp. 10–11.

[28] J. Mikosz, *Prawo do nauki…*, *op. cit.*, p. 983; H. Zięba-Załucka, [in:] W. Skrzydło, S. Grabowska, R. Grabowski (red.), *Konstytucja Rzeczypospolitej Polskiej. Komentarz encyklopedyczny*, Warszawa 2009, entry "Prawo do nauki", pp. 390–391; L. Garlicki, M. Derlatka, *Art. 70*, [in:] *Konstytucja…*, *op. cit.*, p. 221.

[29] J. Mikosz, *Prawo do nauki…*, *op. cit.*, p. 979.

[30] P. Bała, *Konstytucyjne prawo do nauki…*, *op. cit.*, p. 229.

[31] W. Borysiak, M. Królikowski, K. Szczucki, *Comment to Article 70, section I*, [in:] *Konstytucja RP…*, *op. cit.*

opportunities in all their forms (right to education).[32] The right to education, broadly defined in Article 70, also refers to the pursuit of tertiary education, which is not the subject of the analysis, as it is limited only to the right to education of children.

The right to education is granted to everyone regardless of their health status.[33] There is no doubt that Article 70 applies to children with disabilities to the full extent, as well.

For the implementation of this right in the education system, however, a separate system of certifying special educational needs by public psychological and educational counselling centres is in place. It is a certification system independent of the disability certification system implemented by the district disability certification teams. The following categories of pupils with disabilities are eligible to apply for a certificate of the need for special education: those who are deaf, hard of hearing, blind, visually impaired, with motor disabilities including aphasia, with mild, moderate, or severe intellectual disabilities, with autism, including Asperger's syndrome, and with multiple disabilities. The certificate contains recommendations for specific forms of support for the pupil with a disability. This means that the parents need to apply for such a certificate, irrespective of the child's disability certificate, which is used to obtain other rights. The multitude of certification systems is subject to criticism.[34] It requires that documentation as well as medical and other specialist opinions be collected separately. While the psychological and educational counselling centres issue certificates for the period of the educational stage, the district teams issue disability certificates for very short periods even in cases that do not show improvement (every one or two years). Separate and frequent certification procedures necessary to exercise, among other things, the child's right

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[32] J. Mikosz, *Prawo do nauki…*, *op. cit.*, p. 979; P. Bała, *Konstytucyjne prawo do nauki…*, *op. cit.*, p. 237; P. Winczorek, *Komentarz do Konstytucji Rzeczypospolitej Polskiej z dnia 2 kwietnia 1997 r.*, Warszawa 2008, p. 166.

[33] A. Grzejdziak-Przybyłowicz, *Prawo do nauki…*, *op. cit.*, pp. 106–107.

[34] Another certification system covers the incapacity to work of working age people. There are also a number of systems for specific industries. See critical remarks in: K. Roszewska, *Ryzyko niezdolności do pracy*, Warszawa 2018, pp. 330–331.

to education place a significant burden on the families of children with disabilities.

Compulsory education covers all children without exception up to the age of 18, i.e. regardless of their health or disability. The fulfilment of this obligation rests with parents and state institutions. The addressees of the rules under the right to education are therefore not only public authorities but also parents. The compulsory education obligation covers the acquisition of knowledge and skills, while the narrower compulsory school education obligation means participation in school activities.[35]

We should not forget that the right to education and the duty for children to learn, although inextricably linked, are two levels of regulation that should not be confused.[36] However, the correlation of the right with the obligation at the long stage of receiving education has the consequence that the right is sometimes poorly realised (outside higher education) and attention is focused on the fulfilment of the obligation to learn. Meanwhile, the Constitution makes it clear that receiving education is also a right.[37] This reciprocal relationship leads to the conclusion that the enforcement of the obligation must respect the right to education and must not be neglected in the most demanding cases in that it gives the appearance of ensuring the right and the fulfilment of the obligation to learn. Indeed, what children with the most profound disabilities (multiple disabilities, pervasive developmental disorders, intellectual disabilities, mental disability) often face is being 'pushed' out of mainstream (school) education to special schools, but also out of special schools to non-public institutions, and to individual teaching at home or in remedial and educational centres, which are in fact residential centres enabling

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[35] B. Banaszak, *Konstytucja…*, p. 415.

[36] O. Rudak, *Prawo do nauki*, [in:] B. Banaszak, A. Preisner (red.), *Prawa i wolności obywatelskie w Konstytucji RP*, Warszawa 2002, p. 499; S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 640.

[37] A. Dudzińska, K. Roszewska, *Praktyczna realizacja polityki oświatowej wobec uczniów z niepełnosprawnościami*, "Niepełnosprawność. Dyskursy Pedagogiki Specjalnej" 2016, nr 22, p. 187, https://www.researchgate.net/publication/320842947_Praktyczna_realizacja_polityki_oswiatowej_wobec_uczniow_z_niepelnosprawnosciami (accessed on: 21.10.2023).

the 'fulfilment' of the obligation of one-year preschool preparation, compulsory schooling, and compulsory education. In reality, they mainly offer remedial, therapeutic, and improvement activities.[38]

The **rule that education is free of charge** is phrased in a way that makes it an element of the right to education *sensu stricto*, or even a principle of this right. The Constitution stipulates that "Education in public schools shall be without payment. (...)". The requirement that education be free of charge is absolute in the case of public schools, subject to the exception provided for universities (Article 70(2) sentence 1), which is not at issue here. The general prohibition of fees is interpreted as prohibiting public schools from charging tuition and other fees up to the secondary level. It covers the compulsory curriculum in public schools at the primary and the secondary level. Yet the school is not prevented from charging fees for additional activities offered to pupils outside the timetable and lesson hours.[39] Parents may incur expenses for the purchase of books or other teaching aids. In practice, however, the free offer of public schools is often more extensive. However, it is mainly aimed at able-bodied children and does not take into account the special needs of children with various disabilities. A general offer that does not take into account the special needs of children with disabilities provided by public educational and cultural institutions is contrary to the Act on providing accessibility to persons with special needs (2019).[40] In practice, families of children with special educational needs are often suggested to use the offer of social organisations. These organisations either charge for their services or obtain public funds in a competition procedure, where price is an important condition. Thus, even if they address their offer to children with disabilities, they are also unable to ensure the full availability of additional activities for children with the most profound disabilities.

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[38] § 53–59 of the Regulation of the Minister for Education and Science of 30 March 2023 on certain public education facilities; Journal of Laws, item 651.

[39] L. Garlicki, M. Derlatka, *Art. 70*, [in:] *Konstytucja…*, *op. cit.*, p. 752.

[40] Act of 19 July 2019 on providing accessibility to persons with special needs, Journal of Laws of 2022, item 2240, consolidated text.

The **parents' freedom to choose a non-public school** for their children and the right to establish non-public schools is a manifestation of the parents' right to rear their children according to their own convictions (Article 48). This freedom is reinforced by the constitutional right to establish non-public schools by citizens and institutions (Article 70(3) sentence 2). However, this is no absolute right. The law stipulates the conditions under which such institutions may be established, their activities, the principles of teaching supervision over them, as well as the participation of public authorities in their financing. However, under the influence of international legal solutions, it has become standard to provide non-public schools with a fully alternative character to public schools.[41]

Moreover, the parents' freedom to choose a school has a rather non-obvious connection with the education of children with disabilities. This right is often not exercised freely, because of a different vision of education or for religious reasons or world views, but guided by necessity, because of a lack of choice or a lack of enough places in regular or even special public schools.

2.5. Guarantees for the Proper Implementation of the Right to Education

If the essence of the constitutional solution in Article 70 boils down to the broadest guarantee of the right to education in the subjective sense, then all the other provisions of this article must be interpreted in a way that realises this constitutional guarantee to the fullest extent possible. All further sub-sections of Article 70 consequently define the tools for ensuring the exercise of the right to education. In this sense, they are secondary – or instrumental to the fundamental principle expressed in the first sentence of Article 70(1).[42] The fulfilment of legal obligations depends on the existence of appropriate legal, but also extra-legal guarantees

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[41] Cf. S. Jarosz- Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 656.

[42] Judgment of the Constitutional Tribunal of 08 November 2000, SK 18/99, OTK 2000, No. 7, item 258.

that enable their implementation in a changing reality.[43] Article 70 of the Constitution contains several such guarantees. Due to the dispute as to the nature of some of the provisions (whether they shape a subjective right of the citizen or constitute only a programmatic norm addressed to the legislature and public authorities), legal scholars present various lists of these guarantees. Finally, sometimes the same provisions are treated as an element of the right to education and a guarantee *per se* of the realisation of this right. This is because the right to education has a rich content and at the same time establishes a set of guarantees for its proper implementation.[44] If we distinguish the elements constituting the content of the right in the strict sense and, may we add, academic freedom from their guarantees containing the positive obligations of the public authorities, we can include among these guarantees: universal and equal access to education, the establishment and support of systems of individual financial and organisational assistance, the conditions for the establishment and activity of non-public schools, and the autonomy of higher education institutions (which is outside the scope of the present analysis). Certainly, the constitutional guarantees of the right to education are strongly interrelated.[45] Although their importance for the education of children and young people with disabilities has been recognised,[46] they have proved to be insufficient in practice to adopt a legal framework for inclusive education for children with disabilities on an equal basis with other children.

2.5.1. UNIVERSAL AND EQUAL ACCESS TO EDUCATION

Universal and equal access to education is stipulated in the Constitution separately from the right to free education in public schools (Article 70(4) sentence 1). In addition, it is differently worded.

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[43] B. Banaszak, *Podstawowe obowiązki prawne jednostki*, Wrocław 1997, pp. 56–57.

[44] Cf. S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 639.

[45] H. Zięba-Załucka, [in:] W. Skrzydło, S. Grabowska, R. Grabowski (red.), *Konstytucja…*, *op. cit.*, p. 390

[46] P. Bała, *Konstytucyjne prawo…*, *op. cit.*, pp. 447–450.

It sounds like a typical programmatic norm ("Public authorities shall ensure universal and equal access to education for citizens"). At the same time – as indicated above with regard to the legal nature of the right to education – it most often raises the question of whether it can be the basis of a citizen's claim, or whether the manner of implementation of this rule is left to the discretion of the ordinary legislature.

In order to determine the scope of the public authority's obligations, it is crucial to define the concepts of 'universality' and 'equality'. The Constitution guarantees the right to education to everyone, and Article 70(3) stipulates broadly the universal and equal access to education of citizens, which means that universal and equal access should extend, admittedly not to everyone, but certainly, to citizens, and without regard to, among others, their age, state of health, and disability, and without any limitation to specific levels or types of schools.

The addressee of the obligations under this provision is the public authority. And the requirement to ensure universal and equal access to education applies to public schools only.[47] However, it is not limited to a single school.[48]

When interpreting equal access to education, scholars point out that it constitutes a *lex specialis* in relation to the general principle of equality in Article 32 of the Constitution.[49] However, these are two different categories of rules. Article 32 establishes equality as a principle ("All persons shall be equal before the law") and a right conceptualised as the right to equal treatment by public authorities. Sub-section 2, on the other hand, provides for a broad prohibition of discrimination ("No one shall be discriminated against in political, social or economic life for any reason whatsoever"). While Article 70 does not explicitly mention the right to equality in education or the citizen's right to equal access to education, it does

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[47] L. Garlicki, M. Derlatka, *Art. 70*, [in:] *Konstytucja…*, *op. cit.*, p. 755; S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 649.

[48] S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 650.

[49] Cf. S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 650, and the judgment of the Constitutional Tribunal of 16 January 2007, U 5/06, OTK-A 2007, No. 1, item 3, cited below.

address this rule to the public authorities, whose duty it is to ensure universal and equal access. It is more fitting to combine equal access to education with the category of equal opportunities. The purpose and essence of this regulation is to create real, equal educational opportunities for the individual. In this vein, it is interpreted by constitutional case law not only as a "prohibition to establish regulations which would limit the possibility of certain groups of individuals to benefit from this education", but also as a:

> duty of the state to remove actual barriers and restrictions in the use of the public education system. [...] As is clear from the remainder of this provision, this obligation is concretised in the prescription to create and support systems of individual financial and organisational assistance for students and pupils.[50]
>
> Compensatory measures taken by public authorities should primarily address inequalities and factual barriers, including financial ones (...). Indeed, the purpose and essence of this right is to create real educational opportunities for the individual at various levels of education (...).
>
> The state has a duty to shape legislation in such a way that everyone has real access to education in accordance with their aptitudes and abilities. The limitation of educational opportunities in a particular type of institution or in a particular field of study may only result from non-arbitrary and non-discriminatory criteria and may only depend on the pupils' talents and qualifications.[51]

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[50] Judgment of the Constitutional Tribunal of 16 February 2000, Ts 97/99, OTK 2000, No. 1, item 20.

[51] Judgments of the Constitutional Tribunal of 16 January 2007, U 5/06, OTK-A 2007, No. 1, item 3; of 24 September 2013, K 35/12, OTK-A 2013, No. 7, item 94; and of 22 June 2015, SK 29/13, OTK-A 2015, No. 6, item 83.

The Education Law (2016)[52] guarantees pupils with disabilities the opportunity to receive education in all types of schools and according to their individual developmental and educational needs and aptitudes. The choice of a regular, inclusive, or special school is left to parents. Although they have enjoyed this right since the reform of the education law in 1991 and the entry into force of the Act on the education system (1991),[53] for years, most children with disabilities attended special schools and the preferred form of mainstream education was inclusive schools or classes, which did not prove to be a good solution.[54] Significant awareness changes occurred after Poland adopted the UN Convention on the Rights of Persons with Disabilities (2006),[55] hereinafter referred to as CRPD . The number of children with disabilities in regular schools is increasing year by year, as demonstrated by data from the Central Statistical Office. In 2021, 48.3 thousand children out of 151.4 thousand children with certified special education needs were studying at special primary schools.[56]

Further, the Education Law provides for the possibility of individualised education, forms, and curricula as well as remedial classes (Article 1(6–7)). If a pupil requires special organisation of learning and working methods, they may receive special education on the basis of a certificate of special educational needs. Such education may be provided in the form of learning in, respectively, regular kindergartens and schools, inclusive kindergartens, kindergarten divisions in primary schools and schools or divisions, special kindergartens and schools or divisions, as well as other forms of pre-school education and centres referred to in Article 2(7). A certificate of the need for special education specifies the recommended

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[52] Act of 14 December 2016 – Education Law, Journal of Laws of 2023, item 900, consolidated text.

[53] Act of 7 September 1991 on the educational system, Journal of Laws of 2022, item 2230, as amended, consolidated text.

[54] A. Dudzińska, K. Roszewska, *Praktyczna realizacja polityki oświatowej…*, *op. cit.*, pp. 197–198.

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

[56] Główny Urząd Statystyczny, *Osoby niepełnosprawne w 2021 r.*, p. 5, https://stat.gov.pl/obszary-tematyczne/warunki-zycia/ubostwo-pomoc-spoleczna/osoby-niepelnosprawne-w-2021-roku,26,3.html (accessed on: 21.10.2023).

forms of special education, taking into account the type of disability, including the degree of intellectual disability (Article 127(10)(2)). A pupil in special education in any educational institution (not only in a special school or class) should have their pre-school education programme and curriculum adapted to individual developmental and educational needs and psychophysical capabilities, taking into account the recommendations contained in the certificate (Article 127(3)). In addition, the Education Law guarantees transport to a kindergarten, school, or revalidation centre, including their care (Article 32(6), Article 39(4-4a–39a), as well as revalidation classes (Article 109(1)(3)). Furthermore, the school (more precisely: the school principal) is obliged to ensure that the recommendations included in the certificate of special educational needs (Article 68(1)(10)) be carried out. Pursuant to the Act on the education system (1991), the Central Examination Board establishes detailed procedures of adapting the conditions and forms of conducting examinations (Article 9a(2)(10)).

It is widely believed that when it comes to access to education for people with disabilities, not formal (legal) but factual barriers impede access. In other words, the legal system creates conditions for the implementation of universal and equal access to education for children with disabilities, but these are not reflected in reality, and the children still face barriers in practice. The awareness of the existence of these barriers varies, as well. Scholars offer examples of architectural barriers in relation to persons with motor disabilities or communication barriers in relation to persons with sensory disabilities (especially blind and deaf persons). The existence of barriers at the level of higher education is emphasised.[57] This is because these barriers appear in jurisprudence and 'break through' into the public awareness. The common perception that barriers exist does not reflect the reality. Educators highlight quite basic problems at primary and secondary school level, such

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[57] M. Berdel-Dudzińska, *Prawo do nauki a zasada równości w dostępie do edukacji na poziomie szkoły wyższej,* [in:] H. Zięba-Załucka, M. Kijowski, *Zasada równości w prawie,* Rzeszów 2004, pp. 84 et seq.

as the low achievement of pupils with disabilities.[58] At the same time, there are not even any objective and obligatory indicators to evaluate the educational outcomes of schoolchildren with moderate or severe intellectual disabilities who follow a separate core curriculum. Moreover, scholars note weaknesses in inclusive and integrative models that are culturally rooted, but also have to do with the faulty way of organising work in schools and classrooms, which creates the illusion of inclusion (an additional "special" teacher, work according to a special programme, and the requirement to use special methods), the lack of a coherent policy towards inclusive education, and the social exclusion and poverty of families with children with disabilities, which does not remain without its impact on educational opportunities.[59] We can add the widespread lack of architectural adaptations, the lack of safe spaces for children with different needs, overcrowded schools, resulting in excessive stimuli, noise, and stressors, as well as the new responsibilities of regular school teachers for which they are not prepared.[60] The disability community sees the ability and legitimacy of entering or continuing education constantly challenged. The legitimacy of the educational pathway choices made by pupils with disabilities and their parents is sometimes questioned. Finally, families of children with intellectual and psychological disabilities and pervasive developmental disorders note that these children face resentment or even hostility sparked by their very presence in the regular education system. Even the model of inclusive education is sometimes questioned by some educational circles and parents of children attending public schools.

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[58] K. Czerwińska, I. Kucharczyk, *(Nie)efektywność kształcenia uczniów z niepełnosprawnością wzroku kończących gimnazjum*, "Niepełnosprawność. Dyskursy Pedagogiki Specjalnej" 2018, nr 29, pp. 148–166.

[59] J. Rzeźnicka-Krupa, *Edukacja i niepełnosprawność – wyrównywanie szans czy reprodukcja społecznych nierówności*, "Niepełnosprawność. Dyskursy Pedagogiki Specjalnej" 2019, nr 33, pp. 60–61; Z. Janiszewska-Nieścioruk, *O ciągle nierozwiązanych problemach ogólnodostępnej edukacji utrudniających proces inkluzji uczniów/osób z niepełnosprawnościami*, "Niepełnosprawność. Dyskursy Pedagogiki Specjalnej" 2019, nr 33, p. 72

[60] G. Mikołajczyk-Lerman, *Bariery w realizacji prawa do edukacji dzieci z niepełnosprawnościami w opinii ich rodziców. Rekomendacje dla polityki oświatowej*, "Niepełnosprawność. Dyskursy Pedagogiki Specjalnej" 2016, nr 22, pp. 123–127.

And while some reported problems would need to be addressed before the mass inclusion of children with the most profound disabilities, it is surprising to see such categorical opposition to inclusive education.[61]

A review of the problems shows that it is not enough to establish the right to education alone and to ensure objective criteria in school recruitment.[62] Providing universal and equal access to education requires structural, functional, and organisational changes. The legal regulations, which have not been questioned in principle so far, should be examined critically. They fail to ensure that the right to education can be realised under the same conditions as for other children, in the place of residence. Division into school catchment areas at the level of district (rather than communal level) results in schooling often taking place at locations far from the place of residence. Poorly organised free transport does not improve learning conditions as it should. Teachers at regular schools are not required to be prepared to work with pupils with specific needs, e.g., accessibility requirements, text easy-to-read (ETR), assistive and alternative communication (AAC), etc. There is a lack of specialists with knowledge of sign language, or Braille. Although Poland ratified the UN Convention on the Rights of Persons with Disabilities (2006) and adopted the Act on providing accessibility to persons with special needs (2019), pupils still face various, often insurmountable barriers to accessing education. School buildings (especially older ones) have not been adapted to the needs of pupils with motor or sensory disabilities. Very conservative indicators for inclusive education are provided in the Strategy for Persons with Disabilities. For example, the accessibility of primary and secondary schools is planned at

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[61] The School Protection Movement, https://ruchochronyszkoly.pl/category/zagrozenia-szkoly/edukacja-wlaczajaca/; Teachers for Freedom, https://nauczycieledlawolnosci.pl/edukacja-wlaczajaca/ (accessed on: 12.10.2023).

[62] This issue was analysed by the Constitutional Tribunal on the example of university recruitment in the judgment SK 18/99, OTK 2000, No. 7, item 258.

2,000 by 2030, with the total number of such schools in Poland reaching 20,000.[63]

Public entities are obliged under the Act on providing accessibility to persons with special needs (2019) to report on accessibility in the areas of architecture, information and communication, and digitisation (Article 11). Public primary schools (as an example compared to all entities surveyed) reported lower levels of architectural and information and communication accessibility than the national average, and higher levels of digital accessibility.[64] And indeed, the development of new information technologies helps level the playing field when it comes to educational support materials, and the organisation of online education in some cases (e.g. following hospitalisation). The digitisation process was undoubtedly accelerated by the COVID-19 pandemic. Students with disabilities in universities especially benefit from the solutions that were used during the pandemic (e.g. hybrid classes). Yet on the other hand, the lack of accessible textbooks, educational materials and prolonged isolation from the peer group may increase disparities in access to education and contribute to a secondary exclusion.

2.5.2. CREATING AND SUPPORTING SYSTEMS OF INDIVIDUAL FINANCIAL AND ORGANISATIONAL SUPPORT

The implementation of the right to education for everyone requires the use of various forms of assistance in the event of any barriers. Article 70(4), second sentence, stipulates that in order to ensure that citizens have universal and equal access to education, public authorities establish and support systems of individual financial and organisational assistance for pupils and students. The conditions for

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[63] Strategy for Persons with Disabilities 2021–2030, p. 310, adopted by Resolution No. 27 of the Council of Ministers of 16 February 2021 on the adoption of the document Strategy for Persons with Disabilities 2021–2030, Monitor Polski, item 218.

[64] Report on the status of providing accessibility to persons with special needs by public entities in Poland as at 01 January 2021, Ministry of Funds and Regional Policy, Warszawa 2021, p. 95.

providing the assistance are determined by law. The provision does not merely refer to the law with full freedom to shape this assistance but contains binding guidelines for the legislature (in the opinion of some, suggestions as to what the legislature may do[65]). It seems, however, that the wording of the provision implies not just a possibility, but a duty on the part of the law-making body to create and promote various aid schemes. Arguably, the aim is for assistance to reach people with various needs who experience barriers to the exercise of the right to education for various reasons.

The Constitution stipulates individual financial and organisational assistance (Article 70(4) sentence 2). It should not be forgotten that the Constitution was enacted in 1997. Its guarantees therefore reflect the challenges, opportunities, and perceptions of education at that time. Certainly, much greater barriers in the 1990s were faced not only by children with disabilities, but also by children from poor families, children living in the countryside, and Roma children, for whom social assistance was particularly important. It must be noted that such assistance is subsidiary and dependent on the individual situation. Today, significant disparities still exist for children with disabilities. Another major group is refugee children, mainly from Ukraine, but not exclusively. Understanding the historical moment at which the Constitution was adopted, it is therefore important to note that while it recognises the need to support pupils (and citizens in general) to ensure universal and equal access to education, the standard of international protection developed in later years has been further strengthened and expanded. Given the status of ratified international agreements in the Polish legal system, the standard set not only by the Constitution, but also by international law binding on Poland should be taken into account in the design of support systems as a whole.

In the case of children with disabilities, priority is given to systemic solutions, in particular ensuring access to education through the removal of obstacles, the use of reasonable accommodation and universal design, in accordance with Article 24 in conjunction with Article 9 of the UN Convention on the Rights of Persons with

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[65] S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 653.

Disabilities (2006) in relation to not only architectural facilities and educational infrastructure, but also the process of the organisation of teaching, recruitment, methods of education and verification of learning outcomes, textbooks and educational aids, and services other than education in the education system, such as extracurricular activities, excursions, school volunteering, etc. These solutions should be complemented by improving the financial situation of the families of children with disabilities, whose poverty has a negative impact on their equal educational opportunities.

A detailed list of benefits and the rules for granting them are provided for in the Act on the education system (1991)[66] in Chapter 8a on financial assistance for pupils. Financial aid is granted to pupils in order to reduce differences in access to education, to enable overcoming barriers to the access to education resulting from a pupil's difficult financial situation, and to support the education of gifted pupils (Article 90b(2)). Initially, pupils from non-public schools were treated differently in that they were entitled to financial aid only until the end of their compulsory education. The current wording does not distinguish between pupils of public and non-public schools in terms of their right to financial assistance, and grants such assistance to them, if the conditions are met, until they complete their education, but no longer than until they reach the age of 24 (Article 90b(3)(1)). Moreover, financial assistance can be provided to alumni of public and non-public remedial and educational centres attended by children with profound intellectual disabilities, intellectual disabilities, and multiple disabilities. However, this is possible only until they complete their compulsory education (Article 90b(3)(2)).

The Act on the education system (1991) distinguishes two social financial assistance benefits: a school scholarship and a school allowance, as well as several incentive benefits (scholarships for learning achievements or for sporting achievements; scholarships from the Prime Minister; scholarships from the ministers responsible for education and upbringing, for culture, and for national heritage

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[66] Act of 07 September 1991 on the educational system, Journal of Laws of 2022, item 2230, consolidated text.

protection). A pupil may be awarded both social and incentive financial assistance at the same time (Article 90c(4)). In other words, financial assistance is aimed at reducing differences in the access to education, enabling overcoming barriers in access to education resulting from a pupil's difficult financial situation, as well as supporting the education of gifted pupils.[67] The act specifies the subjective scope and the prerequisites for obtaining assistance, including its maximum amount.

In the case of social assistance, the eligibility criterion is the financial situation resulting from low income in the family, in particular when the family has difficulties caused by: unemployment, disability, severe or chronic illness, supporting many children, inability to fulfil caring and educational functions, and alcoholism or drug addiction, as well as when the family is incomplete, or a fortuitous event (Article 90d(1)) or a temporarily difficult financial situation due to a fortuitous event (Article 90e) has occurred. As can be seen, disability or long-term illness per se are not classified as difficult situations entitling to a scholarship. Such a right is based only on a difficult financial situation resulting from low income due to, among others, the presence of disability or chronic illness in the family. In order to obtain a school scholarship, two conditions must be met: a certain maximum income per person in the household and a difficult family situation. Both criteria must be met at the same time.[68] However, from the point of view of a pupil in a difficult financial situation, what is important is the nature of the assistance provided by the school scholarship, and this remains disputed. It is not clear whether the decision to award scholarship is discretionary or whether the awarding body is obliged to grant it if the statutory conditions are met. The second position should be favoured.[69]

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[67] A. Piszko, [in:] *Ustawa o systemie oświaty. Komentarz*, Warszawa 2018, Article 90(b).

[68] Judgment of the Province Administrative Court in Białystok of 2 August 2012, II SA/Sz 349/12, LEX No. 1259431; judgment of the Province Administrative Court in Bydgoszcz of 04 October 2017, II SA/Bd 252/17, LEX No. 2395864.

[69] M. Pilich, [in:] *Ustawa o systemie oświaty. Komentarz*, Warszawa 2015, Article 90(b).

Public funds in the form of a school scholarship are, in principle, earmarked for the specific educational needs of the pupil.[70] Priority is given to assistance in kind (covering the costs of participation in educational activities, costs associated with study away from the place of residence, and the purchase of textbooks). A scholarship may be granted in cash only if it is impossible or inexpedient to grant it in kind. A school scholarship may be granted in one or more forms at the same time.

The school allowance, on the other hand, is an ad hoc form of assistance. It may be granted in the form of a cash benefit to cover educational expenses or in the form of educational assistance in kind, once or several times a year, irrespective of the school scholarship received.

Incentive benefits for academic or sporting performance come in the form of school scholarships or a specific ministerial scholarship. In fact, they can be awarded for general academic performance, for demonstrating "special aptitude" in at least one field of knowledge and achieving good academic results, and for artistic achievements (i.e. for results in artistic and vocational subjects or for achievements in artistic competitions). For these scholarships, the Act also regulates the access criteria and the rules for awarding them.

Moreover, financial assistance both to level educational opportunities and to support gifted children can be provided under government and local government assistance programmes or in the form of incentive scholarships awarded by private institutions. The system of organisational and financial assistance from the public authorities is characterised by multiple instruments, which should promote the proper realisation of the right to education. However, whether such assistance is useful depends on its dissemination, on reaching disadvantaged and gifted pupils, and on its actual proportion in relation to the changing needs of pupils.[71]

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[70] D. Kurzyna-Chmiel, *Oświata jako zadanie publiczne, Rozdział 1. Wokół pojęcia „oświata", 1.5. Ramy systemowej pomocy władz publicznych dla uczniów*, Warszawa 2013, an electronic edition (accessed on: 11.10.2023).

[71] D. Kurzyna-Chmiel, *Oświata jako zadanie publiczne…, op. cit.*

The legislature regulates the organisation of the educational system in a very comprehensive manner in the Education Law (2016)[72] together with numerous implementing regulations. However, when it comes to the implementation of the obligation to provide organisational assistance to pupils with disabilities, it is difficult to reconstruct any coherent scope of this assistance. It derives from a number of regulations and has a different "binding power" on the school authority and the school itself. Elements of organisational assistance aimed at the group of pupils with disabilities may be: postponement of the start of compulsory education, the possibility to extend the educational stage, the obligation of the school principal to implement the recommendations contained in the pupil's certificate of special educational needs; and free transport to the educational institution including care during transport. An important form of support is an additional teacher with qualifications in the special education, employed to co-organise inclusive education, taking into account the implementation of recommendations contained in the certificate of special educational needs, or a teacher's assistant. Remedial classes include, in particular, the development of communication skills by: (1) learning spatial orientation and locomotion, and learning the braille system or other alternative methods of communication – in the case of a blind pupil; (2) learning sign language or other means of communication, in particular assistive and alternative methods of communication – in the case of a disabled pupil with a speech disorder or lack of speech; (3) classes developing social skills, including communication skills – in the case of a pupil with autism, including Asperger's syndrome.[73] In addition, the Education Law (2016) stipulates that if a high number of children apply to a kindergarten or school, disability is one of the criteria to be taken into account when admitting a child to an educational institution (Article 131, Article 134 et seq.).

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[72] Act of 14 December 2016 – Education Law, Journal of Laws of 2023, item 900, as amended, consolidated text.

[73] Regulation of the Minister of National Education of 9 August 2017 on the conditions of organising education, upbringing and care for children and young people with disabilities, social maladjustment and at risk of social maladjustment, Journal of Laws of 2020, item 1309, consolidated text.

However, the extent of this support is often insufficient, aims at improving the individual competences of the pupil themselves, and does not translate into their functioning at school and their educational outcomes. The organisation of transport for pupils with disabilities is highly controversial. The legislature has clarified this obligation in order to limit attempts by local authorities to evade it. However, it is still implemented in violation of the right to education on an equal basis with other children, and even violates the dignity of the child at times, as the transport can take 1.5 hours one way, because, for financial reasons, each ride covers children from a wide geographical area, meaning a long wait for successive children picked up from subsequent schools. In large urban centres, especially in inclusive and integrated education, there are still educational establishments that operate in shifts, making it difficult for these pupils to combine learning and rehabilitation, as well as for parents to reconcile work and care. And school day care centres are overcrowded.

The weakness of the various forms of support are their wide dispersion and casuistic regulations. Some elements of this organisational support derive directly from a provision of the law or from numerous implementing regulations; others may take the form of recommendations from psychological-educational counselling centres. The implementation by the school of the recommendations contained in a pupil's certificate of special education needs is often not sufficient. Their application is secondary, only after the parent has notified the school of the recommendation. The implementation of recommendations can hardly even be called reasonable accommodation, which means necessary and appropriate adaptations (…) if needed in a specific case to ensure that a person can enjoy and exercise all human rights and fundamental freedoms on an equal basis with others (Article 2 CRPD). Recommendations of the psychological-educational counselling centres concern recommended forms of education and the conditions and forms of support for the individual pupil, taking into account specialised equipment and teaching aids, including the use of information and communication technologies (§ 13 of the Regulation on certificates and opinions[74]). They do not solve all the problems related to the barriers to the education of a pupil with a disability. Specific accessibility obligations for all pupils with various disabilities are imposed on public schools by the Act on providing accessibility to persons with special needs (2019). However, due to its general nature aimed at public entities at large, it does not specify a particular accessibility standard for concrete types of public entities, such as educational institutions.

2.6. Conclusions and Recommendations

The Polish Constitution guarantees citizens a relatively high standard of the right to education, corresponding to international standards, and in some respects (notably the payment of tuition fees in state higher education institutions or the setting of the limit of compulsory education) far exceeding them.[75] This does not mean, however, that our standard of the right to education is free of defects. The legal nature of the various elements of the content of Article 70 of the Constitution is questionable. Its weaknesses are sometimes unclear combination of a subjective right with the duties of the public authority expressed with varying categorically (binding the legislature), doubts about the subjective scope of individual rights, and a certain degree of over-regulation.[76] Discussions on the standard of the right to education usually narrowly point to the impact of this standard on disadvantaged groups. As indicated above, problems in the exercise of the right to education of children with disabilities do not arise solely from social attitudes and the practical implementation of the right at school level, but are generated by public authorities or have their origin in legislation.

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[74] Regulation of the Minister of National Education of 7 September 2017 on certificates and opinions issued by the certification teams operating in public psychological and pedagogical counselling centres, Journal of Laws of 2003, item 2061, consolidated text.

[75] S. Jarosz-Żukowska, Ł. Żukowski, *Prawo do nauki…*, *op. cit.*, p. 658.

[76] Ibidem.

Guarantees for the exercise of the right to education do not ensure inclusive education for children with disabilities.

In terms of legal development, changes involving ratified international agreements as well as statutory changes are needed.[77] In order to ensure the exercise of the right to education of children with disabilities, the main recommendations are as follows:

1. Ordering and harmonising numerous provisions on education. Currently, education law is governed by several extensive and repeatedly amended statutory acts: the Act on the system of education (1991), the Act on the financing of educational tasks (2017)[78] and the Education Law (2016). These provisions are accompanied by numerous implementing regulations. The status of teachers is separately regulated in the Teacher's Charter (1982).[79] The multitude of legal acts and the frequent amendments render education law uncertain and complicated. As a result, it is difficult to implement the provisions and, in particular for parents of children with disabilities, to find out their children's rights and guarantees.

2. Signing and ratifying the Optional Protocol to the CRPD and ratifying the Optional Protocol to the CRC on the procedure for making notifications. On this basis, the state party recognises the jurisdiction of the Committee on the Rights of Persons with Disabilities and the Committee on the Rights of the Child, respectively, to receive and consider communications of individuals or groups of individuals under their jurisdiction who claim to be victims of a violation of the Convention by the state party. The CRC

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[77] Some of the recommendations are presented in the article: *The principle of accessibility in the implementation of the rights of children with disabilities – challenges and barriers*, in the monograph *Trends and challenges in the international and national protection of the rights of children with disabilities*, in press. The monograph is the outcome of a research project entitled "Legal protection of children with disabilities within the framework of the Polish-Hungarian Research Platform 2023", implemented by the Justice Institute.

[78] Act of 27 October 2017 on financing educational tasks, Journal of Laws of 2023, item 1400, consolidated text.

[79] Act of 26 January 1982 Teacher's Charter, Journal of Laws of 2023, item 984, as amended, consolidated text.

was the first to prohibit discrimination on the basis of disability and to oblige state parties to implement the right to education on the basis of equal opportunity. The CRPD, in turn, made a definitive paradigm shift in viewing the rights of persons with disabilities, including children, as 'subjects' who enjoy rights that they are able to claim and who make their own decisions about their lives and are active members of society.[80] It is the most comprehensive binding international document on the right to education for children with disabilities. Article 24 imposes specific obligations on states to ensure inclusive education. However, the lack of sanctions under the Protocol makes it an act with limited ability to shape the legal situation of citizens. This curbs the possibility to enforce Convention obligations, even if they become the subject of judicial and constitutional review.[81] What is still left are mechanisms for monitoring compliance with international legal rules through cyclical reports submitted by the government and the legal course before the ECtHR or before the CJ. The reporting procedure is criticised as lengthy and ineffective from the perspective of individual's rights.[82] On the other hand, it provides information on progress in the realisation of social rights and encourages at least upholding the existing standard. Moreover, it has an impact on the promotion of these rights.[83]

3. **Reform the disability and special educational needs certification systems.** The community of persons with disabilities has been calling for years for a reform of many disability certification systems

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[80] Department of Economic and Social Affairs, Convention on the Rights of Persons with Disabilities (CRPD), https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd (accessed on: 5.10.2023).

[81] For more on the implementation of the CRPD, see K. Roszewska, *Proces wdrażania konwencji o prawach osób niepełnosprawnych*, [in:] A. Kalisz (red.), *Prawa człowieka. Współczesne zjawiska, wyzwania, zagrożenia*, t. 1, Sosnowiec 2015, pp. 99–108, in particular p. 101.

[82] A. Bodnar, A. Ploszka, *Polska a mechanizmy międzynarodowej kontroli przestrzegania praw gospodarczych, społecznych i kulturalnych, praw dziecka oraz praw osób z niepełnosprawnościami. Analizy i rekomendacje HFPC z 2014*, pp. 18 et seq.

[83] K. Roszewska, *Ryzyko...*, *op. cit.*, p. 371.

in Poland, for their unification and simplification, and for linking them with functional assessment in order to provide fair and adequate access to services, including education services, and benefits aimed at exercising the right to education.

The work undertaken by the government in response to calls for a uniform system of certification for various purposes or at least coordination in this respect, with a common conceptual system, a system of standardised tools of functional assessment, and a common system of appeals both in administrative and in court proceedings,[84] has not produced a result in the form of a new model of disability certification in Poland. Meanwhile, the system of certification based on functional assessment is the key to adequately selected forms of support addressed, among others, to children with disabilities in the education system.

4. Introducing a clear, obligatory list of tasks that local authorities carry out within the educational subsidy in the Act on financing educational tasks (2017). Local governments indicate that expenditure in subsequent budget years is underestimated. The implementation of the right to education is the local government's task and the income received from the educational subsidy does not cover all statutory tasks. As ruled by the TK in its judgment of 18/09/2006, educational tasks are solely the tasks of local authorities. The guarantees of the state covered by budgetary resources only concern 'necessary measure'. They do not restrict the local authority in its independent decisions to spend its other own income for the implementation of educational tasks and for the actual salaries of teachers and specialists paid. Thus, the state does not have to ensure that all expenses incurred for the implementation of its own educational tasks are covered.[85] However, local governments are not burdened with the implementation of the right to education

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[84] Regulation No. 6 of the Prime Minister of 02 February 2017 on the inter-ministerial team for the development of the disability and incapacity certification system, Monitor Polski, item 167. See on this subject K. Roszewska, *Ryzyko…*, *op. cit.*, pp. 330–331.

[85] Judgment of the Constitutional Tribunal of 18 September 2006, K 27/05, OTK-A 2006, No. 8, item 105.

in a general way only. The implementation of this right has not been left to the discretion of local authorities. They are obliged to fulfil specific statutory duties. Thus, the lack of distinction between tasks carried out as 'necessary measure' and all other tasks leads to competence disputes, encouraging local governments to look for savings in the least representative groups, such as pupils with disabilities, who require high financial expenditures at the same time. Finally, the undefined joint responsibility for the financing of educational tasks by the state and local government disregards international regulations, which stipulate that the state is responsible for the implementation of the right to education.

5. Changing the organisation of the education system in Education Law (2016) to ensure the right to free public school's education in the place of residence on an equal basis with other children. The public education system should guarantee every child with disabilities the right to education in the place where they live rather than within the wide territory of a district. This requires an adequate network of institutions providing inclusive education, and, until it exists, places where special needs education can be provided (with a preference for separate special classes in regular schools rather than separate schools).

6. Introducing education for deaf children in Polish Sign Language, and for children with complex communication needs in AAC and ETR, and the obligation for their teachers and professionals in education to be familiar with Polish Sign Language, AAC, and ETR. Despite the explicit obligation contained in the CRPD (Article 24), Polish schools do not provide education to all deaf children and children with complex communication needs in the languages, modalities, and forms of communication available to them. Even special schools for deaf children are not obliged to provide bilingual education, and in the case of children with complex communication needs, the regulations cover children with intellectual disabilities only to a certain extent, and are marginal in the rest. It is therefore advocated that pupils (including in particular secondary school pupils without intellectual disabilities and students) with complex communication needs, have access to devices and strategies to support communication and assistants to support communication, and that accessible aids and textbooks using AAC and ETR (according to current standards) and a curriculum and certification for AAC and ETR training be developed, as well as that postgraduate studies in AAC and ETR be developed and implemented.[86]

7. Amending the Act on providing accessibility to persons with special needs (2019) aiming to obligate every educational institution, including non-public ones, to ensure accessibility in its educational activities. The CRPD contains provisions directed at other entities.[87] In order to enable children with disabilities to participate fully in education, states parties are required to take appropriate measures to ensure that they have access, on an equal basis with other children, to the physical environment, to means of transport, to information and communication, including information and communication technologies and systems, and to other facilities and services, whether generally available or commonly provided (Article 24 in conjunction with Article 9 of the CRPD). This entails the obligation of states' parties to enforce accessibility also *vis-à-vis* private entities offering products or providing services that are commonly available or commonly provided. In the aforementioned law, the legislature chose to ignore the obligations of private entities under the Convention. It pointed out in the explanatory

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[86] For detailed propositions and recommendations concerning AAC and ETR, see: K. Świeczkowska, M. Grycman, A. Pilch, A. Smyczek, *System wsparcia osób o złożonych potrzebach w komunikowaniu się wymagających wspomagających i alternatywnych metod komunikacji (AAC)*, Edition revised following community consultations carried out between July and December 2021, prepared as part of the project: "Aktywni niepełnosprawni – narzędzia wsparcia samodzielności osób niepełnosprawnych" ("Active people with disabilities – tools to support the independence of people with disabilities") by the Polish Association for People with Intellectual Disability (project partner).

[87] K. Roszewska, [in:] R. Mędrzycki, M. Szyrski, A. Waszkielewicz, M. Wysocki, J. Zadrożny, K. Roszewska (red.), *Ustawa o zapewnianiu dostępności osobom ze szczególnymi potrzebami. Komentarz*, LEX/el 2021, Article 4 sections 7–10.

memorandum to the bill[88] that this would help avoid unnecessary legal complications and administrative costs associated with the need for changes in this area in connection with the future implementation of the Directive on the accessibility requirements for products and services (2019).[89]

In terms of public policy, the following is recommended.

1. Adopting standards for inclusive education at national and local level in line with the CRPD. Accessibility standards are key to implementing the principle of accessibility. Without them, human rights remain 'toothless'. In addition to the implementation of a legal framework for accessibility in national law, the CRPD requires the development and adoption of appropriate accessibility standards (Article 9). Guidelines for the implementation of accessibility are provided in General Comment No. 2 (2014) Article 9, Accessibility[90]. As regards specific rights, general commentaries on these can also be consulted (in the case of education, General Comment No. 4 (2016) on Article 24 – the right to inclusive education).[91] Accessibility standards should be implemented both nationally and locally (and even at the level of institutions related to the realisation of specific rights)[92] and should include private actors. An attempt to prepare national accessibility standards and organisational solutions for education was made in the "Accessible School" project implemented under the Operational Programme Knowledge Education

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[88] Explanatory memorandum to the government's Bill on providing accessibility to persons with special needs, Sejm Paper No. 3579, p. 10.

[89] Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 on the accessibility requirements for products and services, OJ L 151, p. 70.

[90] Committee on the Rights of Persons with Disabilities, General Comment No. 2 (2014), CRPD/C/GC/2.

[91] Committee on the Rights of Persons with Disabilities, General Comment No. 4 (2016), CRPD/C/GC/4.

[92] CRPD/C/GC/4 on Article 24 – the right to inclusive education, p. 8, https://undocs.org/Home/Mobile?FinalSymbol=CRPD%2FC%2FGC%2F4&Language=E&DeviceType=Desktop&LangRequested=False (accessed on: 12.10.2023).

Development 2014–2020, as a pilot of the measure "School without Barriers" – Accessibility Plus Programme.[93]

2. **Improving the flexibility of the system of support for pupils with disabilities** and, where possible, dispensing with the requirement for a certificate of special educational needs. This recommendation has already appeared in the report of the Commissioner for Human Rights titled "Equal Opportunities in Access to Education for Persons with Disabilities. Analysis and Recommendations".[94] The success of this recommendation depends on the gradual implementation of the universal design of all future facilities and solutions and the application of accessibility in the field of education, so that infrastructure, teaching methods, and ways of organising learning are accessible to the largest possible group of children. At the same time, it should be borne in mind that children with the most profound disabilities who require intensive, multi-specialist support, may still require individual solutions.

3. **Clearly distinguishing and defining the responsibilities of various authorities** (including regional and local authorities) and actors (including private actors) that should be exercised to ensure accessibility for children with disabilities. This is required by the Committee on the Rights of Persons with Disabilities in General Comment No. 2 [section 24]. It is also of great importance to develop and strengthen the competences of local authorities responsible for adopting, applying, and monitoring accessibility standards at the local level.

4. **Ensuring access to textbooks and teaching aids in customised formats (including e-books).**[95] This demand has been made for years and reappears in various recommendations. Recently, the shortage of textbooks, educational and exercise materials, and

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[93] https://www.dostepnaszkola.info/projekt/ (accessed on: 12.10.2023).

[94] Bulletin of the Commissioner for Human Rights 2012, No. 7, p. 9.

[95] Bulletin of the Commissioner for Human Rights 2012, No. 7, p. 10.

support books for the education of pupils with disabilities, has been highlighted by the Supreme Audit Office.[96]

5. Ensuring equal access to the out-of-school educational offer for pupils with disabilities. In particular, the offer of private providers often overlooks the needs of children with disabilities. However, accessibility problems likewise apply to extracurricular activities on school premises, school trips, and the local government offer, including activities during the summer and winter holidays for children, and the educational offer of local and state institutions, such as cultural, recreational, and sports institutions.

6. Providing access to specialists and psychological support taking into account the individual needs of pupils with disabilities. empowering professionals working in the education system and providing administrative support for professionals in the face of the increasing bureaucratisation of education.[97]

7. Identifying gaps in the legal system and in public policies in the field of education that hinder the enjoyment of the right to education.

8. Monitoring the situation of pupils with disabilities in the education system and collecting data on children's disabilities in accordance with Article 31 of the CRPD. The Polish Central Statistical Office expanded the areas of research to include the area of disability a few years ago. However, the data collected is still selective and too general.

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[96] Supreme Audit Office, Department of Science, Education, and National Heritage, *Informacja o wynikach kontroli Kształcenie w szkołach specjalnych*, Warszawa 2020, p. 24.

[97] M. Zaborniak-Sobczak, *Konstytucyjne prawo...*, *op. cit.*, p. 313.

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Chapter 3. Conclusions *de lege lata* and Postulates *de lege ferenda* on the Right to the Social Security of Children with Disabilities

> "… the right to social security is not yet a reality for some 71 per cent of the world's population that has no or has only partial access to comprehensive social protection systems. It is clear that countries need to step up measures towards realizing this right."
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> *World Social Protection Report, 2017, p. V*
> *and Report of the Special Rapporteur, 2015, p. 6.*

3.1. Introduction

If vulnerability had degrees, we could say that children with disabilities are the most vulnerable of all in the world.

Families may restrict participation or even hide children from the rest of the community due to stigma or to protect them, reducing the child's access to support, education and other services. Children with disabilities are almost four times more likely to experience violence and up to 17 times more likely to enter institutional care than their peers without disabilities, particularly owing to insufficient support for families, a lack of inclusive education and poverty.

Their dependence on adults also makes them more vulnerable to violence or other forms of abuse and exploitation such as child labour, trafficking, child marriage, teenage pregnancy, and other abusive traditional practices such as female genital mutilation. Even as teenagers, they are often voiceless, growing up in traditional legal and cultural institutions that do not place a high priority on children's rights and needs. Much of the support is provided by families, most often women. Consequently, the autonomy and choice of persons with disabilities are often limited and the economic opportunities of family members providing the support are restricted, especially in situations of intensive support.[1]

At present, countries spend on average only 1.1 percent of GDP on social protection for children (excluding health expenditure), and the amounts vary greatly across countries and regions. While Europe and Central Asia, as well as Oceania, spend more than 2 per cent of GDP on child benefits, expenditure ratios remain well below 1 per cent of GDP in most other parts of the world.[2] Only 35 per cent of children worldwide enjoy effective access to social protection, albeit with significant regional disparities. Almost two-thirds of children globally – 1.3 billion children – are not covered, most of them living in Africa and Asia.[3]

Social protection policies are vital elements of national development strategies to reduce poverty and vulnerability across the life cycle and support inclusive and sustainable growth by raising household incomes, fostering productivity and human development, boosting domestic demand, facilitating structural transformation of the economy and promoting decent work. The Sustainable Development Goals (SDGs) adopted at the United Nations General Assembly in 2015 reflect the joint commitment of countries to "implement nationally appropriate social protection systems for all", including floors for reducing and preventing poverty (SDG 1.3). This commitment to universalism reaffirms the global

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[1] For instance, having a poor parent with a disability increases the likelihood of children aged from seven to 16 years never having been to school by 25 percentage points in the Philippines and 13 percentage points in Uganda. For more, see: World Social Protection Report 2017–19: Universal social protection to achieve the Sustainable Development Goals International Labour Office, Geneva 2017, p. 12.

[2] World Social Protection Report 2017–19: Universal social protection to achieve the Sustainable Development Goals International Labour Office, Geneva 2017, p. 18.

[3] Ibidem, p. 30.

agreement on the extension of social security achieved by the Social Protection Floors Recommendation No. 202, adopted in 2012 by the governments and workers' and employers', organisation' s from all countries.[4]

The research consists of the following parts: basic principles of social rights, social security, analysis of the International legal framework including Convention on the Rights of the Child (CRC), presenting the Hungarian approach of the social security in the Fundamental law, analysis of the social security system and social protection in general, analysis of the social security system in particular in Hungary and finally *de lege ferenda* on the right to social security of children with disabilities.

3.2. Social Rights and the Right to Social Security

> Social security is a quality of human life that can be understood in the context of well-being. Social security is the right of those whose quality of life is generally regarded as acceptable to all [...] In the world of social rights, the right to social security should not be mentioned for moral reasons, as long as the degree of social security is not also a constitutional guarantee of a secure human existence (well-being).[5] At the same time, the declaration of social rights, or some form of regulation of social rights, is a faithful reflection of the values, the vision of humanity and the role of a particular state, and is generally linked

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[4] Ibidem, p. 29; The Joint Statement on Advancing Child-sensitive Social Protection DFID, HelpAge International, Hope & Homes for Children, Institute of Development Studies, International Labour Organization, Overseas Development Institute, Save the Children UK, UNDP, UNICEF and the World Bank, pp. 4, 6 (hereinafter: Joint statement 2019), https://resourcecentre.savethechildren.net/pdf/3840.pdf/ (accessed on: 03.08.2023).

[5] A. Takács, *Szociális jogok az Alkotmányban és a munka alkotmányjogi szerepe*, [in:] B. Molnár, Zs. Gyombolai, A. Téglási (eds.) *Gazdasági alapjogok és az új magyar Alkotmány*. Kiadta az Országgyűlés Emberi jogi, kisebbségi, civil- és vallásügyi bizottsága, Budapest 2011, p. 79.

> to prevailing political views and, of course, to the more narrowly defined conceptions of constitutional law.

The definition of social security is rarely found in international legal sources, while the social security system itself is most often defined in professional literature as – "a set of all measures that should in certain cases (illness, accident at work, old age, death, birth of a child and unemployment) establish a disturbed balance". In the majority of cases, it is assumed that social security represents an umbrella concept, that is, the basic goal of the science of social law, which is achieved through various subsystems, such as social insurance systems and social protection systems. Consequently, social security can be a goal that society strives for in order to ensure decent living conditions and an existential minimum for as many residents as possible, and the aforementioned goal will be achieved by the developed social insurance and social protection system, which will enable individuals to exercise their basic rights and receive appropriate protection in cases of the occurrence of a certain social risk. Therefore, it is the obligation of the state to create a valid normative framework that will regulate the procedure and conditions for exercising social security rights and providing social protection measures. Without developed legal and sub-legal legislation and a clear constitutional framework, as well as appropriate measures of supervision over the implementation of the law, ensuring social security for citizens will be a difficult task for every state.[6]

As regards the integration of social security law into the legal system, one can agree with the views that by its nature it is primarily a public law branch, with administrative law being the closest (especially in procedural norms), and similarities can also be found with financial law (the nature of insurance premiums in the social insurance system is similar to the tax system). At the same time, however, many private law elements can also be found in social security law

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[6] F. Bojić, *Sustainability of the Social Security System – Demographic Challenges and Answers in Romania*, [in:] N. Jakab (ed.), *Sustainability of the Social Security System – Demographic Challenges and Answers in Central-Europe*, Budapest 2023, (under publishing).

(as an example, private law contracts concluded between the provider and the recipient of certain social or health services). We would add to these considerations that social security law has a special relationship with labour law, and we could find several overlaps. There is a particular correlation in the protection of employees caring for children. The basic code of labour law provides these employees (and other groups) with special care and legal protection (interruptions at work, maternity leave, paternity leave, etc.), which is supplemented by the financial security provided by the standards of social security law.[7] *In Hungary*, social law is a separate branch of law and the Hungarian social system is of a mixed nature, with both insurance and benefit elements present, with the insurance elements predominating. Based on this, benefits provided by social law institutions can be broadly grouped into three broad systems: social security benefits, family benefits and other benefits for families with children, and benefits provided by the social administration system. However, this division is not set in stone, and the dynamic nature of social law is constantly changing, and this system may change as the catalogue of protected values expands or contracts.[8]

Modern constitutions have overwhelmingly taken the view that there is a need for some level and type of regulation of social rights in general. The exercise of classical freedoms and social (existential) security are parts of human quality that are mutually dependent. In society, as a kind of moral community, solidarity must be expressed in some form. The modern state must protect the individual against social impossibility. It is true, of course, that the extent of social rights depends on the capacity of the state to deliver, but this should not mean that constitutions do not enshrine some realistic system of support for the vulnerable. Indeed, where the line is drawn between

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[7] M. Dolobáč, *Sustainability of the Social Security System – Demographic Challenges and Answers in Slovakia,* [in:] N. Jakab (ed.), *Sustainability of the Social Security System – Demographic Challenges and Answers in Central-Europe*, Budapest 2023, (under publishing).

[8] H. Tóth, G. Mélypataki, *The Challenge of the Hungarian Social Security System in the Mirror of Demographic Changing*, [in:] N. Jakab (ed.), *Sustainability of the Social Security System – Demographic Challenges and Answers in Central-Europe*, Budapest 2023, (under publishing).

economic policy decisions and constitutional decisions depends on the constitutionalisation of social rights and the quality of the regulation. If the provision of the necessary means of subsistence follows directly from the constitution (human dignity), then it is not an economic policy decision whether to provide the necessary means of subsistence to the citizen, but a matter of fundamental rights.[9]

In Hungary, the Fundamental Law of Hungary, which entered into force on 1 January 2012, significantly amended the fundamental right to social rights. There are many criticicisms that the current Fundamental Law has lowered the level of protection of social security, by not providing social security, but only seeking it. In doing so, it defined the establishment of a social security system as a state objective: "Hungary shall endeavour to provide social security for all its citizens". As the Constitutional Court stated in a 2012 decision, "Article XIX of the Fundamental Law on Social Security does not provide for rights, but rather for obligations and objectives of the state". The legislation in force before 2012 contained a stronger state role. It should be noted that the Fundamental Law is also characterised by the fact that it sets out other state objectives as aspirations; for example, it only seeks to ensure decent housing. In a decision, the Constitutional Court considered that, when drafting the above new concept of the Fundamental Law, it was necessary to reduce the previous entitlements because of "sustainable economic development and the gradually deteriorating demographic situation" and "changed economic circumstances". The positive economic changes in the period that has elapsed have not yet prompted the legislator to amend the Fundamental Law, and the reasoning of the Constitutional Court is therefore questionable.[10] Regarding the level of social protection in Hungary, we agree with Téglási, who stresses that among the various definitions of social security, the distinction between absolute and relative social security should be applied. Absolute security means the threshold of subsistence, the creation of existential security, the guarantee of minimum conditions

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[9] A. Téglási, *The constitutional protection of social rights – with particular reference to the fundamental protection of social security*, Budapest 2019, p. 337.

[10] H. Tóth, G. Mélypataki, *The Challenge…*, *op. cit.*

of subsistence. It is nothing other than the right to a minimum subsistence level or subsistence minimum, which is (also) linked to human life and human dignity. Relative security, by contrast, means the full or partial maintenance of the previous standard of living, or the guarantee of it, in the event of certain social risks. The Constitutional Court thus – without stating it – only guaranteed the protection of absolute social security; but the Court clearly refrained from guaranteeing relative social security when it stated that social security does not mean that the standard of living once achieved by citizens cannot be reduced as a result of adverse economic developments. The definition of social security as an objective of the State within the meaning of Article XIX(1) of the Fundamental Law is thus interpreted as referring (and may refer) only and exclusively to relative social security, as something that the State must only "strive" to achieve, and not to absolute social security, given its close links with the right to life and human dignity, which it must (and does) continue to guarantee unconditionally.[11]

3.3. International Legal Framework

The issue of social security is the subject of several international documents and treaties. Among the most relevant are: ILO Convention No. 102 concerning Minimum Standards of Social Security, 1952, ILO Convention No. 128 concerning Invalidity, Old-Age and Survivors' Benefits, 1967, and the International Covenant on Economic, Social and Cultural Rights (UN), 1966. Of the regional international treaties, the most important are the European Social Charter of 1961, the Additional Protocol to the European Social Charter and, finally, the most recent document, the European Social Charter /Revised/ of 1996.

The Universal Declaration on Human Rights recognizes the right of everyone to social security (Article 22) and affirms that everyone has the "right to a standard of living adequate for the health and well-being of himself and of his family" and the "right to security

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[11] A. Téglási, *The constitutional...*, *op. cit.*, p. 348.

in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control" (Article 25).

The UN legal framework on human rights contains a number of provisions spelling out various rights of children that form part of their right to social protection. These comprise the right to social security, taking into consideration the resources and the circumstances of the child and persons having responsibility for their maintenance, the right to a standard of living adequate for their health and their wellbeing, and the right to special care and assistance. The UN Convention on the Rights of the Child (CRC) states that:

> The States Parties shall recognize for every child the right to benefit from social security, including social insurance, and shall take the necessary measures to achieve the full realization of this right in accordance with their national law (Article 26) (see later).

The International Covenant on Economic, Social and Cultural Rights (ICESCR) further requires States to give the widest possible protection and assistance to the family, particularly for the care and education of dependent children. ILO social security standards complement this framework and provide guidance to countries on how to give effect to the various rights that form part of the right of children to social protection.[12]

The ILO Social Security (Minimum Standards) Convention, 1952 (No. 102), Part VII, sets minimum standards for the provision of family (or child) benefits in the form of either a periodic cash benefit or benefits in kind (food, clothing, housing, holidays or domestic help) or a combination of both, allocated for the maintenance

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[12] https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights (accessed on: 03.08.2023). Article 9 provides a short and general reference on the right of social security, thereby leaving it to the UN specialised agencies (in particular the ILO) to identify the details of this clause. Article 10(2) accords special protection to mothers during a reasonable period before and after childbirth. To working mothers it offers, during such a period, paid leave or leave with adequate social security benefits.

of children. The fundamental objective of family benefits should thus be to ensure the welfare of children and the economic stability of their families.[13]

As specified by the ILO's Committee of Experts on the Application of Conventions and Recommendations, these standards require that family benefits be granted in respect of each child in the family and to all children, for so long as the child is receiving education or vocational training on a full-time basis and is not in receipt of an adequate income determined by national legislation. They should be set at a level which relates directly to the actual cost of providing for a child and should represent a substantial contribution to this cost. Family allowances at the minimum rate should be granted regardless of means. Benefits above the minimum rate may be subject to a means test. Furthermore, all benefits should be adjusted in order

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[13] While Convention No. 102 covers all branches, it requires that only three of these branches be ratified by Member states, which allows for the step-by-step extension of social security coverage by ratifying countries. Among IlO Security Standards we have to mention the following: The Medical Care Recommendation, 1944 (No. 69), which envisages comprehensive social security systems and the extension of coverage to all and laid the foundations for Convention No. 102 (1952); The Medical Care and Sickness Benefits Convention, 1969 (No. 130); and the Medical Care and Sickness Benefits Recommendation, 1969 (No. 134), which makes provision for medical care and sickness benefit; The Employment Promotion and Protection against Unemployment Convention, 1988 (No. 168) and the Employment Promotion and Protection against Unemployment Recommendation, 1988 (No. 176) relates to unemployment benefit; The Invalidity, Old-Age and Survivors' Benefits Convention, 1967 (No. 128) and the Invalidity, Old-Age and Survivors' Benefits Recommendation, 1967 (No. 131) covers old-age benefit, invalidity benefit and survivor's benefit; The Employment Injury Benefits Convention, 1964 (No. 121) and the Employment Injury Benefits Recommendation, 1964 (No. 121) makes provision for employment injury benefit; The Maternity Protection Convention, 2000 (No. 183) and the Maternity Protection Recommendation, 2000 (No. 191) covers maternity benefit; The Equality of Treatment (Social Security) Convention, 1962 (No. 118), the Maintenance of Social Security Rights Convention, 1982 (No. 157) and the Maintenance of Social Security Rights Recommendation, 1983 (No. 167) provide reinforced protection to migrant workers; The Social Protection Floors Recommendation (No. 202) provides guidance for the establishment and maintenance of social protection floors and their implementation within strategies for the extension of social security aiming at achieving comprehensive social security system.

to take into account changes in the cost of providing for children or in the general cost of living.[14]

ILO Recommendation No. 102 further refines and extends the normative framework, aiming at universal protection. Income security for children is one of the basic social security guarantees constituting a national social protection floor, and should ensure "access to nutrition, education, care and any other necessary goods and services" (Para. 5(b)). Although the guarantee should be nationally defined, the Recommendation provides clear guidance on its appropriate level: the minimum level of income security should allow for life in dignity and should be sufficient to provide for effective access to a set of necessary goods and services, such as may be set out through national poverty lines and other comparable thresholds (Para. 8(b)). Providing for universality of protection, the Recommendation sets out that the basic social security guarantee should apply to at least all residents, and all children, as defined in national laws and regulations and subject to existing international obligations (Para. 6), that is, to the respective provisions of the CRC, the ICESCR and other relevant instruments. Representing an approach strongly focused on outcomes, Recommendation No. 202 allows for a broad range of policy instruments to achieve income security for children, including child and family benefits.[15]

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[14] ILO Social security and the rule of law: General survey concerning social security instruments in the light of the 2008 Declaration on Social Justice for a Fair Globalization, Report III (Part 1B), International Labour Conference, 100th Session, Geneva, 2011 (Geneva), paragraphs 184–186.

[15] R202 – Social Protection Floors Recommendation, 2012 (No. 202) See also United Nations Report of the Special Rapporteur on the rights of persons with disabilities (A/70/297), New York 2015, p. 5 (hereinafter: Report of the Special Rapporteur 2015).

The Recommendation reflects the ILO's two-dimensional extension strategy, which provides clear guidance on the future development of social security in its 187 member States, by:

- achieving universal protection of the population by ensuring at least basic levels of income security and access to essential health care (national social protection floors: horizontal dimension); and
- progressively ensuring wider scope and higher levels of protection, guided by ILO social security standards (vertical dimension). For more, see more: World Social Protection Report 2017–19: Universal social protection to

European Social Charter (Revised) (1996), Article 12, guarantees the right to social security and identifies four principles to which the system should comply. Article 12 also refers to the European Code of Social Security of the Council of Europe (1964). This latter is similar to ILO Convention 102, but the minimum requirements of acceptance for ratification are twice as high for the Code.

The American Declaration of the Rights and Duties of Man (1948), Article 16, includes the right to social security in specific areas. The Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social, and Cultural Rights "Protocol of San Salvador" (1988), Article 9 refers to provisions related to old age and disability and to social security benefits for employees in the field of healthcare, work-related injuries, diseases and maternity.

Historically, social protection policies have been constructed from the perspective of the loss of the capacity to earn income and the need for rehabilitation and care. This approach has guided the adoption of ILO Conventions 102, 121 and 128 and national disability contributory income security schemes. While providing essential protection for workers, it has cemented a dichotomy between persons with disabilities deemed able or unable to work and to participate in society contributing to schemes fostering "dependence, segregation and institutionalization of persons with disabilities". The human rights-based approach to disability, which contributed to the adoption of disability anti-discrimination legislations in the 1990s and the United Nations Convention on the Rights of People with Disability (CRPD) in 2006, challenged this entrenched perspective. It reconceptualized disability as the result of the interaction between persons with impairments and diverse barriers which may restrict their participation. This implies policies across sectors that combine the removal of barriers (awareness raising, non-discrimination, accessibility) with the provision of required

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achieve the Sustainable Development Goals International Labour Office, Geneva 2017, pp. 6–8, 13, was adopted virtually unanimously (one abstention) by the Governments, as well as workers' and employers' organisations, of the ILO's 187 Member States.

support (assistive devices, rehabilitation, support services, social protection).[16]

Article 28 refers for the first time in an international instrument to the right to social protection and links it to the right to an adequate standard of living, with reference to adequate food, clothing and housing, and the continuous improvement of living conditions. It also tailors the right to social protection to persons with disabilities, recognizing that they must enjoy this right without discrimination on the basis of disability, and establishes a pathway for their inclusion in all efforts related to the realization of this right.[17]

More specifically, Article 28 creates an obligation for States parties to take appropriate measures to ensure that persons with disabilities receive equal access to mainstream social protection programmes and services – including basic services, poverty reduction programmes, housing programmes, and retirement benefits and programmes – as well as access to specific programmes and services for disability related needs and expenses.[18] These obligations emphasis that social protection should always contribute to the empowerment, participation and inclusion of all persons with disabilities.

Social protection also resonates in other provisions of the Convention, including in relation to the right to live independently and be included in the community (Article 19), respect for home and the family (Article 23), education (Article 24), health (Article 25), habilitation and rehabilitation (Article 26) and work and employment (Article 27). Importantly, social protection interventions should be measured against the Convention's principles of non-discrimination, participation and inclusion, equal opportunities, accessibility, and equality between men and women (Article 3).[19]

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[16] A. Côte, *Disability inclusion and social protection*, [in:] E. Schüring, M. Loewe (eds.), *Handbook on social protection systems*, Cheltenham 2021, p. 358.

[17] Report of the Special Rapporteur 2015, p. 8.

[18] Ibidem.

[19] Ibidem; Joint statement 2019, p. 5.

In addition to Article 7 on children with disabilities, age-specific statements are made in points (d) and (r) of the preamble,[20] Article 3(h), Article 4(3) (inclusion of children with disabilities in legislation), Article 8(2)(b) (raising awareness, including for children up to the age of majority), Article 16(5) (child-centred legislation), Article 18(2) (children's right to acquire citizenship), Article 23(3), (4) and (5) (family rights), Article 24(2)(a) and (3)(c) (integrated education), Article 25(b) (access to health services) and Article 30(5)(d) (participation in cultural and leisure activities).

Social protection is central to the implementation of the CRPD and to ensuring that persons with disabilities are not left behind in efforts to achieve the SDGs. The report of the Special Rapporteur concludes:

> Securing the right of persons with disabilities to social protection must be a priority for States and the international community. Inclusive social protection systems, including social protection floors, can contribute significantly to supporting the social participation and inclusion of persons with disabilities by ensuring income security and access to social services. They can also play an important role in fostering the realization of the Sustainable Development Goals for persons with disabilities. For that purpose, States must move away from traditional disability-welfare approaches and turn towards rights-based ones, and must develop comprehensive social protection systems that guarantee benefits and access to services for all persons with disabilities across the life cycle. The inclusion of persons with disabilities in social protection systems is not only a human rights issue, but also a crucial investment for development that States cannot afford to miss.[21]

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[20] "*... Recognizing that children with disabilities must be guaranteed the enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling further the obligations of States Parties to the Convention on the Rights of the Child to this end...*"

[21] Report of the Special Rapporteur 2015.

Turning to the Convention on the Rights of the Child (CRC), Article 26 deals with the right of the child to benefit from social security and social insurance. As underlined by the Committee, this right is important in itself and plays a key instrumental role in the realization of other Convention rights.[22] It guarantees financial and other support of the child provided by the state in all cases where the adult(s) responsible for the child are not in the position to provide for the child, because they are unemployed or for other reasons, such as illness, disability, childbearing, old age, widowhood, or being a single parent, and in the total absence of both parents (orphanhood) and so on. These are all circumstances that might prevent the adult(s) from securing work and an income.

Contrary to other international legal provisions dealing with the issue of social security, Article 26 does not guarantee the right to social security, but the right to "benefit from" social security. The use of this expression is due to a proposal of the International Labour Organization (ILO) delegation during the drafting of the Convention, which underlined that the recognition to children of the "right to social security" would not mirror the real position of the child in relation to their entitlement to social security benefits. Parents and/or legal guardians hold the rights to receive benefits "by the reason of their responsibility for the maintenance of the child"[23] based on Article 18. Therefore, the position of dependency of the child towards their parents or legal guardians and their entitlement to social security had been more adequately reflected by recognizing the child's right to "benefit from" social security and not the right to social security. Nevertheless, Article 26(2) ensures that applications

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[22] UN Committee on the Rights of the Child, General Comment No. 3 (2003) HIV/AIDS and the rights of the child, 17 March 2003, CRC/GC/2003/3, para. 6; UN Committee on the Rights of the Child, General Comment No. 7 (2005) Implementing child rights in early childhood, 20 September 2006, CRC/C/GC/7/Rev, paras. 10, 26; UN Committee on the Rights of the Child. (2007). General Comment No. 9 (2006) The rights of children with disabilities, 13 November 2007, CRC/C/GC/9, para. 20; W. Vandenhole, *A commentary on the United Nations convention on the rights of the child, Article 26: The right to benefit from social security*, Brill Nijhoff, 2007.

[23] S.L. de Detrick, *A commentary on the United Nations convention on the rights of the child*, Brill Nijhoff, 1999, p. 447.

for benefits can be "made by or on behalf of the child". Furthermore, in the general guidelines for the periodic reports, the Committee asks States Parties to describe in their reports the circumstances and the conditions under which children are authorized to apply themselves directly or through a legal representative to social security benefits.[24]

With reference to the implementation of Article 26, it is worth underlining that it is subject to the provision of Article 4, which provides that States Parties are obliged to "undertake all appropriate, legislative, administrative, and other measures to the maximum of the available resources and where applicable within the framework of the international cooperation"[25]. Therefore, the right of the child to benefit from "social security is not an immediate States Parties' obligation, but one of progressive achievement".[26] So far, the Committee has not yet provided a comprehensive clarification of Article 26 by way of General Comments, nor through the Concluding Observations on reports of States Parties.[27] Therefore, the specific and technical meaning of "social security" needs to be identified in many universal and regional treaties dedicated to the right to social security. In these treaties, "social security" is composed of the nine traditional branches identified by the ILO Convention 102 on Minimum Standards, namely health, care, sickness, unemployment, employment injury, family, maternity, invalidity and survivor's benefits; and a social security system should comply with the following four principles identified by the (Revised) European Social Charter (1996): The social security system should be set up or maintained. A minimum level should be defined for

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[24] R. Ruggiero, *Article 26: The Right to Benefit from Social Security*, [in:] Z. Vaghri et al. (eds.), *Monitoring State Compliance with the UN Convention on the Rights of the Child, Children's Well-Being: Indicators and Research* 25, Springer 2022, p. 218.

[25] R. Hodgkin, P. Newell, & UNICEF, *Implementation handbook for the convention on the rights of the child* (3rd ed.), United Nations Children's Fund 2007, p. 385, https://digitallibrary.un.org/record/620060?lnen (accessed on: 6.11.2020).

[26] S.L. de Detrick, *A commentary…*, *op. cit.*, p. 447; W. Vandenhole, *A commentary…*, *op. cit.*, pp. 24–30.

[27] W. Vandenhole, *A commentary…*, *op. cit.*, pp. 1, 15.

each social security system. The principle of progressive improvement of the system should apply. Equality of treatment should be ensured for nationals of other contracting states, along with "granting, maintenance and resumption of social security rights".[28]

3.4. Analysis of the Inclusive and Child-Sensitive Social Security System and Social Protection in General

While examining the literature on the social protection and social security of children I have found models which can be applied while analyzing the social security system of Hungary from the disabled children's point of view.

First, the following principles should be considered in the design, implementation and evaluation of child-sensitive social protection programmes: concretely, child-sensitive social protection should focus on aspects of well-being that include: providing adequate child and maternal nutrition; access to quality basic services for the poorest and most marginalized; supporting families and caregivers in their childcare role, including increasing the time available within the household; addressing gender inequality; preventing discrimination and child abuse in and outside the home; reducing child labour; increasing caregivers' access to employment or income generation; and preparing adolescents for their own livelihoods, taking account of their role as current and future workers and parents.[29]

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[28] R. Ruggiero, *Article 26…*, *op. cit.*, p. 219.

[29] In other words: avoid adverse impacts on children and reduce or mitigate social and economic risks that directly affect children's lives. Intervene as early as possible where children are at risk, in order to prevent irreversible impairment or harm. Consider the age-and gender-specific risks and vulnerabilities of children throughout the lifecycle. Mitigate the effects of shocks, exclusion and poverty on families, recognizing that families raising children need support to ensure equal opportunity. Make special provision to reach children who are particularly vulnerable and excluded, including children without parental care, and those who are marginalized within their families or communities due to their gender, disability, ethnicity, HIV and AIDS or other factors. Consider the mechanisms and intra-household dynamics that may affect how children are

Second, the Special Rapporteur made the following recommendations to States with the aim of assisting them in developing and implementing the disability inclusive social protection systems expected by the CRPD:

a) Ensure that the right of persons with disabilities to social protection is recognized in domestic legislation and taken into account in national social protection strategies and plans, including nationally defined social protection floors.
b) Implement comprehensive and inclusive social protection systems that mainstream disability in all programmes and interventions, and ensure access to specific programmes and services for disability-related needs.
c) Design disability benefits in a way that promotes the independence and social inclusion of persons with disabilities and does not limit their full and equal enjoyment of other human rights and fundamental freedoms.
d) Ensure that eligibility criteria and targeting mechanisms do not discriminate directly or indirectly against persons with disabilities; disability determination, when established, must respect the rights and dignity of persons with disabilities.
e) Guarantee that benefits and services offered by social protection programmes are relevant for persons with disabilities and consistent with the right to an adequate standard of living.
f) Refrain from adopting any retrogressive austerity measures that directly or indirectly affect the right of persons with disabilities to social protection.
g) Develop disability-related indicators, undertake research on social protection and collect data, disaggregated on the basis of disability and gender, to adequately assess the impact of social protection programmes on persons with disabilities.
h) Establish formal consultative mechanisms to ensure the active involvement and participation of persons with disabilities

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reached, with particular attention paid to the balance of power between men and women within the household and broader community. Include the voices and opinions of children, their caregivers and youth in the understanding and design of social protection systems and programmes. Joint statement 2019, p. 2.

and their representative organizations in decision-making processes related to social protection, including in relation to budget cuts.

i) Encourage international cooperation to support inclusive social protection systems, facilitate cooperation to make mainstream social protection programmes inclusive of persons with disabilities, and develop and improve disability-specific programmes and services.

Thirdly, according to Côte inclusive social protection combines a diversity of schemes to provide basic income security, to cover disability-related costs including support services as well as to grant access to health care and other essential services.[30]

1. Countries have adopted different tax-financed cash transfers which can be broadly divided into three categories depending on their purpose: basic income security, coverage of disability-related costs, and hybrids whose purpose depends on the individuals' circumstances.
2. In-kind support and concessions can respond directly to a disability-related need such as health care, assistive devices or support services which are quite costly and cannot be covered by a basic disability allowance. Other concessions such as free public transportation or tax exemption for disability card holders can contribute to offset some disability-related costs. Concessions that appear to be the most valued are free or heavily subsidized health care, assistive devices and transport and housing and utility bill subsidies. Income tax exemptions are valued in countries with a wide formal sector as they provide relief to many parents of children with disabilities and increase benefits of entering the formal economy.
3. Access to health care, including rehabilitation and assistive technology.
4. Support services such as personal assistance, sign language interpreters, circles of support for persons with intellectual disabilities and respite services are critical for both

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[30] See this system in: A. Côte, *Disability…*, *op. cit.*, pp. 363–364.

the survival and basic socio-economic participation of many persons with significant disabilities.

5. Inclusive combinations of schemes.
6. There are some general design choices to be considered that can have a significant impact on effective support for inclusion of a given scheme.

Therefore, when analyzing and creating the Hungarian (and Polish) effective social protection system for disabled children, these models shall be considered when formulating *de lege ferenda* recommendations.

3.5. Analysis of the Social Security System in Particular in Hungary from the Disability's Point of View

In Hungary, the following division of the system of social law is possible, which is the one most commonly used in the legal literature.[31]

The first group is the insurance system. In Hungary, social security covers health insurance, accident insurance and pension insurance and, more broadly, unemployment benefits. The provision of services through this system constitutes the largest part of the state (social law) functions. The second group is the so-called care or compensation system, in which benefits are linked to objective life situations, with citizens becoming entitled to a service if this particular situation exists, without any other prior criteria. And finally, the third type is the benefit system, which is characterized by means-tested benefits and is subsidiary in nature.

According to this grouping, the Hungarian social system is of a mixed nature, with both insurance and benefit elements present, with the insurance elements predominating. On the basis of the above criteria, benefits provided by social law institutions can be broadly grouped into three broad systems: social security benefits, family benefits and other benefits for families with children, and benefits provided by the social administration system.

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[31] H. Tóth, G. Mélypataki, *The Challenge..., op. cit.*, pp. 50–68.

Table 1. Benefits in cash based on disability

Benefits in cash
Benefits for persons with reduced capacity for work – REHABILITATION PAYMENT
Benefits for persons with reduced capacity for work – DISABILITY ALLOWANCE AND EXEMPTIONAL DISABILITY ALLOWANCE
Benefits for disabled persons – SICKNESS BENEFIT
Family support benefits – FAMILY SUPPORT
Family support benefits – FAMILY ALLOWANCES/FAMILY SUPPLEMENTARY PAYMENTS – EDUCATION SUPPORT
Family support benefits – CHILD CARE ALLOWANCE
Family support benefits – CHILD CARE SUPPORT (CHILD SUPPORT)
Social cash benefits – CARE FOR THE WORKING AGE POPULATION – DISABILITY AND CHILD CARE ALLOWANCE
Social cash benefits – CARE FOR THE WORKING AGE POPULATION – EMPLOYMENT SUBSTITUTION ALLOWANCE
Social cash benefits – CARE ALLOWANCE, INCREASED CARE ALLOWANCE, SPECIAL CARE ALLOWANCE
Social cash benefits – CHILDREN'S HOME CARE ALLOWANCE
Social cash benefits – OLD AGE INCOME
Social cash benefits – ELDERLY CARE SUPPORT FOR LONG-TERM CARERS
Social cash benefits – MUNICIPAL SUBSIDIES
Dependants' cash retirement benefits – ALLOWANCE FOR ORPHANS
State allowances for persons with reduced mobility – ACCESSIBILITY SUPPORT
State aid for persons with reduced mobility – PUBLIC TRANSPORT GRANT
Cash benefits for severely disabled persons – DISABILITY ALLOWANCE
Family support benefits – INFANT CHILD CARE FEES
Family support benefits – CHILD CARE ALLOWANCE

Source: http://kezenfogva.hu/ellatasok_tipus.

Table 2. Benefits in kind, other forms of support and the personal care benefits

Benefits in kind
Benefits in kind for severely disabled persons – PARKING ALLOWANCE
Social benefits in kind – ESTABLISHING ELIGIBILITY FOR HEALTH SERVICES
Social benefits in kind – PUBLIC HEALTH CARE
Child protection benefits in kind – REGULAR CHILD PROTECTION BENEFIT
Other forms of support
Benefits for families – FAMILY BENEFIT reducing the consolidated tax base
Benefits for severely disabled persons – MOTOR VEHICLE TRAVEL DISABILITY
Benefits for severely disabled persons – PERSONAL GRANT reducing the consolidated tax base
Benefit on the basis of social need – CONSUMER TO BE PROTECTED – supply of natural gas
Benefit on the basis of social need – CONSUMER TO BE PROTECTED – electricity supply
Benefit on the basis of social dependency – USER TO BE PROTECTED – water supply
Personal care benefits
Basic child welfare benefits for personal care – DAILY CARE OF CHILDREN
Basic child welfare services providing personal care – CHILD CARE SERVICES
Basic social work activities providing personal care – FAMILY CARE
Basic social work activities providing personal care – CATERING
Basic social work activities providing personal care – HOUSEHOLD SUPPORT
Basic social work activities with personal care – SIGNALLING HOME ASSISTANCE
Basic social services providing personal care – COMMUNITY SUPPLIES

continued Table 2

Basic social services providing personal care – DAILY SUPPLY
Basic personal care services – SUPPORT SERVICES
Specialised social care services providing personal care – ACCOMMODATION AND CARE SERVICES
Specialised social work activities providing personal care – TEMPORARY ACCOMMODATION INSTITUTIONS
Specialised social services providing personal care – RESIDENCES
Specialised social assistance providing personal care – ASSOCIATED HOUSING

Source: http://kezenfogva.hu/ellatasok_tipus.

Table 3. All the services and benefits which might be provided for disabled children from all the services and beenfits available based on disability

Right to benefit from the social security system
MEANS-TESTED
Family support benefits – FAMILY SUPPORT
Family support benefits – FAMILY ALLOWANCES/FAMILY SUPPLEMENTARY PAYMENTS – EDUCATION SUPPORT
Family support benefits – CHILD CARE ALLOWANCE
Family support benefits – CHILD CARE SUPPORT (CHILD SUPPORT)
Social cash benefits – CARE FOR THE WORKING AGE POPULATION – DISABILITY AND CHILD CARE ALLOWANCE
Social cash benefits – CARE ALLOWANCE, INCREASED CARE ALLOWANCE, SPECIAL CARE ALLOWANCE
Social cash benefits – CHILDREN’S HOME CARE ALLOWANCE
INSURANCE BASED
Dependants’ cash retirement benefits – ALLOWANCE FOR ORPHANS
Family support benefits – INFANT CHILD CARE FEES
Family support benefits – CHILD CARE ALLOWANCE

continued Table 3

MEANS-TESTED
Basic child welfare benefits for personal care – daily care of children
Basic child welfare services providing personal care – child care services
Basic social work activities providing personal care – family care
Basic social work activities providing personal care – catering
Basic social work activities providing personal care – household support
Basic social work activities with personal care – signalling home assistance
Basic social services providing personal care – community supplies
Basic social services providing personal care – daily supply
Basic personal care services – support services
Specialised social care services providing personal care – accommodation and care services
Specialised social work activities providing personal care – temporary accommodation institutions
Specialised social services providing personal care – residences
Specialised social assistance providing personal care – associated housing

Source: http://kezenfogva.hu/ellatasok_ipus.

According to the tables, it is obvious that the focus is on the means-tested benefits (in cash, in kind and personal care) while assuring the right to benefit from the social security for disabled children. The amount of mean tested benefits are low and therefore it is questionable whether they can contribute to an adequate standard of living. The disabled child is protected mainly by services offered to the family. In terms of legislation in the area of social security, the legal environment for services has for decades been stable.

According to Côte's inclusive social protection model, we can also conclude the following: Hungary has adopted different tax-financed cash transfers which are hybrids whose purpose depends on the individuals' circumstances. In-kind support and concessions can respond directly to a disability-related need such as health care, assistive devices or support services which are quite costly and cannot be covered by a basic disability allowance. Other concessions such as free public transportation or tax exemption for disability card holders can contribute to offset some disability-related costs. Concessions that appear to be the most valued are free or heavily subsidized health care, assistive devices and transport and housing and utility bill subsidies. Income tax exemptions are valued. Access to health care, including rehabilitation and assistive technology plays also a key role in the system. Support services such as personal assistance, sign language interpreters, and circles of support for persons with intellectual disabilities and respite services are critical. It can be stated that it is an inclusive combination of schemes.

According to the Rapporteur's recommendations we can conclude:

a) that the right of persons with disabilities to social protection is recognized in domestic legislation but is hardly taken into account in national social protection strategies and plans, including nationally defined social protection floors.
b) Implementation of comprehensive and inclusive social protection systems that mainstream disability in all programmes and interventions, and ensure access to specific programmes and services for disability-related needs, has not been realized. The holistic approach in every policy has not been reflected.
c) Disability benefits can not promote the independence and social inclusion of persons with disabilities and does not limit their full and equal enjoyment of other human rights and fundamental freedoms.
d) The eligibility criteria and targeting mechanisms do not discriminate directly or indirectly against persons with disabilities; disability determination, when established, respects the rights and dignity of persons with disabilities.
e) Many more social protection programmes are needed for persons with disabilities.

It is also needed:

1. to develop disability-related indicators, undertake research on social protection and collect data, disaggregated on the basis of disability and gender, to adequately assess the impact of social protection programmes on persons with disabilities;
2. to establish formal consultative mechanisms to ensure the active involvement and participation of persons with disabilities and their representative organizations in decision-making processes related to social protection, including in relation to budget cuts; and
3. to encourage international cooperation to support inclusive social protection systems, facilitate cooperation to make mainstream social protection programmes inclusive of persons with disabilities, and develop and improve disability-specific programmes and services.

There is a particular shortage of foster parents capable of caring for children with dual needs, so these children are almost all in institutional care.[32] Institutionalization is not the way how children should be brought up, as it frequently has bad consequences with regard to their improvement.

3.6. *De lege ferenda* Proposals

Regarding the right of disabled children to benefit from the social security system, I make the following *de lege ferenda.* As the establishment of social rights depends on the financial situation of a state, it cannot be prescribed that the means tested benefits should be of a higher amount so that they contribute to the adequate living standard of disabled children. However, we can formulate the model of social protection in a broader sense consisting of different parts.

A child sensitive social protection system can be understood in a holistic way. It is a combination of means-tested, insurance based and personal care benefits. It is combined by a family friendly

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[32] PHRP Report on children's rights 2021.

labour law regulation. It addresses gender inequality and inequality of forms of work, as those self-employed are discriminated against in their social rights. It is also combined with a stable and effective child protection scheme and with effective tax, financial and employment policy decisions.

In the case of the proper and adequate legislative support of families, dependent disabled children might be provided with the proper improvement they deserve.

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Chapter 4. Support for Parents of Children with Disabilities

4.1. Introduction

The primary duty and right of parents is to bring up their child. Given the age period of children, this is undoubtedly a difficult task, a difficulty compounded by any child's disability. Daily life with a disabled child is complicated. Depending on the type of dysfunction, it requires a great deal of physical strength and mental toughness on the part of the parents. It is clear that such a child, due to their physical or mental dysfunctions, requires more support from the parents, but also assistance from public institutions. This is dictated not only by caring responsibilities, but also by the increased maintenance expenses of such a child, most often due to the need for constant rehabilitation. Assistance from public institutions, although targeted mainly at the disabled child, should bring about a real improvement in the functioning of the whole family, stabilize mutual relations, strengthen family ties and enable self-realization of its members. The aim of this study is to try to answer the questions whether the current legislation provides effective informational, social and material support to families of children with disabilities? Does devoting oneself to a disabled child disorganize the functioning of the family, having a destructive effect on it? The main research problem is the question of the type and extent of support dedicated to a family with a disabled child.

4.2. The Concept of Disability

The purpose of the study is not to analyse the concept of disability; nevertheless, for the sake of the logic of the considerations carried out, it should be emphasis that in the common understanding disability is generally understood to mean a physical or mental condition which limits or completely prevents independent functioning. According to the Sejm of the Republic of Poland, people with disabilities are those whose physical, mental or psychological disabilities permanently or periodically hinder, limit or prevent them from living, learning, working and fulfilling their social roles, therefore, according to legal and customary norms, they have the right to live independent, autonomous and active lives and must not be subjected to discrimination.[1] This is because disability triggers the emergence of certain specific human needs, and their failure to be taken into account in social life leads to such discrimination. Failure to take these needs into account necessarily creates barriers to full participation in social life and can lead to the social exclusion of people with disabilities. The legal definition of disability is contained in the Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities of 27 August 1997,[2] according to which disability means a permanent or periodic inability to fulfil social roles due to a permanent or long-term impairment of the body's functions, in particular resulting in an inability to work (Article 2(10)). The basis for considering a minor under the age of 16 as disabled is the establishment that he/she has a physical or mental impairment of an expected duration of more than 12 months, due to a congenital defect, long-term illness or damage to the body, resulting in the necessity to provide him/her with total care or assistance in meeting the basic needs of life in a manner exceeding the support

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[1] Resolution of the Sejm of the Republic of Poland of 1 August 1997: Charter of Rights of Persons with Disabilities, Monitor Polski 1997, No. 50, item 475.

[2] Act of 27 August 1997 on professional and social rehabilitation and employment of persons with disabilities, consolidated text Journal of Laws of 2023, item 100, as amended.

normally needed by a person of his/her age (Article 4a)[3]. All these conditions must occur together.

A child's disability is assessed for a specified period of time, but for a period not exceeding 16 years of age; the assessment of the child's ability to improve his or her functioning is decisive. A certificate of disability is issued upon application submitted to the county/city Disability Assessment Board by the child's legal representative. A certificate on the degree of disability is issued to a person who has reached the age of 16. The legislator provides a gradation of disability, establishing three degrees of disability – mild, moderate, or severe. The degree of disability is either temporary or permanent. For children up to the age of 16, no degree of disability is determined. The formal legal status of a disabled person depends on obtaining a disability certificate, which makes it possible to benefit from various forms of assistance.

The Convention on the Rights of Persons with Disabilities, drawn up in New York on December 13, 2006,[4] takes a different approach to disability, and adopts a human-rights model of disability. Moreover, the concept is dynamic and evolves as a result of the interaction between people with dysfunctions and the barriers created by human and environmental attitudes that impede their full and effective participation in society, on an equal basis with others (Article 1). In addition, the universality of the rights of people with disabilities and the problems associated with their observance further testify to the universal nature of disability. In view of this, the States Parties express their conviction that a universal and comprehensive international convention to promote and protect the rights and dignity of persons with disabilities is needed and will significantly contribute to remedying the profound social disadvantages of persons with

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[3] The criteria for assessing disability in persons up to the age of 16 are set out in the Regulation of the Minister of Labour and Social Policy of 1 February 2002 on the criteria for assessing disability in persons up to the age of 16, Journal of Laws of 2002, No. 17, item 162.

[4] Convention on the Rights of Persons with Disabilities, drawn up at New York on 13 December 2006, Journal of Laws of 2012, item 1169.

disabilities and promote their participation in the civil, political, economic, social and cultural spheres on an equal opportunity basis.[5]

4.3. Duty to Support Parents of Children with Disabilities

The emergence of a disability in a child is always a difficult experience for the whole family. "The illness of one family member modifies the functioning conditions of the whole family and triggers the need to activate adaptation measures. A new system of family dynamic equilibrium is created".[6] The child's disability causes a change in the family's previous way of functioning and life plans, their hierarchy of values, attitude towards faith and attitudes towards the environment. Family members are faced with entirely new challenges that force them to comprehensively reorganize their lifestyles. This applies in particular to the parents of a child with a disability, who, according to the provisions of the Act of 25 February 1964 Family and Guardianship Code[7], have the obligation to provide for the child's care and upbringing until the child reaches the age of majority (Article 95 § 1 in conjunction with Article 92). The above is a consequence of parental authority, which is vested

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[5] See Preamble to the Convention on the Rights of Persons with Disabilities. More broadly on the concept of disability, among others: M. Szeroczyńska, *Niepełnosprawność i osoba niepełnosprawna. Definicje*, [in:] A.M. Waszkielewicz (red.), *Polska droga do Konwencji o prawach osób niepełnosprawnych ONZ*, Kraków 2008; A. Błaszczak (red.), *Najważniejsze wyzwania po ratyfikacji Konwencji o Prawach Osób Niepełnosprawnych*, "Biuletyn Rzecznika Praw Obywatelskich" 2012, nr 10; M. Paluszkiewicz, *Prawne pojęcie niepełnosprawności*, "Studia Prawno-Ekonomiczne" 2015, t. 95; T. Degener, *Disability in Human Rights Context*, "Laws" 2016, No. 5; D.E. Lach, *Kilka uwag o nowych instrumentach wsparcia dla osób niepełnosprawnych*, "Praca i Zabezpieczenie Społeczne" 2018, nr 12; C. Budo, D.S. Bălăuță, F.L. Vlaicu, *The Role of the Family in the Social Integration of the Child with Disabilities*, "Journal Plus Education. Educatia Plus" 2021, Vol. 28, No. 1.

[6] R. Porzak, *Choroba somatyczna i jej wpływ na funkcjonowanie rodziny*, [in:] Z.B. Gas (red.), *Psychologia wychowawcza stosowana. Wybrane zagadnienia*, Lublin 1995, p. 151.

[7] Act of 25 February 1964 Family and Guardianship Code, consolidated text, Journal of Laws of 2020, item 1359, as amended.

in both parents and which should be exercised as the child's welfare and the public interest require (Article 93 § 1 in conjunction with Article 95 § 3). The parents shall bring up and direct the child under their parental authority. They are obliged to take care of the child's physical and spiritual development and to prepare him or her properly for work for the good of society in accordance with his or her talents (Article 96 § 1). Before making decisions on important matters concerning the child's person or property, they should listen to the child, if the child's mental development, state of health and degree of maturity so permits, and take into account the child's reasonable wishes as far as possible (Article 95 § 4). Parents are thus faced with the challenge of meeting the specific life and developmental needs of a child with a disability, adapting their existing life (marital, family, social, professional) to the new situation and adapting to the subsequent challenges of having and raising a child with a disability. Added to this is the need to deal with the further consequences of this particular life situation – marital crises, health problems, adaptation difficulties, problems obtaining support, and symptoms of burnout (apathy, indifference, aggression, powerlessness, doubt, insomnia) resulting from experiencing chronic life stress that is very difficult to work through[8]. Without the support and help of others, it will be difficult for a family with a child with a disability to cope with these challenges.

Faced with the experience of disability, it has been noted that parents of children with disabilities go through the following stages of coming to terms with this fact in turn:

1. a period of shock – also called a critical period or a period of emotional shock,
2. a period of emotional crisis, which is also called a period of despair or depression,
3. a period of apparent adjustment,
4. a period of constructive adjustment.

All families with a child with a disability have to go through all these stages. It is stressed that many families, however, stop

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[8] For more details, see: C. Maslach, M. Leiter, *Prawda o wypaleniu zawodowym. Co robić ze stresem w organizacji*, Warszawa 2011.

in the period of apparent adjustment, unable to overcome it. Very few, only about a third of parents, make it to the final, fourth stage. Only they are able to create opportunities for the child to develop properly.[9]

A child with a disability changes the organisation of the family life system in basically all its aspects, starting with the material situation, the family structure, the emotional bonds between family members, the fulfilment of functions carried out by the family, the parents' educational attitudes, the working life, and the social and cultural life of the family, resulting in a crisis situation for everyone in the system.[10] The way in which parents of a child with a disability cope with a crisis situation is highly individualized, determined on the one hand by the personal resources of the parents, and on the other hand by the social support they have been given, especially from those closest to them – family, friends, and acquaintances. Institutional support is also very important, especially over a longer period of time.[11] The support of loved ones and institutional assistance are among the most important factors determining both the quality of life of people with disabilities and their families.[12]

Support for parents of children with disabilities is a concept that describes the support activities of individuals and non-governmental institutions as well as institutional support. Undoubtedly, the support provided to parents of a child with disabilities must be multifaceted and multidimensional, while being consistent and long-term. The basic forms of support include:

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[9] A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] I. Obuchowska (red.) *Dziecko niepełnosprawne w rodzinie*, Warszawa 1991, p. 21.

[10] For more details, see: E. Janion, *Dziecko przewlekle chore w rodzinie*, Zielona Góra 2007, pp. 66–71.

[11] A. Jazłowska, H. Przybyła-Basista, *Doświadczanie stresu i odnajdywanie pozytywnych aspektów rodzicielstwa w kontekście wychowywania dziecka z niepełnosprawnością intelektualną*, "Dziecko Krzywdzone. Teoria, Badania, Praktyka" 2019, nr 2, p. 95.

[12] I. Olsson, L. Roll-Pettersson, *No, no, you cannot say that! Perceptions and experiences of parents of preschool children with intellectual disabilities in Sweden*, "European Journal of Special Needs Education" 2012, No. 1, p. 71.

1. emotional support – it is supposed to build a sense of security, create bonds of mutual trust, acceptance and care, transmit sustaining emotions, reducing anxiety and suffering;
2. informational support – aimed at better understanding of the situation, building knowledge of how and where to seek support and help;
3. instrumental support taking the form of instruction, boiling down to the exchange of information on ways of acting, attitudes and behaviours, possibilities of action;
4. material support involving giving material or financial assistance to a person in need;
5. spiritual support – the task of helping a person to understand his or her position in an existential context, providing support by referring to certain values, ideas and beliefs of the person in need, showing the role of suffering in human life and then making sense of this experience.[13]

Each of these types of support is important and each contributes first to the acceptance of the child with a disability and the associated limitations and additional responsibilities, then to action to overcome the limitations and take on these responsibilities. People with disabilities, especially children, need more support than others normally receive in order to live at a similar level. Providing support is a prerequisite for ensuring the most optimal development of a child with a disability.

In view of the unambiguously defined constitutional principles – subsidiarity, social solidarity, protection and care of marriage and family by the state, provision of special health care for children and persons with disabilities – assistance to parents of children with disabilities should be one of the basic elements of a well-thought-out, comprehensive and perspective-oriented state social policy. For since "the Republic is the common good of all citizens"

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[13] H. Sęk, R. Cieślak, *Wsparcie społeczne – sposoby definiowania, rodzaje i źródła wsparcia, wybrane koncepcje teoretyczne*, [in:] H. Sęk, R. Cieślak (red.), *Wsparcie społeczne, stres i zdrowie*, Warszawa 2004, p. 21.

(Article 1 of the Constitution of the Republic of Poland),[14] it must also take into account the needs of the most vulnerable who cannot meet their justified needs on their own. The right to special assistance from the public authorities applies primarily to families in a difficult material and social situation, which includes families experiencing disability.

A family with a child with a disability needs and benefits from many sources and types of support at different stages of the functioning of that support. Parents of a child with a disability expect first and foremost assistance in terms of rehabilitation, which offers a chance to minimise developmental difficulties, followed by material assistance to meet the increased needs of supporting a child with a disability. Only comprehensive support and assistance to parents of children with disabilities allows them to adapt constructively to the situation, maintain their mental balance, reduce the risk of burnout and even depression.

The process of constructive adaptation for parents of a child with a disability depends on many factors, among which the way in which information about the child's disability is communicated is important. Information about the child's disability is in most cases conveyed by medical professionals. The way it is communicated should be adapted to the parents' characteristics, such as their emotional state, level of education, language competence, previous experience with disability, socio-economic situation, level of expectations from the child, information needs, and cultural or religious differences. Inadequate communication of information, problems in accessing information, and limitations in accessing support are invariably the main difficulties faced by parents of children with disabilities.[15] Adopting positive coping strategies, eliminating or minimising feelings of insecurity and hopelessness about their situation, and how quickly they recognize the potential joys of having a child, all depend on the appropriate communication

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[14] Constitution of the Republic of Poland of 2 April 1997 (Journal of Laws of 1997, No. 78, item 483, as amended).

[15] A. Żyta, K. Ćwirynkało, *Wspieranie rodzin dzieci z niepełnosprawnością – perspektywa zmiany*, "Wychowanie w Rodzinie" 2015, nr 1, p. 393.

of information. As a rule, a child's disability is communicated by doctors, but this information is usually reduced to telling the child's parents that the child is developing abnormally. It is emphasis that medical staff are insufficiently prepared to communicate information to parents about their child's disability. The manner of communication leaves much to be desired, particularly when it comes to the formulation of the message, its content and the conditions in which it is delivered. Doctors also often lack empathy and objective communication of the description of the illness, and do not know how to enter into a conversation with the closest relatives of a child with a disability in a moment that is very difficult for them and saturated with negative emotions. Parents of disabled children are often not informed what help they can get and to whom they should turn for it. So they get such knowledge on their own from the Internet, from friends, from NGOs.[16] Meanwhile, gaining full access to information about support options often enables many other needs to be met, creating a sense of security for parents.

Informational support is extremely important, especially at the stage of initial adaptation to the situation, when parents find out about their child's disability and want to understand its nature, management and treatment, and receive guidance on what they can and should do to improve the quality of life of their child and family. Research carried out in Poland and around the world shows that invariably the most important expectations of parents of children with disabilities are: to obtain reliable information on disability, specialist services, shorter waiting times for advice, material support, increased cooperation and collaboration of all institutions dealing with the child with a disability and his/her family, and comprehensive assistance to the whole family and not only to the disabled person.[17] It is important that access to information is quick, simple, easy to read and that information is provided in an understandable way. It is particularly important that there should be an integrated

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[16] M. Buchnat, *Oczekiwania i doświadczenia wsparcia rodziców dzieci z niepełnosprawnością*, "Interdyscyplinarne Konteksty Pedagogiki Specjalnej" 2021, nr 33, p. 12.

[17] Ibidem, p. 10.

support system enabling comprehensive information to be obtained in one place, presenting the case from the beginning, providing the same documents, avoiding being sent from one office to another, and multiplying applications, which not only complicates but also lengthens the procedure for obtaining assistance. This kind of specific path, this kind of support to guide where to go, what to do, is currently the biggest problem facing families with a disabled child.

Prompt, reliable information enables parents to begin therapy immediately, which not only improves the child's current state of health, but also prevents it from worsening and increasing disorders. In other words, the sooner psychomotor, rehabilitation or improvement measures are taken, the greater their impact on the way a disabled child develops. This is all the more so because the nervous system of a young child (especially up to the age of two) is very plastic. It is therefore easier to compensate for its developmental deficits. Young children show faster progress in development, which is due to their greater susceptibility to the programmes of influence implemented towards them. Early development support also helps prevent the development of bad habits, which are difficult to eliminate later if they become entrenched in the child. Thus, starting therapy as early as possible (from the first months of a child's life) allows for the optimal reduction of differences in development between a disabled child and its healthy peers, which gives the child a chance for later contact with them,[18] proper socialisation and consequently social integration.

4.4. Material Support

The primary form of support for children with disabilities and their parents is financial provision. It is difficult not to notice the constant deficit of financial resources on the part of the majority of families of children with disabilities, due to the increased need for health

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[18] A. Mikler-Chwastek, *O zaletach wczesnego wspomagania rozwoju małych dzieci*, [in:] A. Twardowski (red.), *Wspomaganie rozwoju dzieci z rzadkimi chorobami chromosomowymi*, Poznań 2008, pp. 86–87.

services and rehabilitation services. Opportunities for systematic treatment and rehabilitation often depend on families' material resources, while the lack of such resources automatically limits a child's opportunities for development and reduces that child's chances of achieving independence in the future. Financial support enhances, therefore the ability of parents of children with disabilities to provide for themselves in other areas of functioning. Such support includes: family allowance and supplements to family allowance; care allowance: attendance allowance and attendance benefit; a one-off allowance for the birth of a child diagnosed with a severe and irreversible disability or an incurable life-threatening illness incurred during the prenatal period or at birth; social assistance benefits and a range of other forms of material and non-material support to compensate for limitations arising from disability. In order to receive this type of support, it is necessary to document the child's condition by obtaining a disability certificate. Such a certificate is issued, depending on the place of residence, by the County or Municipal Disability Assessment Boards.

Pursuant to the Act of 28 November 2003 on Family Benefits,[19] the family of a disabled child is entitled to: family allowance and supplements to family allowance; care benefits: attendance allowance and attendance benefit. Family allowance is granted in order to partially cover the expenses connected with the maintenance of the child (Article 4). The granting of this benefit is subject to the fulfilment of an income criterion. In the case of a disabled child, the income criterion – normally PLN 674 per month per family member for family benefits – is increased to PLN 764. Parents can count on a benefit of PLN 95 for a child up to the age of 5, PLN 124.00 – for a child over 5 up to the age of 18, and PLN 135 for a child over 18 up to the age of 24. For a disabled child, the family allowance is increased by an allowance for education and rehabilitation of that child (pursuant to Article 13 of the Act in the amount of PLN 90 per month per child up to the age of 5 or PLN 110 per month per child over 5 up to the age of 24). This allowance is intended to cover

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[19] Act of 28 November 2003 on family benefits, consolidated text, Journal of Laws of 2023, item 390, as amended.

expenses related to the rehabilitation or education of a child up to the age of 16, if the child has a disability certificate; from 16 to 24, if the child has a moderate or severe disability certificate. Apart from this, the Act introduces a number of manifestations of legal privileges related to disability – the period of payment of an allowance for the care of a disabled child during parental leave has been extended to 72 months (PLN 400), the amount of allowance for single parenting of a disabled child has been increased by PLN 80 in relation to the basic amount (PLN 193 per child; however, no more than PLN 386 for all children) and commencement by a disabled child of education at school outside the place of residence (due to residence in a locality where a primary, lower secondary, upper secondary or artistic school is located – in the amount of PLN 113).

The attendance allowance, pursuant to Article 16 of the Act, is due to: a disabled child; a disabled person over the age of 16, if they have a certificate of a significant degree of disability; a disabled person over the age of 16 with a certificate of a moderate degree of disability, if the disability arose until the age of 21; and a person over the age of 75. The allowance is granted to partially cover expenses resulting from the need to provide care and assistance of another person in connection with an inability to lead an independent life. The attendance allowance is not dependent on the income received by the parents of a disabled child. The amount of the attendance allowance as at 1 March 2023 is PLN 249.39 per month. When the right to the attendance allowance is established, it is valid for the period for which the disability certificate was issued (for a fixed period). The right to the attendance allowance is established until the last day of the month in which the assessment expires. However, a person placed in a 24-hour maintenance institution is not entitled to the attendance allowance if the person's stay and the services provided are partly or fully financed from the state budget or the National Health Fund. In addition, such a person, normally entitled to a care allowance, is not entitled to care allowance.

According to article 16a of the Act, the nursing benefit is due to, inter alia, the mother or father, or other persons on whom the child relies, in accordance with the provisions of the Act of 25 February 1964. Family and Guardianship Code, if they take care of a person who is under 18 years of age and has a considerable degree of disability or a disability certificate with the following indications: the need for permanent or long-term care or assistance of another person in connection with a significantly limited possibility of independent existence and the need for permanent co-participation of the child's guardian in the child's everyday life in the process of treatment, rehabilitation and education. Obtaining this benefit is not conditional on resigning or not taking up employment in order to care for the disabled person, which ensures the possibility to obtain resources to better fulfil their parental duties. This is all the more so as caring for a disabled child is expensive. The right to attendance allowance is established indefinitely. An exception applies if the disability certificate or degree of disability has been issued for a limited period. In such a situation, the right to this benefit is established until the last day of the month in which the assessment expires. The granting of this benefit does not depend on the family income criterion. The nursing benefit as of 1 January 2023 was PLN 2,458 per month. The amount of the nursing benefit is increased by 100% for the second and each subsequent person over whom care is exercised. The head of the local authority, the mayor or the president of the city pays a contribution for pension and disability insurance and health insurance for a person collecting a nursing benefit.

It should be added that for persons residing in their area, the municipal council may establish benefits other than those specified in the Family Benefits Act. These will be different forms of assistance, e.g. an interest-free loan or an allowance intended for a specific purpose – the purchase of medicines for instance. Pursuant to Article 22b(2) of the Family Benefits Act, detailed rules for granting such benefits and their amount are determined by a resolution of the municipal council. This depends, of course, on the wealth of the municipality, as the payment of such benefits is financed from the municipality's own funds.

Pursuant to Article 10 of the Act of 4 November 2016 on support for pregnant women and families „Za życiem",[20] the mother or father

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[20] Act of 4 November 2016 on support for pregnant women and families „Za życiem", consolidated text, Journal of Laws of 2023, item 1923.

of a child, the legal guardian or the actual guardian, is entitled to a one-off benefit for the birth of a child diagnosed with a severe and irreversible disability or an incurable life-threatening illness that arose during the prenatal period of the child's development or during childbirth (the so-called "pro-life" benefit). It has a fixed value set at PLN 4,000 per child and it is entitled regardless of income. The benefit is not due in the case of stillbirth or if the child has been placed in an institution providing round-the-clock maintenance.

Pursuant to the Act of 12 March 2004 on social assistance,[21] a family with a disabled child may be granted a periodic allowance (Article 38) and a purpose-specific allowance (Article 39) in order to meet an essential living need, e.g. to cover the costs of medicines or treatment (without direct reference to disability). A formal and legal condition for receiving benefits from the social welfare system is meeting the income criterion established by the Regulation of the Council of Ministers of 15 July 2021 on verified income criteria and amounts of cash benefits from social welfare,[22] which is PLN 776 for a person running a household alone and PLN 600 for a person in a family. A disabled child who requires partial care and assistance in meeting the essential needs of life may be granted regular care services, specialized care services or a meal, provided in a support centre (Article 51). A disabled person requiring round-the-clock care, unable to function independently in daily life and who cannot be provided with the necessary assistance in the form of care services, is entitled to be placed in a social welfare home (Article 54). Among the types of social welfare homes, provision is made for social welfare homes for children and adolescents with intellectual disabilities and for persons with physical disabilities (Article 56, points 5 and 6). The Act also provides cover for persons who, due to the need to provide direct personal care for a long-term or seriously ill family member and a mother, father or sibling not

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[21] Act of 12 March 2004 on social assistance, consolidated text, Journal of Laws of 2023, item 901, as amended.

[22] Regulation of the Council of Ministers of 15 July 2021 on verified income criteria and amounts of cash benefits from social assistance, Journal of Laws of 2021, item 1296.

living together, resign from employment or are on unpaid leave. Pursuant to Article 42 of the Act, a social assistance centre or a social services centre pays a pension and disability insurance premium for such a person if the income per person in the family of the caring person does not exceed 150% of the income criterion amount per person in the family, and the caring person is not subject to compulsory pension and disability insurance on other grounds or does not receive a pension or disability allowance.

The provisions of the Act of 9 June 2011 on family support and the foster care system,[23] provide for special types of institutions for children with disabilities – specialist, professional foster families and care and educational institutions of a specialist-therapeutic type, where children requiring special, individual care are placed, due to their health condition requiring the use of specialist care, rehabilitation and revalidation. Pursuant to Article 81 of the Act, a foster family or a family run orphanage is entitled to a child maintenance allowance of no less than PLN 200 per month for a disabled child with a disability certificate or a certificate with a significant or moderate degree of disability.

Pursuant to Article 10 of the Act of 27 August 1997 on Vocational and Social Rehabilitation and Employment of Persons with Disabilities, the basic forms of activity supporting the process of social and vocational rehabilitation include subsidized participation in a rehabilitation turnout (Article 10c)[24] and participation in occupational therapy workshops (Article 10f). A disabled person may apply for co-financing of participation in a rehabilitation turnout if the average monthly income, within the meaning of the Act on Family Benefits, divided by the number of persons in a joint household, calculated for the quarter preceding the month in which

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[23] Act of 9 June 2011 on family support and the foster care system, consolidated text, Journal of Laws of 2023, item 1426, as amended.

[24] Rehabilitation turnout means an organised form of active rehabilitation combined with elements of rest, the aim of which is the general improvement of psycho-physical fitness and development of social skills of participants, inter alia, through establishing and developing social contacts, pursuing and developing interests, as well as through participation in other activities provided for in the programme of the turnout.

the application is submitted, does not exceed 50% of the average remuneration in the national economy per person in a joint household (65% of the average remuneration in the case of a single person). The amount of subsidy is 27% of the average salary in the national economy for a disabled person up to the age of 16, a disabled person aged 16-24 who is studying and not working, regardless of the degree of disability, and a disabled person with a significant degree of disability, and 18% of the average salary for the disabled person's guardian. Occupational therapy workshops, on the other hand, serve for the general improvement and development of the disabled person's skills in performing activities of daily living and personal resourcefulness, as well as preparing him or her for life in a social environment, i.e. developing the ability to plan and communicate, make choices, decide on his or her own affairs, as well as improving their mental condition. In addition to this, the workshops are intended to contribute to the development of the psycho-physical abilities necessary for future work and to the development of basic and specialized vocational skills, enabling people to take up employment in a vocational activation establishment or other gainful employment or vocational training.

Allowances and benefits are not the only measures parents of children with disabilities can count on. Financial support in the form of subsidies from the State Fund for Rehabilitation of Disabled Persons (PFRON) or support offered by the National Health Fund (NFZ) should also be mentioned. Co-financing from PFRON makes it possible to finance, most often in part, expenses related to a stay at a rehabilitation camp, removal of architectural barriers (handrails, ramps, lifts, hoists), and the purchase of orthopaedic and rehabilitation equipment and aids (hearing aids, glasses, wheelchairs, orthopaedic shoes, nappies, bedsores). The amount of subsidy depends on the income criterion per person in the family. On the other hand, the support offered by the NFZ includes: reimbursement of certain medical devices; nursing home long-term care; long-term home care for mechanically ventilated children and adolescents with respiratory insufficiency (requiring invasive or non-invasive, continuous or periodic respiratory therapy, who at the same time do not have to stay in intensive care units or in institutions providing

24-hour health care services); the costs of the stay of patients requiring 24-hour nursing, caring and rehabilitation services in care and treatment and nursing care institutions.

It is also possible to benefit from a rehabilitation allowance[25] in the form of a deduction from income of the amount spent for rehabilitation purposes and those related to facilitating the performance of activities of daily living. These amounts can take the form of unlimited expenses and limited expenses. Expenditure that is not limited in amount can be used by disabled persons as well as by persons whose dependants were disabled during the tax year. Unlimited expenses that can be deducted from income include:

1. adaptation and furnishing of dwellings and residential buildings;
2. adaptation of motor vehicles;
3. purchase and repair of individual equipment, devices and technical tools necessary for rehabilitation and facilitating the performance of activities of daily living, according to the needs resulting from the disability, with the exception of household equipment;
4. purchase of publications and training materials (aids);
5. paid stay at a rehabilitation camp;
6. paid stay at a spa treatment facility, stay at a therapeutic rehabilitation facility, care and treatment facilities and payment for rehabilitation procedures;
7. nursing care at home for a disabled person in the period of a chronic illness preventing mobility and care services provided for disabled persons classified in the 1st group of disability;
8. payment for a sign language interpreter;

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[25] The rehabilitation allowance is regulated in two tax laws – in Article 26(1)(6), (7a–7g) and (13a) of the Personal Income Tax Act of 26 July 1991 (consolidated text, Journal of Laws of 2022, item 2647, as amended), and in Article 11(1) of the Act of 20 November 1998 on Lump Sum Income Tax on Certain Income Earned by Natural Persons (consolidated text, Journal of Laws of 2022, item 2540, as amended).

9. camps and holidays for children and young people with disabilities and children of disabled persons who are under 25 years of age;
10. paid, necessary transport to necessary therapeutic and rehabilitation procedures: a disabled person – by ambulance of sanitary transport; a disabled person classified in the 1st or 2nd group of disability and children with disabilities up to the age of 16, also by means of sanitary transport other than ambulance;
11. paid travel by means of public transport related to the stay: on a rehabilitation holiday; in spa treatment centres, therapeutic rehabilitation centres, care and treatment centres and nursing care centres; on colonies and camps for children and young people with disabilities and children of persons with disabilities who are under 25 years of age.

Expenses limited by amount (in 2023. maximum amount of PLN 2,280 could be deducted), include: payment of guides for blind persons of the 1st or 2nd group of disability and persons with locomotor disabilities classified in the 1st group of disability; costs of maintenance of an assistance dog; expenses for maintenance of a car connected with its use, owned (or co-owned) by a disabled person or a person who has a disabled person or disabled children under 16 as dependants – for the purposes connected with transport to necessary medical and rehabilitation treatments.

A disabled person classified as having a significant or moderate degree of disability, who has significantly impaired ability to move independently; a disabled person under 16 years of age, who has significantly impaired ability to move independently; an institution providing care, rehabilitation or education to disabled persons who have significantly impaired ability to move independently is entitled to a parking card.[26] The certificate on disability, on the degree of disability or on indications of relief and entitlements must include an indication for the issuance of a parking card, otherwise a parking

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[26] The rules for granting and using a parking card are laid down in the Act of 20 June 1997 – Road Traffic Law, consolidated text, Journal of Laws of 2023, item 1047, as amended.

card will not be issued. A certificate with a moderate degree of disability must additionally have one of the symbols indicating the cause of the disability: 04-O (visual impairment); 05-R (locomotor impairment); 10-N (neurological disease). A disabled person, holding a parking card, driving a motor vehicle marked with such a card, may disobey certain traffic signs prohibiting movement or parking. This also applies to the driver of a vehicle who is transporting a disabled person with a parking card.

Disabled persons and parents of disabled persons are also entitled to other concessions, among which it is necessary to point out: public transport concession; train concession; exemption from the obligation to pay the radio and television licence fee; postal concessions and special entitlements in Polish Post offices; museum concessions; exemption from the tax on civil law transactions (when purchasing rehabilitation equipment, a wheelchair, a moped, a motorbike or a passenger car for one's own needs).

4.5. Modification of Working Conditions

The legislator meets the expectations of families of children with disabilities by introducing modifications to the labour law. It is obvious that caring for a disabled child makes the professional sphere of a person's life more difficult, as it requires the parents of disabled children to be more committed at the expense of their time available for work. In view of this, the Act of 26 June 1974 Labour Code[27] grants special rights to employees – parents of children with disabilities; they can apply for: to perform intermittent work; to have mobile working hours; to have an individual working time schedule; to perform work in the form of telework. Such a concession in favour of an employee – the parent of a child with a disability – allows him/her to reconcile childcare with work, allows him/her to remain professionally active, protects him/her from marginalisation, but also – last but not least – relieves the state budget from having to support

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[27] Act of 26 June 1974 Labour Code, consolidated text, Journal of Laws of 2023, item 1465.

a parent who would have to give up work at the price of caring for a child with a disability. The application may be submitted by an employee-parent of a child who has:

1. a certificate of disability or a certificate with a moderate or significant degree of disability;
2. an opinion on the need for early support of the child's development, a certificate on the need for special education or a certificate on the need for remedial classes;
3. a certificate on a severe and irreversible handicap or an incurable life-threatening illness, which arose during the prenatal period of the child's development or during childbirth.

The employer is obliged to grant such a request, unless it is not possible to do so due to the organisation of work or the type of work performed by the employee. It should be added that this entitlement also applies to the employee-parent once the disabled child has reached the age of 18.

An employee-parent of a disabled child who requires personal care is also entitled to take an extended parental leave of up to 36 months, but no longer than until the child reaches the age of 18. Additional parental leave is a special leave aimed at the employee's care of a disabled child. This leave is granted regardless of whether parental leave has been taken. This means that parents of a child with a disability are entitled to two types of parental leave, one of which they should take before the child reaches the age of four, while they are entitled to take the other until the child reaches the age of 18.

4.6. Non-Institutional Support

The assistance provided to parents of children with disabilities by the state is essential. No less important is the non-institutional support provided outside the state apparatus, by various associations, foundations, non-profit organisations or NGOs. Such support should be in the nature of a subsidiary accompaniment to the parents of a child with disabilities, without attempting to replace the parents in the process of counteracting the dysfunctions resulting from the disability. No one knows the child and his/her needs better than his/her parents; moreover, no one has the right to replace the parents in the care and parenting process.

Parental support is desirable, even necessary, above all in relieving the parents of the excessive burden of the daily care of a child with disabilities, which can hinder them from fulfilling their other social roles – that of spouse, the parent of other children, employee, etc. The support they receive, which amounts to periodically taking over some of the responsibilities of parents of children with disabilities, not only makes it easier for them to fulfil these varied roles, but also to maintain their psychological balance.

Self-help takes different forms – it includes activities in associations, participation in occasional actions and programmes, often arranged through social networks and online forums (e.g. fundraising), as well as the exchange of information or sharing of experiences on websites for parents of children with disabilities. Individuals affiliated to different types of support organisations support each other in such a way that they develop an attitude of self-reliance, activity and the ability to use the knowledge gained to overcome the difficulties encountered.[28] Families of children with disabilities in self-help groups exchange experiences, offer their knowledge about their child's illnesses, methods of diagnosis, types of therapy, availability of treatment, etc. to others. Many time families of children with disabilities are there to help other parents who find themselves in a similar life situation to their own, who feel lost in a complicated system of institutional support and overwhelmed by the fact of their child's disability, uncertain of their child's fate and aware of their own limitations. Thanks to the mutual exchange of information, experiences, and emotions, the roles of the recipient and the donor of social support intermingle. This is why families of children with disabilities strive to organise themselves for joint actions in order to improve the situation of their children, but also their own situation, as well as to promote, maintain and restore

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[28] M.A. Sierecka, *Wolontariusze wsparciem dla rodzin z dzieckiem niepełnosprawnym*, "Niepełnosprawność – Zagadnienia, Problemy, Rozwiązania" 2018, t. 3, nr 28, p. 136.

good functioning and normal relations in the community.[29] Any assistance and social support provided to the family of a child with a disability has a significant impact on the functioning and dynamics of the bonds within the family, the degree of permanence of feelings between its members. In families that have been deprived of such support, it has been observed that they succumb more easily to difficulties, become closed in on themselves and isolated from the social environment.[30]

Associations, foundations and other organisations whose statutory activities include organising and providing assistance to people with disabilities can also support children with disabilities by donating funds for their treatment, rehabilitation, the purchase of medicines, medical equipment, educational aids or other needs.

Non-profit organisations or NGOs are an important element of any effectively and democratically functioning state. They carry out tasks that arise from state policy or those that neither public nor private profit-oriented entities undertake despite an existing demand. They provide services, often filling a gap that is not filled by the public and market sectors. The non-governmental sector offers "the provision of counselling and information services (arranging paperwork, obtaining rehabilitation equipment, organizing leisure activities), providing educational services (courses, training), providing assistance in finding a job (job placement), and providing psychological assistance (helplines) and in-patient assistance (shelters, night shelters)"[31] It is also involved in setting up and running its own centres, facilities, day care centres and supporting others. It works to protect children's health by providing financial

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[29] B. Szluz, *Wsparcie społeczne rodziny osoby niepełnosprawnej*, "Roczniki Teologiczne" 2007, nr 10, p. 210.

[30] For more details, see: E. Minczakiewicz, *Wsparcie społeczne rodziny jako czynnik modelujący i kształtujący więzi w rodzinie wychowującej dziecka z głębszą niepełnosprawnością intelektualną*, [in:] J. Głodkowska (red.), *Roczniki Pedagogiki Specjalnej*, t. 12–13, Warszawa 2002, pp. 268–291.

[31] I. Hebda-Czaplicka, *Możliwość społecznej integracji osób niepełnosprawnych*, [in:] B. Balcerzak-Paradowska (red.), *Sytuacja osób niepełnosprawnych*, Warszawa 2002, p. 94.

and psychological support to both the child and its parents.[32] Non-profit organisations or NGOs carry out numerous projects, actions and social campaigns to raise awareness of the problems of people with dysfunctions and their families, to organize counselling and assistance. Their activities also include initiatives to change legislation, to finance the specific needs of people with disabilities, to adapt infrastructure to their needs, to manage leisure time, and to provide transport services.[33]

A special role is played by volunteers, who, through their activities, instill a sense of security, give support and make illness or disability more than just suffering. Volunteers broaden the possibilities of people who are sick or disabled and enable them to overcome the resulting limitations. Volunteering for families of children with disabilities is first and foremost about being with other people, giving them your time, your good intentions, yourselves. It is also an extraordinary challenge, as children with disabilities need special care.[34] Volunteers organise happenings, and inform about and participate in social campaigns to support people with disabilities and their families. This form of helping others is an example of pro-social behaviour for the benefit of others, of selfless dedication to those in need of support. Volunteers help families with a disabled child in a variety of ways. Their help mainly consists of playing with the children, helping them with their studies and filling their free time. Often parents of children with disabilities, due to the amount of expenses they incur for rehabilitation, among other things, use volunteer tutors. By helping parents of children with disabilities, they are with them, accompanying them through the difficulties of illness or disability and motivating them to be active and to take action. In addition, volunteers can also participate in the rehabilitation or

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[32] J. Meissner-Łozińska, *Instytucje i organizacje wspierające dziecko i rodzinę*, [in:] U. Gruca-Mąsik (red.), *Pomoc, opieka, wsparcie dziecka i rodziny*, Rzeszów 2006, p. 85.

[33] J. Szymanowska, *Rodzina z dzieckiem niepełnosprawnym. Pomoc i wsparcie*, Białystok 2008, p. 48.

[34] M.A. Sierecka, *Wolontariat wśród osób niepełnosprawnych jako przykład zachowania prospołecznego*, "Niepełnosprawność – Zagadnienia, Problemy, Rozwiązania" 2016, nr 20, pp. 36–37.

therapy of children with disabilities and learn to provide assistance under the guidance of qualified professionals.[35]

The principles of volunteer work, their rights and obligations are regulated by the Act of 24 April 2003 on Public Benefit Activity and Volunteerism.[36] The proper implementation of the provisions of the Act is supervised by the Department of Social Economy and Public Benefit established at the Ministry of Family, Labour and Social Policy.

4.7. Summary

All of the above-mentioned forms of support, both institutional and non-institutional, can contribute to improving the quality of life of a child with disabilities, as well as to supporting his or her parents in their daily challenges. Of course, they will not eradicate the disability of a child with a disability, but they will at least contribute to alleviating the associated constraints of the child with a disability and his or her parents and the increased expenses they incur as a consequence of increased health and rehabilitation needs. There is no doubt whatsoever that appropriate support is considered a key issue determining the quality of life of persons with disabilities and their families.

To be effective, this support should be provided as soon as possible. The use of support depends on access to information about its types and the conditions for obtaining it. In view of this, it is a matter of priority to create a single, coherent and comprehensive system of managing an integrated package of services for the support of families of children with disabilities. Such a system should ensure effective access to information on the forms of support available to such families. This information should be unified, provided in an understandable way, and based on an up-to-date offer prepared

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[35] M.A. Sierecka, *Wolontariusze wsparciem…*, *op. cit.*, p. 142.

[36] Act of 24 April 2003 on public benefit activity and voluntary work, consolidated text, Journal of Laws of 2023, item 571.

by centres supporting such families.[37] The creation of such a system would allow quick access to information and, consequently, to obtain support also in other areas of life. It seems fundamental for the proper support of the family of a child with a disability to establish a body that would provide the necessary information, coordinate medical and therapeutic activities, provide the necessary guidance, and be able to direct the actions taken.

The way in which parents cope with their difficulties and the process of adaptation to the life situation in which they find themselves, altered by their child's disability, depends, of course, in addition to individual personal characteristics, on the support they receive. The quality of this support, its availability and the timing of its receipt, determine the adaptation process. It allows parents to regain confidence in their abilities, strength and the motivation to continue to act constructively and hope for the future, and at the same time prevents the occurrence of low self-esteem or even depression.[38]

A family with a child with disabilities can be provided with a fairly wide range of financial and institutional support. The measurability of the assistance offered and its adequacy or proportionality to the needs of a family with a child with disabilities remains a completely different issue. It is obvious that due to the child's disability these needs are much higher. The presentation of the catalogue of benefits offered and the amount of these benefits makes it possible to conclude that they are in significant conflict with the sphere of actual needs. The amounts of support received, although significantly increased over the past few years, are still highly inadequate. This is all the more so because every family in which at least one member is disabled incurs much higher than average operating costs. The above is a consequence of the increased health needs of a disabled person. Therefore, parents of children with disabilities should have a full opportunity to earn a living, especially as the benefits offered to them are not high. Moreover, the opportunity to work will bring tangible benefits not only to the parents of children with

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[37] M. Buchnat, *Oczekiwania…*, *op. cit.*, pp. 18–19.

[38] Ibidem, p. 17.

disabilities, but also to the state, as the higher the income, the higher the tax revenue, but also the better the material situation of families.

It seems necessary, therefore, to increase the interaction and cooperation of all institutions dealing with the child and family and to diversify assistance aimed at helping the whole family, not only the person with a disability.

Parents who dedicate themselves to their children with disabilities cannot be left alone, they cannot be excluded from society. They must remain physically fit and mentally balanced, all the more so as they have to deal on a daily basis with their child's disability, which in most cases cannot be overcome, and which must be lived with. One solution is the government's respite support programme, which allows another carer, often a volunteer, to take over the parent's duties on a periodic basis, thus providing an opportunity for respite and improves relationships within the family. This is where the role of volunteers and personal assistants becomes particularly apparent. Through support in activities of daily living, they make it possible for people with disabilities to enter the workforce and develop professionally. Through such support, people with intellectual disabilities have a better chance of inclusion and social rehabilitation. This, in turn, contributes to increasing the level of independence of children with disabilities. Thus, adequate support for children with disabilities will contribute to greater independence in adulthood. It therefore seems necessary to introduce such publicly funded forms of assistance as soon as possible. At the same time, the personal assistant should not be treated as a form of assistance of a social nature, but as part of a broader policy of equalising opportunities for people with disabilities.

The current approach to the system of supporting people with disabilities should be changed from an individual approach to disability, known as the paternalistic-medical, to a human rights model of disability, consistent with international standards, in which disability is perceived as a dynamic phenomenon, the result of an interaction between individual factors on the individual's side and environmental factors.

It is necessary to work closely with people with disabilities and the organisations representing them on the designed elements of the support system. When designing, enacting and implementing laws, policies or programmes relating to any kind of support, public authorities and institutions should consult and actively cooperate with various groups of people with disabilities through the organisations that represent them.

It is extremely important not to allow social support to replace a person's other options for solving problems. It is also dangerous if support is provided continuously, because the person then begins to lose the ability to cope independently in a critical situation, and thus his or her dependence on help and support from others increases.[39] However, all help and support is intended to be subsidiary, which means that it should not stifle expressions of independence or take away one's own initiative in overcoming one's own limitations.

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[39] M.A. Sierecka, *Wolontariusze wsparciem…*, *op. cit.*, p. 130.

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Chapter 5. Topical Issues of the Procedural Rights of Children with Disabilities in Hungarian Private Law

5.1. Introduction

According to Article XV of Fundamental Law of Hungary "Everyone shall be equal before the law. Every human being shall have legal capacity. By means of separate measures, Hungary shall protect families, children, women, the elderly and those living with disabilities. According to Article XVI(1) Every child shall have the right to the protection and care necessary for his or her proper physical, mental and moral development." The Fundamental Law of Hungary also highlights certain groups to be protected. This includes families, which are the smallest basic units of society, children, women, the elderly and the disabled.

In Hungary, we can find out about the proportion of people with disabilities and the type of their disability from the data of the Central Statistical Office. Based on data from the 2016 census, 408,022 people live with some form of disability.[1] Among them, 22,857 are children under the age of 14, and 33,923 are children and young adults between the ages of 15 and 29. Unfortunately, the statistical data do not include the exact number of children under 18, i.e., minor children. From this data, it can be concluded that a significant

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[1] Data provided by the Central Statistical Office, https://www.ksh.hu/stadat_files/ege/hu/ege0033.html (accessed on: 15.09.2023).

number of disabled persons belong to the older age group,[2] and the proportion of children with disabilities does not exceed 10%.[3]

Based on the above-mentioned authorisation of the Fundamental Law of Hungary a separate act, the *Act of XXVI of 1998 on the Rights of Disabled Persons and Ensuring Their Equal Opportunities* (hereinafter: Act on the Rights of Persons with Disabilities) regulates the rights of disabled persons. This act declares that disabled people are equal members of society with equal dignity, who are able to live with the rights and opportunities that belong to everyone only with significant difficulties or not at all.

The purpose of this act is to *define the rights of disabled persons,* the means of enforcing the rights, as well as to regulate the complex rehabilitation to be provided to such disabled persons, and as a result of all this, to ensure equal opportunities, independent living and active participation of disabled persons in social life.

Among the basic principles of the Act on the Rights of Persons with Disabilities,[4] this law states that the state is obliged to ensure the enforcement of the rights of disabled persons and the operation of the institutional system that compensates for the disadvantages of disabled persons in accordance with the current opportunities of the national economy. Due to their condition, disabled persons are less able to live with the rights they deserve equally with everyone else, so it is justified that they should be given an advantage

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[2] The largest share of the disabled population, almost half, is made up of people with mobility impairments. Between 2011 and 2016, the number of people with intellectual disabilities and autism increased. In: *Microcensus 2016. Characteristics of the population with disabilities and those restricted due to health reasons*, https://www.ksh.hu/docs/hun/xftp/idoszaki/mikrocenzus2016/mikrocenzus_2016_8.pdf (accessed on: 15.09.2023).

[3] For more, see: G. Fruzsina, *Fogyatékkal élő gyermekek helyzete Magyarországon*, [in:] O. Szeibert (ed.), *Gyermekjogi panoráma*, Budapest 2019, pp. 243–263.

[4] The Act on the Rights of Persons with Disabilities set up the National Disability Council, which has been operating as a counselling body of the Government and as a major forum for civil dialogue since 1999. Moreover, the Act on the Rights of Persons with Disabilities provides for specific rights of people with disabilities, such as – to give but a few examples – the rights to rehabilitation, to aid, to assistance services, to early development and to integrated or protected access to the labour market.

in every possible way. This Act enumerates the same rights of children with disabilities as non-disabled children in the field of education but does not mention the right of children to participate.

In Hungarian private law, the legal framework related to the participation of disabled children is determined by international legal conventions and EU law.[5] In this context, based on the relevant explanations and literature, we established that Article 12 of the Convention on the Rights of the Child (hereinafter: CRC) introduces the *fundamental principle* that all children capable of forming a view are entitled to express that view and have it taken seriously. It is a right that is particularly challenging in societies where children's views tend to be largely disregarded. The challenge is far greater for children with disabilities, who are widely assumed to lack the capacity or experience to make a significant contribution. The Convention on the Rights of Persons with Disabilities (hereinafter: CRPD) recognises that children with disabilities are commonly denied the right to be heard. Article 7 therefore obliges governments to ensure that they are "provided with *disability and age appropriate assistance* to realize that right" on an equal basis with others. The Committee on the Rights of the Child has provided a detailed analysis of how to interpret Article 12 of the CRC[6] and has also provided guidance on its implementation with regard to children with disabilities. Children with multiple and profound disabilities, including very young children, are able to form views, although they may need appropriate help in expressing them. What Article 12 requires is that adults commit to hearing those views with respect. The implementation of Article 12 requires *recognition of non-verbal forms of communications* such as body language, facial expression,

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[5] See more about this topic: Zs. Wopera, *The rights of participation of children with disabilities in cross-border family matters*. The study was made in the framework of the Polish-Hungarian Research Platform 2023 (PHRP) project and is under publication.

[6] For more, see: Implementation Handbook for the Convention on the Rights of the Child, Fully Revised Third Edition, United Nations Children's Fund, Geneva 2007, https://www.unicef.org/media/96496/file/Implementation%20Handbook%20for%20the%20Convention%20on%20the%20Rights%20of%20the%20Child.pdf (accessed on: 15.09.2023).

touch, sign language, play or drawing and painting, because some children use these ways to make choices, express preferences and demonstrate understanding of their environment.[7]

In 2015, "Report on access to justice for children with mental disabilities – International standards and research results in ten European countries" (hereinafter: Report) was published, which examines – among others – the procedural status of children with disabilities in 10 EU member states.[8] One of the member states was Hungary. We will refer to the report's findings in the study.

One of the most striking findings of the research is that it is complete missing the data that would reveal the number of children with mental disabilities who come into contact with the justice system, the type of their disability, and the outcome of the procedure. Although each state is involved has a human rights monitoring system, this marginalised group of children is rarely the focus of their attention.[9]

In the Hungarian regulations, the examination of the right to the participation of children with mental disabilities[10] is also relevant, because the participation of people with physical disabilities in court proceedings is basically a matter of accessibility.[11]

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[7] Take us seriously! Engaging Children with Disabilities in Decisions Affecting their Lives, UNICEF 2013, pp. 6–7, https://www.unicef.org/media/126316/file/Take-Us-Seriously.pdf (accessed on: 15.09.2023).

[8] Report on access to justice for children with mental disabilities – International standards and research results in ten European countries (A mentális fogyatékossággal élő gyermekek hozzáférése az igazságszolgáltatáshoz – Nemzetközi sztenderdek és kutatási eredmények tíz európai országban) MDAC Mental Disability Advocacy Center 2015. European Commission ISBN 978-615-80236-3-4 (hereinafter: Report), http://www.mdac.org/sites/mdac.info/files/access_to_justice_children_ws2_standards_and_findings_hungarian.pdf (accessed on: 15.09.2023).

[9] Report, p. 5.

[10] Report, p. 6.

[11] The following report presents a negative picture of procedural legal status of children with disabilities: Rights of persons with disability or reduced rights? (Fogyatékos személyek jogai vagy fogyatékos jogok?) Parallel report of the Hungarian civil caucus on the UN Convention, Budapest 2010, ISBN 978-963-88487-1-0 p. 206, https://mek.oszk.hu/13000/13044/13044.pdf (accessed on: 15.09.2023).

In Hungary, establishing contact with children with disabilities is also quite difficult, as many courts and offices are still not barrier-free. In addition, judges do not receive training on how to communicate with a visually impaired or hearing impaired or intellectually disabled child.[12]

In this study, in the light of the above-mentioned requirements, we will analyse the Hungarian civil substantive law and civil procedure law regulations from the point of view of what regulations they contain regarding the participation of disabled children in civil proceedings.

5.2. The Legal Framework of the Right of the Participation of Children with Disabilities in Hungarian Civil Substantive Law

The basic private law rules for minors can be found in two parts of *Act V of 2013 on the Civil Code* (hereinafter: Civil Code): in Book Two, entitled "The Individual as subject of Law", and in Book IV, entitled "Family Law Book".

5.2.1. A MINOR CHILD AS A SUBJECT OF LAW IN THE CIVIL CODE

In Hungarian law, in accordance with international legal regulations, a minor is a person under the age of eighteen.[13] Minors under the age of fourteen shall have no capacity to act. Minors shall have limited capacity to act if they have reached the age of fourteen. A minor child under the age of 18, regardless of whether he is disabled or not disabled is under parental custody. There is a special rule that minors having reached the age of seventeen may be placed

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[12] See more: K. Visontai-Szabó, *A gyermek jogainak érvényesülése a magyar polgári eljárásjogban*, "Erdélyi Jogélet" 2020, No. 10, pp. 84–110.

[13] CRC, Article 1.

by the court, under the rules applying to adults, under custodianship limiting their capacity to act partially or in full.[14]

According to the Civil Code a minor child shall be subject either to parental custody or guardianship. Parental custody includes the right and obligation to determine the minor child's name, to care for and bring the child up, to determine the place of residence and manage the minor child's assets, as well as the right to appoint a guardian and to exclude someone from being a guardian.[15]

The content of parental custody includes the *obligation to legally represent the child.* The parents exercising parental custody shall have the right and obligation to represent their child in his personal and property matters.

This means that the parent or guardian has the right to initiate an action on behalf of the minor, and the parent or guardian provides the legal representation of the child in the lawsuit as well. Those actions where there may be a conflict of interest between the parent and the child are of course an exception to this provision. This can happen e.g. in proceedings to establish parentage or in proceedings to terminate parental custody. This issue is properly settled by substantive and procedural rules.

Of course, this rule mentioned above does not apply to the hearing of the child, which is the child's personal declaration of rights, which the child himself makes in court. (See later in detail)

It is also important to emphasise that the parent shall not represent his child in cases in which the parent himself, his spouse, cohabitant, lineal relative or any other person whose statutory representation is performed by the parent is a party of opposing interest regarding the child. If the parent who is the statutory representative of the child cannot act in the child's affair by virtue of an Act or upon the order of the guardianship authority, due to conflict of interests or any other obstacle, the guardianship authority shall appoint an *ad hoc guardian* for the child. The appointment of an ad hoc guardian may be applied for by any interested party, any authority or it can also take place ex officio. For the purposes of the appointment

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[14] Section 2:18 (1) of Civil Code.

[15] Section 4:146 (2) of Civil Code.

of an ad hoc guardian, the parent shall be required to notify, without delay, the guardianship authority of the parent not being allowed to act due to the grounds specified earlier. The ad hoc guardian shall have the same competence as the guardian in the case.[16]

5.2.2. THE CHILD'S RIGHT TO PARTICIPATE IN CIVIL PROCEEDINGS AFFECTING HIM OR HER

The Family Law Book of the Civil Code places great emphasis on ensuring that the minor child has the opportunity to participate and express views in the proceedings affecting him or her.[17] The Civil Code provision *"Involving the child in the decision-making"* is of fundamental importance.[18]

According to Section 4:171(4) of the Civil Code, in the procedures for settling the exercise of parental custody and for the child's placement with a third party, the court shall hear both parents, except for irremovable obstacles, and "*must inform the child who has sufficient understanding* about the opportunity of expressing his or her own views. In justified cases or if requested so by the child, either directly or with involving an expert, the child shall be heard as well. For a child older than fourteen, the consent of the child shall be required for any decision on parental custody and placement regarding him, unless the child's choice endangers his development."

It is important to emphasise that *Act LXII of 2021 on international judicial cooperation related to parental responsibility* (hereinafter: Parental Responsibility Act) supplemented the cited provision of the Civil Code by stating that the *court must notify the child*

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[16] Section 4:163 of Civil Code.

[17] See more: B. Tóth, *A kiskorú személyek és a polgári igazságszolgáltatás kapcsolata*, "Miskolci Jogi Szemle" 2021, No. 5, pp. 620–633.

[18] According to Section 4:148. of Act V of 2013 on Civil Code "The parents are obliged to inform the child of any decisions affecting him; they shall ensure that their child who is of sound mind may express his views before the decisions are taken, and in the cases specified by an Act decide jointly with his parents. The parents shall take the child's views into account with appropriate weight, according to his age and maturity".

of the possibility to express his or her views. With this provision, the Hungarian legislation took a great step in the direction of child-friendly justice. The amendment entered into force on August 1, 2022, and must also be applied in ongoing procedures.

The court's obligation to notify, does not mean that it orders the child to be heard, but that the court informs the child who *has sufficient understanding* that, if he or she wishes, he can express his or her views in some form during the procedure. In the notification sent to the child, the court informs the child that he or she can express his/her views in different ways. They can do this in writing, in the form of any electronical message, video message or drawing, which they can send to the court electronically with the help of their parents or even independently, namely the child does not have to appear in court.[19]

We have to mention that this regulation is otherwise flexible, because it is up to the court at which stage of the first-instance procedure to inform the child of the possibility to express his or her views.

Returning to the topic of the court's notice, in my opinion it is reasonable to send the notice to the child at the beginning of the preparatory stage of the civil procedure,[20] and, if the child requests to be heard, it must be done as soon as possible within the framework of the preliminary taking of evidence. It's important to use notices with different content and language in court proceedings according to age groups. It may be necessary to standardise the wording of court notices with the involvement of psychological experts so that it is sufficiently "child-friendly".[21]

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[19] See more: K. Ocskó, *Right of the child to express his or her views*, [in:] Zs. Wopera (ed.), *Commentary on the Act CXXX of 2016 on Code of Civil Procedure*, Budapest 2019, pp. 163, 172.

[20] See more about the new Hungarian Civil Procedure Code: A. Nagy, *Reform of the Hungarian Code of Civil Procedure with special regard to rules of taking of evidence*, "Baltija Publishing" 2020, No. 1, http://baltijapublishing.lv/omp/index.php/bp/catalog/download/35/534/1142-1?inline=1 (accessed on: 15.09.2023).

[21] In 2022, the Children's Rights Cabinet of the National Office of the Judiciary (NOJ) prepared four notification-samples with the involvement of child psychologist experts. The samples were made for four age groups: 0–6 years old, 6–10 years old, 10–14 years old and 14–18 years old. The use of these

The Civil Code guarantees the participation of the affected child not only in actions related to parental custody, but also in *action settling contact*. According to the Civil Code, the child must be heard in actions settling contact. This means that the court or the guardianship authority[22] not only notifies the child of the possibility to express views but must ensure that the child shall be heard. The court or the guardianship authority shall decide on the contact with the child taking the age, health and living conditions of the child, the parents' personal conditions and the opinion of the child who has sufficient understanding into consideration.[23]

The regulation of the Civil Code strengthening the right of the child to express his or her views was implemented by the Parental Responsibility Act, which reflected the legal development that took place at the international level in the last decade in the field of taking children's rights seriously, child-centered justice, and the regulation of cases involving parental responsibility.

It is important to mention that the regulations of the Civil Code guarantee every child the right to express views in the procedures affecting them and do not make any difference on the basis of disability.

5.2.3. DEFINITION OF "CHILD WHO HAS SUFFICIENT UNDERSTANDING"

It should be noted that Hungarian civil law does not define the concept of the "child who has sufficient understanding". According to the Hungarian judicial practice, "the court must examine the child

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notification-forms is not mandatory for the courts and they are available as a recommendation on the courts' internal interface. The forms were prepared with age-appropriate language.

[22] The guardianship authority shall decide on the contact with the child if no matrimonial action or action for settling parental custody is pending.

[23] Section 4:181 (1)–(2) of the Civil Code.

who has sufficient understanding in each case, in which the age is not a determining factor."[24]

Hungarian family law regulations do not specify the age at which a child has sufficient understanding. Among the relevant laws there is only the Section 2 a) of 49/1997. (IX. 10.) where the government decree on guardianship authorities and the child protection and guardianship procedure defines "a child who has sufficient understanding: [as] a minor who, in accordance with his age and intellectual and emotional development, is able – during his hearing – to understand the essential content of the facts and decisions affecting him, to foresee the expected consequences."

The Supreme Court of Hungary reached a similar conclusion in its Directive No. 17 on aspects related to the placement of a child: "A child can be considered to have sufficient understanding, if due to his age and situation, he is able to form his views independently and without influence."

Based on legislation and judicial practice, this is clearly a subjective category. The court must decide whether the child has sufficient understanding and whether an uninfluenced opinion can be expected from him. The legal practitioner can find out about this based on the child's age and the parents' statement, and if necessary, a psychologist can decide on this issue. At the same time the Supreme Court of Hungary in its civil decision took the position that the determination of the child who has sufficient understanding is not a professional matter. In this case, the court can take a position without appointing an expert.

Based on the above, it is therefore clear that there is no uniform standard for the judicial determination of the existence of sufficient understanding, the assessment of which is based on a thorough

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[24] Hungarian legislation attaches great importance to the expressed will of the child, and if it can be established that it reflects the child's well-considered, considered and sufficiently justified views, the child's will must be evaluated. The only limitation in this is if it can be determined from the child's age, maturity, and expressions that he or she has not sufficient understanding: he or she is not able to express a view on the given issue independently and without influence. Decision of Curia (Supreme Court of Hungary, published in No. 298 of 2019).

consideration of the circumstances in each case, of which the child's age is an important, but not the only, decisive factor.[25]

What must be examined is the question how should the child who has sufficient understanding be interpreted for a child with a mental disability? Can the court decide not to notify the disabled child, because he does not have sufficient understanding anyway? Or does it depend on the seriousness and degree of the mental disability?

The answer to these questions is clear, because the court cannot ignore notifying the child about the possibility of expressing their views because, according to the court, the child with a mental disability cannot have sufficient understanding. The same procedure must be followed even if the law requires not only the notification of the child, but also the hearing of the child, such as in an action for the settling of contact. In this regard, the Hungarian court is bound by the CRPD adopted by Hungary, Article 7 paragraph 3 of which makes it clear that States Parties shall ensure that *children with disabilities have the right to express their views freely* on all matters affecting them, their views being given due weight in accordance with their age and maturity, *on an equal basis with other children*, and to be provided with disability and age-appropriate assistance to realise that right. Article 7 paragraph 3 of the CRPD therefore clearly omits any reference to the child's sufficient understanding (the capacity to form a view), because it would empty the right of a child with an intellectual disability to express a view.[26]

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[25] For more, see: Zs. Boros, *Interviewing the minor child*, [in:] Zs. Wopera (ed.), *Commentary on the Act CXXX of 2016 on Code of Civil Procedure*, Budapest 2019, p. 1144.

[26] See more: R. Sandland, *A Clash of Conventions? Participation, Power and the Rights of Disabled Children*, "Social Inclusion" 2017, Vol. 5, Issue 3, p. 99.

5.2.4. THE WAYS OF HEARING THE CHILD: DIRECTLY OR WITH INVOLVING AN EXPERT

According to the above-mentioned provision of the Civil Code, the court hears the child *directly* or with *involving an expert*.[27]

If the court considers that it wants to obtain the child's opinion in the case by hearing it, it must also decide whether to do so through a direct hearing or an expert. As a general rule, the method of hearing is therefore always chosen by the judge. Judges have very different opinions as to whether it is appropriate to hear the child directly or with involving an expert.[28]

The *child's directly hearing* must be conducted in a way that takes into account the child's age and level of maturity. In order to get to know the position of younger children, different communication from the judge is necessary than in the case of teenager. But in all cases, it is necessary to approach the child directly, with sincere interest. If the hearing is done correctly by the judge - and with appropriate discretion - it can allow the child to express his own wishes and relieve him of any sense of responsibility or guilt he may have felt towards his parents. At the same time, it is advisable to inform the child during the hearing that the court will take his views into account but will not decide exclusively on the basis of it or in accordance with it.

If the court decides to *hear the child with involving an expert*, it appoints a forensic psychologist expert. In the order on the appointment of the expert, the court must indicate, the questions to which the expert must answer.

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[27] Section 171(4) of Civil Code: "(…) In justified cases or if requested so by the child, either directly or with involving an expert, the child shall be heard as well".

[28] See more about this topic: H. Kozák, *A gyermekek bíróság általi meghallgatásának gyakorlata*, "Családi Jog" 2011, No. 1, pp. 23–30; K. Visontai-Szabó, *A bizonyítás szempontjai és nehézségei a szülői felügyelet rendezésére irányuló perekben*, "Családi Jog" 2015, No. 1, pp. 24–35; V. Ádámkó, *Az ítélőképessége birtokában lévő gyermek véleményének meghallgatása - különös tekintettel a gyermekelhelyezésre*, "Családi Jog" 2015, No. 3, pp. 10–16.

When asking questions, the experts themselves determine what examination methods they use with the help of methodological letter No. 20 on the scope and activities of forensic psychologist experts of the National Institute of Forensic Medicine.

In my opinion, the hearing of the disabled child can also take place directly, if the judge has sufficient empathy or special qualifications that ensure the continuation of communication with the mentally disabled child. The child's disability in itself is not a reason for the child to be heard only by an expert.[29]

5.3. Right of Participation in Hungarian Civil Procedure Law

The *Act CXXX of 2016 on Code of Civil Procedure* (hereinafter: Civil Procedure Code) which entered into force on January 1, 2018, took into account the strong protection of the *best interests of child as a primary consideration,* when defining family law procedures and developing its special regulations.[30]

Before analyzing these provisions, let's review the general provisions regarding the *child's procedural legal status* in Hungarian civil procedural law.

In the regulatory system of the Code of Civil Procedure, minors *appear in three roles*: they can be *witnesses*, they can be *party* according to the rules on legal capacity, and they can also be *interested person* in action related to parental custody.

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[29] See more: Zs. Boros, *Interviewing the minor child*, [in:] Zs. Wopera (ed.), *Commentary on the Act CXXX of 2016 on Code of Civil Procedure*, Budapest 2019, pp. 1141–1149.

[30] See more: Zs. Wopera, *Strengthening the right of children to express their views in family law procedures*, "European Integration Studies" 2023, No. 1 (under publication).

5.3.1. RULES RELATED TO A MINOR'S LEGAL CAPACITY TO ACT

According to the Civil Procedure Code if a person may enjoy and be bound by rights and obligations under the rules of civil law, *he may be party to a court action.*[31] This is called procedural capacity to be a party. A person may participate as a party if he has full capacity to act under the rules of Civil Code. Since civil procedural law does not recognize *limited procedural capacity to act*, a person under the age of 18 does not have procedural capacity to act, even if he has already reached the age of 14.

A party shall act through his statutory representative in the action if the party does not have any procedural capacity to act. Therefore, as a general rule, the parent acts as the legal representative instead of the child, who does not have the procedural capacity to act.

If a child doesn't have statutory representative the court shall appoint a *guardian ad litem* for a party, if the party has no capacity to act and does not have a statutory representative, so, for example, in the event that the minor child has neither a parent nor a guardian.[32] The Code of Civil Procedure does not contain any special provisions regarding the procedural legal capacity of minors according to whether the child is disabled or not.

5.3.2. SPECIAL RULES REGARDING THE CHILD'S PARTICIPATION IN FAMILY LAW PROCEEDINGS

In family law procedures, such as in matrimonial proceedings, special rules apply to the representation of the child and the participation of the *minor as an interested party*. In actions related to personal status[33] special rules apply to the legal actions of children who have

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[31] Section 33 of Civil Procedure Code.

[32] Section 76–77 of Civil Procedure Code.

[33] According to the Civil Procedure Code an action related to personal status means an action on custodianship, a matrimonial action, an action for the establishment of parentage, an action related to parental custody, actions related to contact with the child and actions related to the termination of adoption. (Section 429).

reached the age of 14. According to Section 431(2) of Civil Procedure Code, a person having limited capacity to act, whose personal status is affected by the action, shall have *full procedural capacity to act during the action.*

This means that a child who has reached the age of 14 can make a valid procedural statement if he is a party in an action related to his personal status without the consent of his legal representative. Although we must add that the child is rarely be a party in actions related personal status, but it can happen, e.g. also in an action to terminate parental custody, where the child who has reached the age of 14, can also initiate the procedure.

It is important to emphasize that the Civil Procedure does not differentiate between the regulations for children in this area as well, depending on whether the child is disabled or not.

5.3.3. INTERVIEWING A CHILD AS AN INTERESTED PERSON

As I mentioned earlier, the Civil Procedure Code contains precise procedural rules for the hearing of minor children as an interested person in actions related to personal status, which are considered to be a very forward-looking provision.[34]

5.3.3.1. *The Current Regulation on the Interviewing of a Minor Child as an Interested Person*

According to Section 473 of Civil Procedure Code, if the court decides in the course of the action to interview a minor child as an interested person, in justified cases it shall simultaneously appoint ex officio a guardian ad litem for the minor. The court may interview the minor child in the absence of the parties or their representatives as well. The court shall summon a minor below the age of fourteen through his statutory representative, calling upon him to ensure that the minor will appear. If a minor above the age of fourteen

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[34] See more: Zs. Boros, *Interviewing…*, *op cit.*, pp. 1141–1149.

is summoned, the court shall notify his statutory representative of the summons, even if the representative is also summoned to the hearing. The interview of the minor shall be conducted in a suitable atmosphere and in a manner that is understandable for him, taking his age and level of maturity into account. At the beginning of the interview, the minor shall be asked his name, place and date of birth, mother's name and domicile, and he shall be informed that all statements made during the interview must be in accordance with the truth, and that he may refuse to make a statement or answer individual questions. If the court appointed a guardian ad litem for the minor, the provided information shall also cover the procedural role, rights and obligations of the guardian ad litem. The minor child shall be interviewed by the chair. The parties may propose questions before the interview, even if the minor is interviewed in the absence of the parties. The guardian ad litem may propose questions during the interview of the minor. The chair may allow the guardian ad litem to ask the minor questions directly. The chair shall decide whether the proposed and the directly asked questions are admissible. At the end of the interview, while the minor is still present, the testimony recorded in the written minutes shall be read out, and if the minutes are recorded by making a sound recording of the contents of the minutes, it shall be recorded in the presence of the minor. The occurrence or omission of this shall be recorded in the minutes. The minor may correct or supplement his testimony while it is being read out or recorded. With the permission of the chair, the minutes may be supplemented or modified according to any remarks made by the guardian ad litem or the parties, if the interview is conducted in the presence of the parties. If it is dismissed, the respective request of the guardian ad litem or the parties shall be recorded in the minutes. If the minor is interviewed in the absence of the parties, the chair shall present the minutes of the interview to the parties.[35]

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[35] Section 473 of Civil Procedure Code.

5.3.3.2. *The Place of Hearing of the Minor Child*

In relation to this regulation, it should be mentioned that the Hungarian courts have child-friendly *children's hearing room*,[36] where minor children can be heard by the court in a child-friendly environment.[37] Children under the age of 8–10 are typically heard in these children's hearing rooms, older children prefer to be heard in the courtroom. These children's hearing rooms are suitable for the courts to hear older but mentally disabled persons, e.g. children with Down syndrome. It may also be suggested that the hearing of an adult person, but who is mentally disabled, will also take place in this friendly environment.

5.3.3.3. *De lege ferenda Proposals for the Development of Interviewing a Minor Child as an Interested person*

In my opinion, the current procedural law regulations cited above could be further developed as follows. In order for the minor child to be able to express a truthful view in family law procedures affecting him or her, it is reasonable to make it a general rule that the court hears the child in the *absence of the parties*, typically the child's parents. If, according to the court's judgment, this would be against the child's best interests, it may allow the presence of either party (parent) at the child's hearing. This may be justified, for example, in the case of younger or disabled children.

It would be a great step forward compared to the current regulations to require that the guardian assigned to support a minor child

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[36] https://birosag.hu/birosagokrol/gyermekkozpontu-igazsagszolgaltatas/gyermekmeghallgato-szobakrol; https://balassagyarmatitorvenyszek.birosag.hu/galeria/20131103/torvenyszeken-belul-gyermekmeghallgato-szoba (accessed on: 15.09.2023).

[37] The Guidelines of the Committee of Ministers of the Council of Europe on child-friendly justice states that "as far as appropriate and possible, interviewing and waiting rooms should be arranged for children in a child-friendly environment" (point 62, p. 30), https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016804b2cf3 (accessed on: 15.09.2023).

be a lawyer with a professional qualification in children's law or, in the case of a disabled child, a specialist with special knowledge. Such a qualification can mean a specialist qualification in mediation, psychology or family law, as well as children's law or disability law.

It is reasonable to introduce changes in the current Hungarian regulations that serve to ensure that minors can express his or her views freely without fear of consequences. To this end, the court *ex officio* excludes the public from the part of the trial in which the court hears the child, and also does not allow the recording of the child's hearing by continuous audio and video recording.

If the court hears the child in the absence of the parties, the separate protocol recording the child's statement is kept separate and closed among the documents.

In order to protect the child, it may also be justified to stipulate that the court may only refer to the child's statement in the justification of the judgment to the extent necessary, keeping the child's interests in mind.

5.3.4. MINOR CHILD AS A WITNESS

According to Section 298 of Code of Civil Procedure a minor person below the age of fourteen shall only be interviewed as a witness if the evidence expected from his testimony cannot be replaced in any other way. On the occasion of interviewing a minor witness, his statutory representative may be present. During the interview, the warnings and information shall be communicated in an understandable manner, taking into account the age and degree of maturity of the minor witness. The interview shall be conducted in an atmosphere and manner that is suitable and understandable for the minor. If a minor witness below the age of fourteen is interviewed, he shall be informed of his obligation to speak the truth instead of the consequences of perjury, in a manner that is understandable for him, considering his age and degree of maturity. If the witness is a minor below the age of fourteen, all statements on processing his personal data in a confidential manner and on refusing to give testimony shall be made by his statutory representative, and the right of appeal against the decision imposing an obligation to testify shall be exercised by his statutory representative. If there is a conflict of interest between the minor witness and his statutory representative, an ad hoc guardian appointed by the guardianship authority at the court's request shall be entitled to the rights of statutory representative.

The law does not specify an age as a condition for testifying, from which it follows that minor under the age of fourteen, i.e. children, can also be heard as witnesses. This section of the Civil Procedure Code regulates the hearing of minors under the age of fourteen as witnesses as an exception, thus ensuring that the child only has to participate in the justice system ultimately, if it is justified by an important procedural interest.[38]

The suitability of a child to testify is a question that, with general life experience, the court can judge independently, without the use of an expert.[39]

As we see the Civil Procedure Code contains detailed procedural rules for the hearing of minor children as an interested person, as a witness or a party in actions related to personal status, which are considered to be very progressive provisions.

At the same time, the Civil Procedure Code *does not contain any provisions* on the form of "disability-appropriate assistance" provided for in paragraph 3 of Article 7 of the CRPD[40], which has also been ratified by Hungary.

Neither the parent providing the legal representation of the disabled child, nor the *guardian ad litem* appointed by the court, nor the *ad hoc guardian* appointed by the guardianship authority need to have any special expertise.

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[38] See more: A. Nagy, *The Taking of Evidence, Witnesses*, [in:] Zs. Wopera (ed.), *Commentary on the Act CXXX of 2016 on Code of Civil Procedure*, Budapest 2019, pp. 782–783.

[39] Decision 2011/ 2318 of Curia (Supreme Court of Hungary).

[40] States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

It is also worth emphasizing that the supported decision-making[41] that has existed in Hungary since 2013 cannot be used to support disabled children, because it only supports adults with disabilities.

5.4. Children's Right to Participate in Guardianship Proceedings

The purpose of this study is not to analyze the participation rights of disabled children in administrative procedures. But since, in addition to the courts, the guardianship authorities also play a significant role in family law cases, it is at least necessary to mention the forward-looking changes that have taken place in this area as well. The guardianship authorities have a particularly task in regulating contact.

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[41] According to Section 2:38. § of Civil Code the guardianship authority shall, at the adult's request and *in order to avoid limiting his capacity to act*, appoint a supporter for the adult who, due to not being entirely of sound mind, needs help in administering some of his affairs or making his decisions. If, during the procedure for placement under custodianship affecting capacity to act, the court considers that not even the partial limitation of the capacity to act is justified, but the person concerned needs help in administering some of his affairs, due to not being entirely of sound mind, it shall reject the request for placement under custodianship, and shall notify the guardianship authority of its decision. The supporter shall be appointed by the guardianship authority, based on the court decision, in agreement with the person concerned. The appointment of a supporter shall be without prejudice to the adult's capacity to act. At the same time as the Civil Code entered into force, a separate act, the Act CLV of 2013 introduced the legal institution of supported decision-making in Hungarian Law. Although the new Civil Code, adopted in 2013, contains a partial reform of Hungary's mental capacity legislation, the new regulation fails to meet the requirements of Article 12 of the CRPD. The Civil Code introduces the possibility of supported decision-making, but it does not abolish substitute decision-making. The Act preserves the models of plenary and partial guardianship as instruments of substitute decision-making. A further point of concern is that the regulation of the Civil Code does not sufficiently recognize the situation-specific character of mental capacity. See more about this topic: A. Szerletics, *Paternalism vs. autonomy? Substitute and supported decision-making in England and Hungary*, "Hungarian Journal of Legal Studies" 2021, Vol. 62, Issue 1, pp. 75–95, https://akjournals.com/view/journals/2052/62/1/article-p75.xml (accessed on: 15.09.2023).

As in civil proceedings, the child's participation is also ensured in guardianship proceedings. Act XXXI of 1997 on the protection of children (hereinafter: Child Protection Act) declares among the basic principles of the law that the requirement of equal treatment must be guaranteed during the protection of children.

The Parental Responsibility Act amended Section 128 of the Child Protection Act. According to this, the parent and other legal representative, the caregiver, the child with limited capacity to act, the person whose capacity to act is partially limited with regard to the legal declaration arising in the guardianship procedure, and the incapacitated child has sufficient understanding must be heard in the guardianship procedure, and in any case the person towards whom an obligation wish to establish, as well as - as necessary - other close relatives of the child. In the guardianship procedure, the child who has sufficient understanding to make judgments must be notified of the possibility to make a statement – in addition to informing the legal representative at the same time.

5.5. Conclusions and *de lege ferenda* Proposals

Summarizing our analysis so far, it can be concluded that the Hungarian procedural law regulations must be developed so that children with disabilities also have a genuine and effective opportunity to participate in the proceedings. For this, it is necessary to provide disability-appropriate assistance who can use their expertise to help disabled children express their views.

We agree with the findings of the Report[42] cited at the beginning of the study, makes the following recommendations in order to improve access to justice for children with mental disabilities.

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[42] Report to access to justice for children with mental disabilities. International standards and research results in ten European countries (A mentális fogyatékossággal élő gyermekek hozzáférése az igazságszolgáltatáshoz. Nemzetközi sztenderdek és kutatási eredmények tíz európai országban) MDAC Mental Disability Advocacy Center 2015. European Commission, http://www.mdac.org/sites/mdac.info/files/access_to_justice_children_ws2_standards_and_findings_hungarian.pdf (accessed on: 15.09.2023).

Legislatures should develop national plans that show how the rights of children with disabilities can be achieved. It is important that the following principles are the main drivers of these plans:

- freedom from discrimination (CRC Article 2; CRPD Article 3 (b) and Article 5);
- the best interests of the child (CRC Article 3; Article 7(2) CRPD);
- recognition of the developing abilities of the child (CRC Article 5; CRPD Article 3(h));
- equal protection and benefits provided by the law (CRPD Article 5);
- social participation and inclusion (CRC Article 12).[43]

The Report emphasizes that the procedural rules and rules of the provision of taking of evidence of the national legal systems must be amended, because they do not attach sufficient importance to the testimony and statements of children with intellectual or cognitive disabilities, and they must help the child to express his or her own views and preferences.[44]

It follows that legal proceedings must reach a certain level of flexibility to be able to meet the needs of each child at the same time and the provision for individualized appropriate assistance. Available forms of assistance should include sign language, augmentative and alternative communication (including interpreters trained to communicate with children with mental disabilities), and all other forms, tools and methods of communication chosen by the child with mental disabilities. As soon as the child comes into contact with the justice system, an "individual survey" must be conducted. This ensures that children themselves have a role to play in the decision-making process and are fully involved in the assessment of their best interests through provision of reasonable assistance where necessary.[45]

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[43] Ibid, p. 14.

[44] Ibid, p. 21.

[45] Ibid.

Despite of the difficulties in the field of access to justice for children with disabilities, there are clearly forward-looking steps in legislation and judicial practice.

Section 113(4) of Civil Procedure Code guarantees, that persons with hearing difficulties and deaf-blind persons shall be entitled to use sign language or another special communications system specified in an Act and known by the person concerned. At request, persons with hearing and speech disabilities may submit written statements in place of a hearing.

According to Section 61 of Civil Procedure Code the court shall assign a sign language interpreter, if doing so is necessary to enforce the rights specified in the above mentioned section of the Act.

This provision shall also be applied in the case of hearing a disabled minor as an interested person.

So, in order for hearing-impaired or deaf-blind or speech-impaired parties and other persons to be able to exercise their legal rights and fulfill their obligations without restriction, the Civil Procedure Code regulates several solutions. In this regard, the Civil Procedure Code specifically provides for the use of sign language in the case of hearing-impaired or deaf-blind persons, which is highlighted in the Fundamental Law by the fact that, according to paragraph (3) of Article H) "Hungary protects the Hungarian sign language as part of Hungarian culture". In addition to the use of sign language, the Civil Procedure Code also allows the person concerned to use other special communication systems known to him, defined by law. A hearing-impaired or speech-impaired person may, if he so requests, make a statement in writing instead of a hearing.

The other positive legal institution that can be further developed is the *children's rights representative*.

According to the Section 11 of Child Protection Act, the *children's rights representative* ensures the protection of the rights of the child receiving child protection care and helps the child to learn about and enforce his rights, as well as to learn about and fulfill his duties. The children's rights representative pays special attention to the protection of children who require special care. The child rights representative e.g., helps the child to formulate his complaint, can initiate its investigation or a procedure, helps the child in accessing care appropriate to his condition, as well as in formulating related comments and questions at the hearing held by the guardianship authority.

The children's rights representative is entitled to request information, documents and information in the operational area of the child welfare or child protection service provider and to obtain information on the spot. The child rights representative is obliged to handle the child's personal data in accordance with data protection legislation.

The children's rights representative is entitled to meet the child personally at the time initiated by him, without the presence of the head of the child welfare and child protection service provider or his staff, including the foster parent. The child rights representative is employed by the ministry.

In my opinion, there are plenty of development opportunities in the legal institution of the children's rights representative. It would be necessary to extend the authority of the child rights representative to protect the rights of disabled children in civil actions and guardianship proceedings even if the child has a legal representative. This would require significantly more child rights representatives.

But in addition to the children's rights representative that currently exists in Hungarian law, a *children's rights lawyer* could be introduced as a new legal institution, among whom those with such special qualifications would be able to support the participation of a disabled child in civil proceedings.

The court would be obliged to appoint a children's rights lawyer to the minor child as an interested person, if requested by any party (e.g. the parent) or by the minor child who has sufficient understanding, or if the court decides to hear the minor child as an interested person in the action.

The court could appoint a children's rights lawyer even if it detects a circumstance that makes it necessary for a child's rights lawyer to participate in the proceedings in order to protect the interests of a minor child, especially in the case of a disabled child.

The children's rights lawyer informs the minor child about the course of the procedure, his/her procedural rights, the procedural acts that affect him/her, as well as the content and legal effects of the court decisions that affect him/her, he/she is obliged to be present at the hearing of the minor child, must convey the opinion of the minor child to the court and the participants in the procedure towards, can also make a proposal to the court on the content of the measure or judicial order serving the best interests of the minor child.

In addition to the civil proceedings, it would also be possible to appoint a children's rights lawyer in proceedings before the guardianship authority, defining the types of proceedings in which the appointment of a child rights lawyer is mandatory in order to protect the interests of the child, or where this depends on the discretion of the guardianship authority. If a disabled child is involved, the appointment of a children's rights lawyer would be mandatory.

In summary, it can be concluded that in recent years, significant progress has been made in Hungarian private law in terms of ensuring the opportunity for children with disabilities to express their views. In accordance with Article 12 of the CRC, the analyzed provisions of the Civil Code and the Civil Procedure Code provide the child with the opportunity to express views, with the court being obliged to notify the child of this. This notification cannot be omitted due to the fact that the child is disabled. The Hungarian procedural regulations and institutional background should develop in such a way that the disabled child is provided with disability appropriate assistance during the procedure in order to be able to realize their right in genuine and effective way.

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Chapter 6. The Right to Participation in Cultural Life for Children with Disabilities. Challenges and Opportunities

6.1. Introduction

Cultural heritage plays an important role in every person's life, defining who we are, how we think, and how we function in society. Through the set of the values, norms and ethics it contains, it influences the shaping of the identity of individuals and social groups. It allows people to understand their past and its achievements as well as preserve the traditions of given communities, which is important from the viewpoint of building a sense of national identity. In addition, it provides people with the inspiration for creativity and self-expression and plays a significant role in the process of social integration, because common traditions and cultural practises can help people establish relationships, build social bonds and support unity in multicultural communities. Therefore, it is not surprising that the right to participate in cultural life has been recognised as a fundamental human right, as indicated by Article 27 section 1 of the Universal Declaration of Human Rights, according to which: "Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits". Although this act is not binding, the idea of this right is reflected in international law, among others: in Article 15 of the International Covenant on Economic, Social and Cultural Rights. However, the implementation and provision of this fundamental right may encounter difficulties resulting from, among others: the economic and health situation or lack of accessibility related to infrastructure.[1] The social group at risk of this type of limitations are the people with disabilities, including children, who, due to their special needs, require the adaptation of places and goods included in the scope of cultural heritage so that they can fully use them, and therefore, who have suffered social exclusion. Therefore, in Article 30 section 1 of the Convention on the Rights of Persons with Disabilities,[2] an obligation is imposed on its signatories, in accordance with:

> States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities: (a) Enjoy access to cultural materials in accessible formats, (b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats, (c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

In addition, the Convention on the Rights of the Child[3] in Article 31, recognising the fundamental importance of culture in the lives of children and in the process of their upbringing, has concluded a guarantee according to which:

> 1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts. 2. States Parties shall respect

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[1] P. Goroń, *Osoby z niepełnosprawnościami nowym odbiorcą kultury?*, [in:] E. Dąbrowska-Prokopowska, P. Goryń, M.F. Zaniewska (red.), *Kultura w Polsce w XXI wieku: konteksty społeczne, kulturowe i medialne*, Białystok 2020, pp. 59–70.

[2] Convention on the Rights of Persons with Disabilities adopted by the UN General Assembly on 13 December 2006 (Journal of Laws 2012, item 1169).

[3] Convention on the Rights of the Child, adopted by the United Nations General Assembly on 20 November 1989 (Journal of Law 1991, No. 120, item 526).

> and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

Therefore, it is worth considering how the above-mentioned right of access to cultural life is understood in practice, what barriers children with disabilities encounter and what legal solutions have been adopted to eliminate them. Thus, the aim of this article will be to analyse the legal provisions as well as mechanisms and institutions aimed at ensuring that children with special needs realise their fundamental rights. For this purpose, the following methods will be used: dogmatic-law and empirical-law.

6.2. The Scope of the Right to Participate in Cultural Life

In the preparatory documents of the Universal Declaration of Human Rights, the right to participate in cultural life was understood as the freedom of individuals and communities to participate in culture and the right to access it.[4] The idea of this right understood as freedom assumes that it can be considered in two categories – positive and negative.[5] The positive aspect assumes "freedom to", which imposes on individual countries the obligation to ensure such activities and mechanisms that will allow individuals and entire communities to have free access to cultural goods. The negative aspect assumes 'freedom from', which connotes the adoption by states of an attitude consisting of refraining from any actions that may limit this access through all kinds of barriers.

An attempt to define what cultural life is was made in General Comment No. 21 issued by the Committee on Economic, Social

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[4] C. Romainville, *Defining the right to participate in culturaln life as a human right*, "Netherlands Quarterly of Human Rights" 2015, Vol. 33, No. 4, p. 419.

[5] M. Odello, *The right to take part to cultural life: General Comment No. 21 of United Nations Committee on Economic, Social and Cultural Rights*, "Anuario Espanol de derecho internacional" 2011, Vol. 27, p. 499.

and Cultural Rights, in which it was stated that the concept of culture, "is a broad, inclusive concept encompassing all manifestations of human existence. The expression 'cultural life' is an explicit reference to culture as a living process, historical, dynamic and evolving, with a past, a present and a future", adding at the same time that:

> culture, for the purpose of implementing Article 15(1)(a), encompasses, inter alia, ways of life, language, oral and written literature, music and song, non-verbal communication, religion or belief systems, rites and ceremonies, sport and games, methods of production or technology, natural and man-made environments, food, clothing and shelter and the arts, customs and traditions through which individuals, groups of individuals and communities express their humanity and the meaning they give to their existence, and build their world view representing their encounter with the external forces affecting their lives. Culture shapes and mirrors the values of well-being and the economic, social and political life of individuals, groups of individuals and communities.[6]

Therefore, the adopted understanding corresponds to the anthropological concept of understanding culture as a specific set of ideas, values, ethics, way of life and social relations, i.e. aspects closely related to human nature and people's actions. In this context, culture can take on various expressions: traditional culture, higher culture, popular culture and digital culture.[7]

The literature also notes that participation in cultural life can be related to three levels: "home-based (watching TV, listening to the radio, reading books and newspapers, watching and listening to recorded sound and images, reading and using computers and the Internet), going out (visits to cultural venues such as the cinema,

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[6] United Nations Committee on Economic, Social and Cultural Rights, General Comment No. 21, GE.09-46922 (E) 070110, pp. 4–5 (hereinafter: GenCom21).

[7] L. Shaver, C. Sganga, *The right to take part in cultural life: Copyright and Human Rights*, Yale Law School Legal Scholarship Repository, https://openyls.law.yale.edu/handle/20.500.13051/1600 (accessed on: 22.11.2023).

theatre, concerts, museums, monuments and heritage sites) and identity building (covers amateur cultural practices, membership of cultural associations, popular culture, ethnic culture, community practices and youth culture)".[8] Each of these levels must meet the basic conditions guaranteeing equal and non-discriminatory access to the exercise of the right to participate, which includes: availability,[9] accessibility,[10] acceptability,[11] adoptability[12] and appropriateness.[13]

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[8] E. Ardielli, *Are foreign cultures interesting for EU citizens? Comparative study across EU member countries*, "ACC Journal" 2018, Vol. 24, Issue 3, p. 9.

[9] "Availability is the presence of cultural goods and services that are open for everyone to enjoy and benefit from, including libraries, museums, theatres, cinemas and sports stadiums; literature, including folklore, and the arts in all forms; the shared open spaces essential to cultural interaction, such as parks, squares, avenues and streets; nature's gifts, such as seas, lakes, rivers, mountains, forests and nature reserves, including the flora and fauna found there, which give nations their character and biodiversity; intangible cultural goods, such as languages, customs, traditions, beliefs, knowledge and history, as well as values, which make up identity and contribute to the cultural diversity of individuals and communities. Of all the cultural goods, one of special value is the productive intercultural kinship that arises where diverse groups, minorities and communities can freely share the same territory", GenCom21, p. 4.

[10] "Accessibility consists of effective and concrete opportunities for individuals and communities to enjoy culture fully, within physical and financial reach for all in both urban and rural areas, without discrimination. It is essential, in this regard, that access for older persons and persons with disabilities, as well as for those who live in poverty, is provided and facilitated. Accessibility also includes the right of everyone to seek, receive and share information on all manifestations of culture in the language of the person's choice, and the access of communities to means of expressions and dissemination", GenCom21, p. 5.

[11] "Acceptability entails that the laws, policies, strategies, programmes and measures adopted by the State party for the enjoyment of cultural rights should be formulated and implemented in such a way as to be acceptable to the individuals and communities involved. In this regard, consultations should be held with the individuals and communities concerned in order to ensure that the measures to protect cultural diversity are acceptable to them", GenCom21, p. 5.

[12] "Adaptability refers to the flexibility and relevance of strategies, policies, programmes and measures adopted by the State party in any area of cultural life, which must be respectful of the cultural diversity of individuals and communities", GenCom21, p. 5.

[13] "Appropriateness refers to the realization of a specific human right in a way that is pertinent and suitable to a given cultural modality or context, that is, respectful of the culture and cultural rights of individuals and communities, including minorities and indigenous peoples", GenCom21, p. 5.

The entity of the right to participate in cultural life is "everyone". Such widely adopted terminology means that it can be used by individuals, social groups and entire communities.[14] Moreover, this wording is inclusive because it does not introduce any discriminatory grounds that would make it impossible to exercise this right. This is, of course, related to the fact that the right to participate in cultural life is a human right, which means that it flows from the dignity of the human person and is universal, indivisible and inalienable. It is available to everyone regardless of their race, religion, age, social status, gender, sexual orientation, disability or any other condition. Hence, this right includes also children, including those requiring special needs, in the case of whom the right to participate in cultural life is one of the fundamental rights, because it is "through cultural life and the arts that children and their communities express their specific identity and the meaning they give to their existence, and build their world view representing their encounter with external forces affecting their lives".[15]

In the case of the implementation of the right to participate in the cultural life of disabled people, contained in Article 30 of the CRPD, it is emphasised that this right cannot be read without referring to the content of the entire CRPD, because "The CRPD involves a groundbreaking 'paradigm shift' from perceptions of persons with disabilities as 'objects' of charity, from the medical model, towards viewing persons with disabilities as holders of rights".[16] Participation in culture must also be conceived of as an expression of personhood and dignity.[17] Participation must be afforded to

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[14] See: United Nations Committee on Economic, Social and Cultural Rights, General Comment No. 17 (2005) The right of everyone to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he or she is the author (Article 15 paragraph 1(c), of the Covenant), GE.06-40060 (E) 020206.

[15] United Nations Committee on the Rights of the Child, General Comment No. 17 (2013) on the right of the child to rest, leisure, play, recreational activities, cultural life and the arts (Article 31), CRC/C/GC/17.

[16] A. Leahy, D. Ferri, *The right to participate in cultural life of persons with disabilities in Europe: Where is the paradigm shift?*, "European Journal of Disability Research" 2022, No. 16-4, p. 6.

[17] European Association of Service Providers for Persons with disabilities, 2020. The art of inclusion. Disability and diversity in arts and culture: Conference report.

persons with disabilities on an equal basis with others, and States Parties must address the barriers, socio-economic disadvantages, and combat stigma, all of which hamper cultural participation, interpreted in a broad manner as access to television programmes, films, theatre and other cultural activities, as well as places where cultural performances are held or services are provided, and monuments and sites.

6.3. Barriers to the Access to the Right to Participation in Cultural Life for Children with Disabilities

The inclusive cultural participation of children with disabilities is a crucial aspect of ensuring their rights and promoting equality. However, several barriers hinder their access to cultural activities and opportunities. These barriers can include physical accessibility limitations, lack of different forms of accommodation and adaptations, limited awareness and understanding of disability issues among cultural organisations and the general public, financial constraints, and a fragmented approach to promoting accessibility or lack of trained staff who can provide necessary support and assistance. In addition to physical obstacles, nebulous societal attitudes and entrenched stereotypes associated with disability can amplify additional barriers. These sociocultural constraints can result in disabled children being subjected to explicit discrimination as well as implicit biases.[18] This often leads them to face not just an intimidating stigma but also exclusion from participatory cultural spaces and engagement activities – settings that should naturally welcome individuals of all walks of life without any prejudiced resistance or inhibition.

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[18] See more: S. Loga, N. Pistoljevic, E. Švraka, V. Daneš, B. Šošić, *Current state and perspectives of child and adolescent psychiatry and psychology in Bosnia and Herzegovina*, (1 January 2017), https://scite.ai/reports/10.5644/pi2017.173.02 (accessed on: 22.11.2023).

6.3.1. PHYSICAL BARRIERS

Physical barriers are not just tangible obstacles that prohibit smooth operations in a particular environment – they also play a critical role in communication and interaction that hinder accessibility and participation for individuals with disabilities or limitations. These barriers include inaccessible architecture and a limited availability of assistive technologies.[19] Inaccessible architecture poses a major challenge for persons with disabilities. This includes buildings that lack ramps or elevators, that have narrow doorways and hallways, inaccessible restrooms, and inadequate signage for individuals with visual impairments.[20]

Physical barriers also include inaccessible transportation options such as the lack of wheelchair-friendly transport facilities. This can significantly limit travel for those with physical or mobility impairments, thus hampering their social, cultural, and economic participation.

A significant barrier is the lack of supporting technologies that can facilitate the reception of culture. This applies in particular to induction loops, guides in braille, special software for visually and hearing for impaired people, and the lack of transcription of radio and television broadcasts.

Moreover, the Committee on the Rights of Persons with Disabilities in Concluding Observations relating to reports sent by individual countries regarding the implementation of the CRPD provisions provides detailed examples of barriers preventing the full realisation of the right to participate in cultural life. These are among others: the lack of accessibility of public libraries, museums, touristic areas and monuments; barriers that persons with disabilities encounter to benefiting from the personal assistance services necessary to exercise the right to sport and entertainment;[21] failure

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[19] See: P. Szulc, *Bariery w życiu codziennym i ich wpływ na jakość życia osób z niepełnosprawnościami*, "Przegląd Krytyczny" 2021, Vol. 3, No. 2, pp. 51–64.

[20] See more: A. Naami, *Breaking the Barriers: Ghanaians' Perspectives about the Social Model*, "Disability CBR & Inclusive Development" 2014, Vol. 25, No. 1.

[21] Concluding observations on the combined second and third periodic reports of Germany.

to ratify the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired or Otherwise Print Disabled;[22] lack of play, recreation, leisure and sporting activities for children with disabilities, lack of support provided to the organisational structure for deaf sports and lack of recognition of the Deaf Olympics[23].

6.3.2. SOCIAL BARRIERS

Children with disabilities often face myriad challenges, one of which is the lack of participation in cultural activities due to societal discrimination, stigmatisation, and a pervasive lack of awareness about disability itself.[24] These barriers, while often thought to be entrenched in traditional or cultural beliefs, also extend from misconceptions surrounding the causes and types of disabilities. Perceptions often emerge around disabilities being punishments or bad omens, which unfortunately create an atmosphere of stigma and discrimination. Such negative attitudes, coupled with their harmful psychosocial consequences, create a significant societal hurdle for disabled individuals and their families to surmount. A survey conducted in Bosnia and Herzegovina revealed disturbing statistics, showing that 45% of people would not accept a child with intellectual disabilities as their own child's best friend, highlighting the deep-rooted prejudice and stigmatisation faced by children with disabilities.[25] This societal discrimination exacerbates these children's exclusion from typical activities, including participation in cultural institutions.

Discrimination can manifest in various ways. For instance, a child with a physical disability may be excluded from participating

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[22] Concluding observations on the initial report of Togo.

[23] Concluding observations on the initial report of France.

[24] See: F. Bariffi, *Awareness-raising*, [in:] I. Bantekas, M.A. Stein, D. Anastasiou (eds.), *The UN convention on the rights of persons with disabilities: A commentary*, Oxford 2018, pp. 230–231.

[25] S. Loga, N. Pistoljevic, E. Švraka, V. Daneš, B. Šošić, *Current state...*, *op. cit.*, p. 18.

in dances because of the perception that they wouldn't be able to keep up with their peers. Similarly, a child with a learning disability might be overlooked for roles in school dramas because of a prevailing belief that they may struggle with memorising lines or cues. Stigma further compounds this challenge by fostering a hostile social landscape for children with disabilities. In various societies, there remains an unfounded trepidation or mortification associated with interactions involving disabled individuals. This deeply ingrained bias can lead to social repudiation and the marginalisation of children living with disabilities, curbing their opportunities to partake in cultural activities.

Social barriers are the most difficult challenge that children with disabilities have to face.

6.4. Good Practices for Eliminating Barriers in Access to Cultural Heritage. Review of Legal Solutions

Article 9 of the CRPD requires States Parties to take appropriate measures to ensure that persons with disabilities have access, on an equal basis with others, to the physical environment, means of transport, information and communication, including information and communication technologies and systems, as well as to other facilities and services commonly available or provided in both urban and rural areas. For this purpose States Parties must: develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public; ensure that private entities that offer facilities and services that are open or provided to the public consider all aspects of accessibility for persons with disabilities; provide training for stakeholders on accessibility issues facing persons with disabilities; provide signage in braille and in easy-to-read and understand forms in buildings and other facilities open to the public; provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public; promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information. The above guidelines should also be implemented in the context of guaranteeing the right of disabled people to participate in cultural life. Therefore, it is worth analysing how the States parties fulfil their obligations by reviewing the legal solutions and good practises adopted in individual legislation. For this purpose, reports that States parties are obliged to submit to the United Nations on the implementation of the provisions of the CRPD, as well as national strategies regarding actions taken for persons with disabilities, may be used. It is worth emphasising that in addition to national activities, efforts are also being made internationally to ensure equal access to cultural heritage for persons with disabilities. An example of this is the Marrakesh Treaty, which provides for a mandatory exception to copyright for the benefit of blind, visually impaired, and otherwise print disabled persons. It facilitates the cross-border exchange of accessible copies developed under the exception. All EU member states have transposed the Treaty, adapting its internal regulations to its provisions. For example, the Copyright Act (404/1961) in Finland lays down restrictive provisions for copyright on making works available to persons with disabilities. Copies of a published work may be made by means other than recording sound or moving images for use by people with visual impairments and others who, owing to a disability or illness, cannot use the works in an ordinary manner. The copies thus made may be used for communication with such persons by means other than transmission on radio or television.[26]

D. Ferri and A. Leahy, as part of their research on access to culture for people with disabilities, noticed that "that States Parties to the CRPD [were] starting to view cultural participation as a facilitator of self-expression for people with disabilities, underpinning an affirmation of their dignity". For example, the Latvian report (CRPD/C/LVA/1, para. 370) mentions various opportunities for Deaf people, citing "a variety of creative self-expression measures". The Lithuanian report refers to "artistic ability development classes" (CRPD/C/LTU/1, para. 305) and the Brazilian report indicates

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[26] Initial report submitted by Finland under Article 35 of the Convention, due in 2018.

cultural activities aimed at the "development of skills for the expression of creativity and perception" (CRPD/C/BRA/1, para. 247). The Slovakian report mentions the availability of "active and passive culture" (CRPD/C/SVK/1, para. 390); likewise, the 2nd/3rd report of Tunisia refers to people with disabilities benefitting from cultural activities "as both recipients and participants" (CRPD/C/TUN/2-3, para. 204).[27] These studies show a change in the perception of access to the cultural heritage of disabled people. The authorities of individual countries recognise the benefits that broadly understood culture brings to human development, especially during adolescence. Thanks to this paradigm shift, as a result of the activities undertaken, more and more actions and events are organised to include children with disabilities in cultural life.

To eliminate individual physical barriers, including those related to access to infrastructure, current legal regulations in individual countries require the elimination of these types of difficulties. For example, in Poland, these issues are regulated in the Construction Law,[28] in which Article 5 requires that newly constructed public utility facilities and multi-family residential buildings be built in such a way as to provide disabled people with the necessary conditions to use them. This accessibility involves the construction of a hardened access to the building with a width of at least 1.5 m, and at least one access must provide disabled people with access to the entire building or the part of it that they can use; creating parking spaces for persons with disabilities; ensuring the availability of elevators for persons with disabilities or providing a ramp or installing an appropriate access device. However, it should be remembered that most cultural buildings are historical monuments in which interference with the building's structure may become problematic due to their technical condition or location. Examples include the ruins of castles or religious buildings located on hills or other elevations, accessible only by winding and unpaved roads. In addition, buildings

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[27] D. Ferri, A. Leahy, *The Right of People with Disabilities to Participate in Cultural Life: Is Cinderella Going to the Ball?*, [in] S. Robinson, K. Fisher (eds.), *Elgar Handbook on Disability Policy*, Cheltenham 2023, p. 8.

[28] Journal of Law of 1994 No. 89, item. 414.

of particular artistic value, constituting a cultural asset in themselves due to their construction or finishing techniques used, may be difficult or sometimes impossible to adapt to the needs of disabled people. Financial considerations related to the adaptation of such buildings are also an important issue. In such cases, state authorities should look for alternative solutions, such as an online walk, which would allow people who cannot get to them due to walking difficulties to still explore the monuments.

To eliminate physical barriers, cultural places should be equipped with appropriate technical and ICT tools that will facilitate the movement or understanding of a given work of art by recipients. In the manual created by the Ministry of Infrastructure in Poland "Standards for the accessibility of buildings for people with disabilities", it was pointed out that in order to eliminate physical barriers, the concept of universal design should be used, which assumes paying attention to elements such as: the entrance zone, the wayfinding system, typhlographic plans, induction loops, graphic symbols and pictograms, text information, surface markings, height of communication routes, rest areas, handrails and vertical and diagonal platforms.

Reports sent to the United Nations show that most countries are adapting their legislation to meet the requirements of greater accessibility. An example might be The Norwegian Act on Equal Opportunities and Accessibility for Persons with Disabilities, which ensures that cultural institutions and events are accessible to all individuals, encompassing provisions for physical accessibility, sensory adaptations, and communication assistance; or Australia's Disability Discrimination Act, which ensures that cultural institutions provide reasonable forms of accommodation and support to facilitate participation for individuals with disabilities.

A good practise used by some countries is the possibility of organising an exhibition of photos or artefacts in an accessible place or adapting the website of a given cultural entity to the needs of people with disabilities, so that they can become acquainted with its collections. To this end, individual legislatures should adopt laws to increase digital accessibility, as Poland did by adopting the Act of 19 July 2019 on ensuring accessibility for persons with special needs, which sets out requirements to ensure minimum digital accessibility for persons with disabilities.

There is also a practise to adopt regulations related to the accessibility of television programmes for persons with disabilities. An example of such a solution is Article 18a of the Polish Broadcasting Act, according to which television broadcasters are obliged to ensure the availability of programmes for persons with disabilities due to visual impairments and hearing impairments by introducing appropriate facilities such as audio description, subtitles for the deaf and translations into instant messaging, so that at least 10% of the quarterly programming time, excluding advertising and teleshopping, has such facilities.

6.5. Conclusions

The concept of unfettered access to cultural life is fundamentally entwined with the aspiration to assimilate every individual into societal structures on an impartial and equal basis. States are actively urged to increase their efforts in heightening accessibility, augmenting data collection, and aligning a disability approach in accordance with Article 1 CRPD. Ensuring access to the right to participate in cultural life is crucial for children with disabilities. It is not only a matter of equal opportunities but also a fundamental right for these children to experience and engage in cultural activities. Despite the recognition of children's rights, there are still challenges in implementing policies and legislation to promote smooth transitions and true inclusion for children with disabilities. Access to cultural life gives the ability to meet cognitive needs, develop curiosity about the world, foster the desire to experience beauty, and have positive impressions and the joy of contacts with people.[29]

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[29] See: B. Borowska-Beszta, "*Cuda świata noszą pustkę. Cuda to moja jedyna droga". Udział w kulturze osób z niepełnosprawnością intelektualną: założenia, uwarunkowania, formy i inspiracje*, [in:] *Osoby z niepełnosprawnością intelektualną w instytucji kultury*, M. Herkt, A. Mieszała (red.), Centrum Turystyki Kulturowej Trakt, Poznań 2019, p. 40.

The analysis conducted showed that the states parties to the convention make some efforts to ensure that people with disability, including children, realise their fundamental right to participate in cultural life. However, this topic requires a holistic approach that includes not only legal solutions, but also a social understanding of the issue of disability. Actions taken by individual countries are not sufficient, as highlighted by the Committee on the Rights of Persons with Disabilities in the Concluding Observations. In many cases, persons with disabilities are further deprived of their basic rights, which is related to a misunderstanding of their situation or financial issues that determine the possibility of eliminating barriers. We as a society still have a long way to go to fully include persons with disabilities in social life, including cultural life, although the first steps have already been taken.

Based on the above analysis, in order to guarantee better access to cultural life for children with disabilities, the following recommendations can be proposed:

1. Standardisation of accessibility – The goal is to introduce uniform accessibility standards for cultural institutions like museums, theatres, cinemas, art galleries, libraries and cultural centres. Such standards must consider both physical (ramps, elevators, adapted restrooms) and digital infrastructure (websites, mobile applications) needs.
2. Funding accessibility – Special funding or grant programmes should be established for facilitating the adaptation of facilities and services on the part of cultural institutions to the people with disabilities. This could involve funding for infrastructure modernisation, staff training, and development of technologies that facilitate access.
3. Supporting assistive technologies – The development and implementation of assistive technologies, such as audio description systems, subtitles for theatre plays and movies, sign language interpretations, and other means of perception for cultural content, to enable people with a variety of types of disability to perceive cultural content should be undertaken.
4. Education and awareness – Organising awareness educational campaigns for the general public on the needs of people

with disabilities and enhancing cultural inclusiveness. Staff of cultural institutions should undergo training and capacity-building on all aspects of hosting a person with a disability and organizing accessible cultural events.

5. Collaboration with non-governmental organisations – Closer cooperation between cultural institutions and NGOs representing various communities of persons with disabilities, which could also be advisory bodies and partners when performing accessibility projects.
6. Monitoring and evaluation – Introducing in cultural institutions a system of accessibility monitoring and evaluation. Regular reporting and auditing of accessibility facilitates monitoring progress and helps to identify gaps in establishments that may need improvement.
7. Accessibility of programmes and events – Requiring that cultural programmes and events be accessible to people with disabilities. This may include providing sign language interpretation, audio description, subtitles, and materials in formats adapted to various needs.
8. Legislative support for employees with disabilities – Facilitating the employment of people with disabilities in the cultural sector through the introduction of tax and other types of incentives to employers hiring people with disabilities, support for education, training, and internship programmes, etc.

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