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CHALLENGES IN THE LIVES OF CHILDREN WITH DEVELOPMENT DISABILITIES AND THEIR PARENTS IN THE CITY OF VUKOVAR

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ABSTRACT

Children with development disabilities are guaranteed at the international and national full and effective participation in society on an equal basis with others. They exercise their rights in the family and community in which they live. Therefore, the family and the community, as well as public policies, are factors that affect the life and realization of the rights of children with development disabilities.

The aim of the paper is to gain insight into the community support for children with development disabilities and their families as well as into the realization of the rights of children with development disabilities in the city of Vukovar from the perspective of their parents.

The qualitative research was conducted with parents of children with development disabilities. The results indicate the following challenges faced by parents of children with development disabilities living in the city of Vukovar: late diagnosis, lack of public and community services and professionals, lack of understanding and support in the family and community, lack of information about the rights of children and parents, challenges in the field of education, absence of parents' right to balance professional and private life, lack of leisure time for parents and fear of parents for the future of the child.

Keywords: *Children with development disabilities, city of Vukovar, Convention on the Rights of the Child, Convention on the Rights of Persons with Disabilities, family*

1. INTRODUCTION

Children with developmental disabilities (hereinafter: children with DD) represent the most vulnerable group of society that struggles with multiple threats in all spheres of life. On the one hand, these are children who represent a vulnerable group of society due to their psychological and physical immaturity, which makes them dependent on adults. On the other hand, people with disabilities historically struggle with discrimination and stigma in society, as well as obstacles in exercising their rights daily. When we combine these two vulnerable groups, we get children with DD who, compared to healthy children, stay in institutions more often, die more often, are more often exposed to violence and neglect, are more often exposed to a lack of education, employment and a greater risk of poverty.[1] Children with disabilities often suffer additional vulnerability and discrimination based on gender, ethnicity, poverty or living in alternative forms of care. These are cumulative factors of the risk of social exclusion, which has a negative impact on the quality of life and development of children.[2]

According to UNICEF data,[3] there are around 240 million children with DD in the world, that is, one out of ten children have DD. The Republic of Croatia also records an increase in children with DD. In Croatia, on September 1, 2022 there were 69,953 children with DD, while in 2012 there were 38,196 children with DD. This represents an increase of 31,757 children with DD in the past ten years.[4]

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[1] Rešetar, B., *Prava djece s invaliditetom – prava djece s problemima mentalnog zdravlja*, Socijalna psihijatrija, Vol. 45, No. 1, 2017, p. 5.; World Health Organization (WHO) and UNICEF, *Global report on children with developmental disabilities – From the margins to the mainstream*, 2023, iv, [https://www.unicef.org/media/145016/file/Global-report-on-children-with-developmental-disabilities-2023.pdf], Accessed 10 April 2024.

[2] Borić, I.; Mataga Tintor, A., *Studija o participaciji djece iz ranjivih skupina u Hrvatskoj,* Ured UNICEF-a za Hrvatsku, Zagreb, 2022, p. 26-27, 118-119. Available [https://www.unicef.org/croatia/media/12201/file/Studija%20o%20participaciji%20djece%20iz%20ranjivih%20skupina%20u%20Hrvatskoj.pdf], Accessed 9 April 2024; Bouillet, D., *S one strane inkluzije djece rane i predškolske dobi*, Ured UNICEF-a za Hrvatsku i Pučko otvoreno učilište „Korak po korak", Zagreb, 2018, p. 22. Available [https://www.unicef.hr/wp-content/uploads/2018/12/S_one_strane_inkluzije_FINAL.pdf], Accessed 9 April 2024.

[3] UNICEF, *The world's nearly 240 million children living with disabilities are being denied basic rights.* Available [https://www.unicef.org/turkiye/en/press-releases/fact-sheet-worlds-nearly-240-million-children-living-disabilities-are-being-denied], Accessed 9 April 2024.

[4] Croatian institute of public health, 2012 -2022 (Hrvatski zavod za javno zdravstvo 2012-2022). *Izvješće o osobama s invaliditetom u Republici Hrvatskoj.* Available [https://www.hzjz.hr/cat/periodicne-publikacije/], Accessed 10 April 2024; In Portal – News portal za osobe s invaliditetom, *Značajan porast - djece s teškoćama u razvoju svake je godine sve više*, 2019. Available [https://www.in-portal.hr/in-portal-news/moderna-vremena/19162/znaajan-porast-djece-s-teskocama-u-razvoju-svake-je-godine-sve-vise], Accessed 10 April 2024.

Children are guaranteed at the international and national level the right not to be discriminated against other children, i.e. full and effective participation in society on an equal basis with others. Children exercise their rights in the family and community in which they live. Therefore, the family and the community, as well as public policies, are factors that affect the life and realization of the rights of children with DD. Thus, an ecological framework situates individual development within concentric circles of influence radiating outwards, including family, community, institutions, politics and the environment.[5]

Caring for a child with DD is a very dynamic process full of challenges. The family where the child lives experiences specific challenges of caring for a child with DD. In addition, families are often the only providers and coordinators of care for a child with DD.[6] Accordingly, parents' care for children with DD gives parents the right to participate in the evaluation of the situation, and in proposing and deciding on the creation of public policies at all levels.[7]

In the Croatian context, the Ombudsman for Persons with Disabilities points out that children in schools with DD are still primarily viewed through their disability. Early intervention is unavailable, so only every eighth child has access to early intervention services. There is a lack of professionals in Croatia, and the spatial and financial capacities of social service providers are limited. Therefore, children wait too long for psychosocial support or assessment by a speech therapist.[8]

The goal of this research is to gain insight into the way parental care is provided for children with DD from the parents' perspective based on the area of the city of Vukovar. Therefore, this paper first presents the theoretical and legal framework that defines children with DD and prescribes their rights. This is followed by an overview of previous research that related to the lives of children with DD and their parents in Croatia. The central part of the paper presents the research of the lives of children with DD from the perspective of their parents in the city of Vukovar. Finally, the conclusion focuses on the recommendations to the city of

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[5] Borić, I.; Mataga Tintor, A., *op. cit.*, note 2, p. 89; WHO and UNICEF, *op. cit.*, note 1, p. 1.

[6] Currie, J.; Kahn, R., Children with disabilities: Introducing the issue, *The Future of Children*, Vol. 22, No. 1, 2012, p. 6; Vash, C. L.; Crewe, N. M., *Psihologija invaliditeta (prijevod 2. izdanja),* Naklada Slap, Jastrebarsko, 2010, p. 64-85; Leutar, Z. *et al.*, *Obitelji osoba s invaliditetom i mreže podrške*, Pravni fakultet Sveučilišta u Zagrebu, Zagreb, 2008.

[7] Ombla, J., *Skrb o odrasloj djeci s invaliditetom: pilot istraživanje percepcije i iskustva roditelja*, Jahr, Vol. 14, No. 1, 2023, pp. 21-44.

[8] Ombudsman for persons with disabilities (Pravobranitelj za osobe s invaliditetom), *Report on the work of the Ombudsman for Persons with Disabilities (Izvješće o radu pravobranitelja za osobe s invaliditetom),* Pravobranitelj za osobe s invaliditetom, Zagreb, 2022, p. 94-96. Available [https://posi.hr/izvjesca-o-radu/], Accessed 10 April 2024.

Vukovar based on which it is possible to improve the lives of children with DD and their parents in the community of the city of Vukovar where they live.

2. CONCEPT AND RIGHTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

World Health Organization (hereinafter: WHO) and the United Nations Children's Fund (hereinafter: UNICEF) developed a joint definition of children with DD for the needs of the Global report on children with DD (2023). „Children and young people with DD refer to children and young people with health conditions that affect the developing nervous system and cause impairments in motor, cognitive, language, behaviour and/or sensory functioning. In interaction with various barriers and contextual factors, these impairments may hinder a child's full and effective participation in society on an equal basis with others. These include a range of underlying health conditions such as autism, disorders of intellectual development and other conditions listed in the International Classification of Diseases 11th Revision under neurodevelopmental disorders and a much broader group of congenital conditions (such as Down syndrome) or conditions acquired at birth (such as cerebral palsy) or during childhood".[9]

In the Croatian legal system, children with DD are defined in the Social Welfare Act[10] and the Act on the Register of Persons with Disabilities.[11] According to the Social Welfare Act, children with DD are children who, due to physical, sensory, communication, speech-language or intellectual difficulties, need additional support for development and learning with the aim of achieving the best possible developmental outcome and social inclusion.[12] The Act on the Register of Persons with Disabilities defines children with DD as children whose full, effective and equal participation in society, in the interaction of the child's abilities and surrounding factors, is limited.[13]

The rights of children with DD are stipulated at the international level by the UN Convention on the Rights of the Child[14] (hereinafter: UNCRC) and the UN Convention on the Rights of Persons with Disabilities.[15] (hereinafter: UN-

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[9] WHO and UNICEF, *op. cit.*, note 1, p. 1.

[10] Official Gazette, No. 18/22, 46/22, 119/22, 71/23, 156/23.

[11] Official Gazette, No. 63/22.

[12] Art. 15 of the Social Welfare Act.

[13] Art. 2 of the Act on the Register of Persons with Disabilities.

[14] Official Gazette of the SFRY, International Agreements, No. 15/90, Official Gazette, International Agreements, No. 12/93, 20/97, 4/98, 13/98.

[15] Official Gazette, International Agreements, No. 6/07, 3/08, 5/08.

CRPD). The UNCRC and the UNCRPD commit governments to policy changes that contribute to creating the conditions for children with DD to enjoy optimal health and inclusion.

The UNCRC includes a stand-alone provision on children with DD in Article 23. prescribing that „states parties recognize that a child with DD should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community."[16] The child with DD has a right to special care and states parties shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.[17] Recognizing the special needs of a child with DD, assistance shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.[18] The rights of children with DD are further interpreted in a series of comments of UN Committee on Children's Rights (hereinafter: CRC). When interpreting the rights of children in early childhood, the UN Committee on Children's Rights points out that early childhood is the period during which disabilities are usually identified and the impact on children's well-being and development recognized. Young children should never be institutionalized solely on the grounds of disability. It is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realization of their rights. Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers).[19] In the context of the special rights of children with disabilities, the UN Committee on Children's Rights considers the problem of children's accessibility to public services. The physical inaccessibility to public transportation and other facilities including shopping areas, recreational facilities among others, is a major factor in the marginalization and exclusion of children with disabilities

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[16] Art. 23, para. 1 of the UNCRC.

[17] Art. 23, para. 2 of the UNCRC.

[18] Art. 23, para. 3 of the UNCRC.

[19] Para. 36 (Implementing rights in early childhood) of the General Comment No. 4 (2003) – Adolescent health and development in the context of the Convention on the Rights of the Child, Committee on the Rights of the Child, CRC/GC/2003/4, 1 July 2003.

as well as markedly compromising their access to services, including health and education.[20]

In the footsteps of the UNCRC, the UNCRPD continues to develop the international protection of the rights of children with DD. The article 7 of the UNCRPD prescribes that children with disabilities have the right to enjoy all human rights and fundamental freedoms on an equal basis with other children. Children with disabilities have rights with respect to family life just like other children. States Parties are obliged to provide early and comprehensive information, services and support to children with disabilities and their families.[21] In the field of education, children with DD must not be excluded from the general education system based on disability, regardless of whether it is free primary education or secondary education.[22] Children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system.[23] Finally, it is essential that children with disabilities are heard in all procedures affecting them and that their views be respected in accordance with their evolving capacities. Children should be equipped with whatever mode of communication to facilitate expressing their views.[24]

3. PREVIOUS RESEARCH ON THE LIFE OF CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR PARENTS IN CROATIA

Most children with DD live in families with their parents, where parental care of these children represents an extraordinary responsibility and demands that go beyond the obligations of typical parental care of children. These are intensive care requirements, long-term care that lasts throughout childhood and often continues after the child reaches adulthood.[25] The care of a child with DD differs from the typical parental responsibilities in several segments: the time of care is longer and

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[20] Para. 39. of the General Comment No. 9 (2006) – The rights of children with disabilities, Committee on the Rights of the Child, CRC/C/GC/9, 27 February 2007 (hereinafter: CRC General Comment No. 9); WHO and UNICEF, *op. cit.*, note 1, p. 2; Schulze, M., *Understanding The UN Convention On The Rights Of Persons With Disabilities. A Handbook on the Human Rights of Persons with Disabilities (Third Edition).* Paper Slam, Inc., New York, 2010, p. 68-69. Available [https://www.internationaldisabilityalliance.org/sites/default/files/documents/hi_crpd_manual2010.pdf].

[21] Art. 23, para. 3 of the UNCRPD; Schulze*, op. cit.*, note 20, p. 126.

[22] Art. 24, para. 2 of the UNCRPD.

[23] Art. 30, para. 5 d) of the UNCRPD.

[24] Para. 36 of the CRC General Comment No. 9.

[25] Ombla*, op. cit.*, note 7, p. 22.; Milić Babić, M., *Obiteljska kohezivnost u obiteljima djece s teškoćama u razvoju*, Nova prisutnost, Vol. 10, No. 2, 2012, p. 209-214.

the demands of care are more frequent with a higher probability of more intensive care in frequent health care crisis situations.[26]

In recent years, several research have been conducted in Croatia on the lives of children with DD and their parents from the parents' perspective. For example, research on the quality of life of parents of children with DD,[27] research on social support for parents of children with DD[28], research on the satisfaction of parents of children with DD with the Croatian social welfare system,[29] research on social-professional support and assistance to children with DD from the perspective of parents.[30]

Research by Rašan et al. (2017) showed that parents of children with DD are exposed to numerous new situations, such as the search for professional support, increased financial expenses, the necessity of acquiring new knowledge and skills related to the child's type of DD, time management related to taking care of the child, greater absence from the workplace, and sometimes giving up one's own career. All the above can affect the high level of stress and changes in parents' behaviour and the quality of life of the entire family. Unlike many Western systems, where parents of children with DD are provided with a system of support by various experts, in Croatia such a form of support is still in its infancy.[31]

Research by Blažević Simić and Đurašin (2020) shoved that mother of children with DD face numerous challenges (e.g. stress and fatigue) and use various strategies (e.g. planning carefully and consulting other parents or experts) to organise family leisure that is beneficial for the child with DD as well as for the family.[32]

Research by Gović and Buljevac (2022) showed that the parents of children with DD evaluated the professionalism of experts, the improvement of the quality of

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[26] Ombla, *op. cit.*, note 7, p. 22.

[27] Buljevac, M. *et al.*, *Kvaliteta života odraslih osoba s intelektualnim teškoćama i njihovih roditelja: spoznaje i specifičnosti*, Ljetopis socijalnog rada, Vol. 29, No. 3, 2022, pp. 381-411; Blažević Simić, A.; Đurašin, M., *Oprostite, čije slobodno vrijeme?! Iskustvo slobodnog vremena obitelji djeteta s teškoćama u razvoju,* Hrvatska revija za rehabilitacijska istraživanja, Vol. 56, No. 1, 2020, pp. 107-131; Rašan, I. *et al.*, Doživljaj samoga sebe i okoline kod roditelja djece urednog razvoja i roditelja djece s razvojnim teškoćama, *Hrvatska revija za rehabilitacijska istraživanja*, Vol. 53, No. 2, 2017, pp. 72-87.

[28] Leutar, Z.; Oršulić, V., *Povezanost socijalne podrške i nekih aspekata roditeljstva u obiteljima s djecom s teškoćama u razvoju,* Revija za socijalnu politiku, Vol. 22, No. 2, 2015, pp. 153-176.

[29] Gović, J.; Buljevac, M., *Sustav socijalne skrbi iz perspektiva roditelja djece s teškoćama u razvoju*, Revija za socijalnu politiku, Vol. 29, No. 2, 2022, pp. 213-227.

[30] Ombla, *op. cit.*, note 7; Vlah, N. *et al., Nepovjerenje, spremnost i nelagoda roditelja djece s teškoćama u razvoju prilikom traženja socijalno-stručne pomoći*, Jahr, Vol. 10, No. 1, 2019, pp. 75-97.

[31] Rašan *et al.*, *op. cit.*, note 27, p. 73.

[32] Blažević Simić and Đurašin, *op. cit.*, note 27, p. 129-130.

life due to the possibility of free time and the exercise of various rights among the positive aspects. Among the negative aspects they pointed out certain shortcomings related to the work of social welfare canters, a disability evaluation authority („*jedinstveno tijelo vještačenja*"), an ineffective system of information on rights and insufficient emergency responses in the Croatian system.[33] Although the research by Buljevac et al. (2022) relates to adults with disabilities, it confirmed that the quality of life of adults with intellectual difficulties and their parents is determined through different subjective and objective indicators, and it is affected by various factors such as support, social networks, formal support system, but also by certain characteristics of individuals. Persons with intellectual difficulties influence the quality of life of their parents, and the parents affect the quality of life of their adult children with intellectual difficulties.[34]

According to research by Ombla (2023) parents in Croatia appreciate the accessibility and competence of experts as well as the support they receive outside the formal system (friends, family members, other parents). However, they also point out that the lack of (in)ability to exercise rights related to the health system, the social welfare system and the education system, makes their everyday life difficult. The existing social rights are insufficiently sensitive and they encounter certain difficulties when exercising them.[35] A few foreign and national studies have shown that community support for parents who care for a child with DD is extremely important, whether it is informal support from family, friends, civil society organizations, or support from public services.[36]

STUDY PURPOSE AND RESEARCH QUESTIONS

The purpose of this research was to gain insight into the community support for children with DD and their families as well as to gain insight into the realization of the rights of children with DD in the city of Vukovar from the perspective of their parents. The following questions were asked:

1. What challenges do parents of children with DD face?
2. What are the disadvantages and opportunities in the lives of children with DD and their parents in the city of Vukovar?
3. Is the support of the Vukovar community to children with DD and their parents satisfactory?

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[33] Gović and Buljevac, *op. cit.,* note 29, p. 223.

[34] Buljevac *et al.*, *op. cit.*, note 27, p. 400.

[35] Ombla, *op. cit.*, note 7, p. 24.

[36] *Ibid.*, p. 23.

4. METHODOLOGY

For the purposes of the research, the authors used a qualitative research method.[37] Such research enables us to have a better and clearer insight into the data to be able to explain and describe a certain topic. This method helps us to better understand social phenomena.[38] The interview is the most used method in qualitative research, because of the flexibility it offers.[39] The authors created a semi-structured interview based on three research questions, with each research question being further elaborated. The questions were formulated in accordance with the general research area and the purpose of the research. The authors also created a Protocol for qualitative data collection, which contains a list of questions and is stored together with the recording of the interview. A semi-structured interview with an open-ended type of question made it possible to maintain the direction of the research topic, leaving space for the participants to share their experiences.

The research was conducted with parents of children with DD, and the sample of respondents was purposive. Purposive sampling requires the deliberate selection of information-rich units on the basis that they allow the researcher to learn as much as possible about the phenomena of interest. Researchers select units of analysis precisely because they will allow the researchers to answer the research questions in a way that is as meaningful and informative as possible.[40] Therefore, the respondents were members of the civil society organization (CSO) - "Who is afraid of tomorrow?" in Vukovar. The interview was conducted with those parents who volunteered and agreed to participate and who have a minor child with DD and reside in the city of Vukovar.

Eight parents (N=8) participated in the research, of which there were seven mothers (N=7) and one father (N=1). They are the parents of a total of eight children with DD (N=8) aged from four to seventeen. Four children have autism spectrum disorders (N=4), two have multiple disabilities (N=2), one has a speech and understanding disorder (N=1) and one has a motor impairment (N=1).

Before conducting the research, CSO "Who is afraid of tomorrow?" in Vukovar received a letter via e-mail with an explanation of the purpose of the research and

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[37] Ugwu, C. N.; Eze Val, H. U., *Qualitative Research*, Idosr Journal of Computer and Applied Sciences, Vol. 8, No. 1, 2023, pp. 20-35; Buljan, I., *Izvještavanje o rezultatima kvalitativnih istraživanja*, Zdravstveni glasnik, Vol. 7, No. 2, 2021, pp. 49-58.

[38] Mejovšek, M., *Metode znanstvenog istraživanja u društvenim i humanističkim znanostima (2. dopunjeno izdanje)*, Naklada Slap, Jastrebarsko, 2013.

[39] Clark, T. *et al., Bryman's Social Research Methods (Sixth Edition)*, Oxford University Press, Oxford, 2021.

[40] *Ibid.*, p. 537-541.

a request for cooperation. Parents were informed about the purpose of the research and the principles of anonymity and voluntary participation. Parents were given a contact phone number to participate in the research (the so-called volunteer sample). Before conducting the interview, the purpose of the research and the method of conducting the interview, the voice recording of the conversation and the protection of personal data were again explained to the parents. The interviews were conducted during August and early September 2023, and the interview was conducted in the premises of the CSO, in a family home or a coffee bar and lasted between 25 and 45 minutes.

The collected data, i.e. the recorded interviews, were stored on the computer and a transcript of the interview was created. The transcripts were stored on a separate medium so that the data could not be connected, and a special name was determined for each participant.

As one of the most frequently general strategies for doing qualitative data analysis, we used a thematic analysis. Thematic analysis is dependent on coding as a way of identifying themes in the data.[41] The data were summarized by coding and defining key terms.[42] From the analysed data, themes and sub-themes emerged, which are listed in the rest of the paper. The most illustrative quotes are listed next to each theme and sub-themes.

5. RESULTS

The received data were analysed according to the predefined research questions. The results overview is divided into three sections. The first section refers to challenges that parents of children with DD face, the second section refers to disadvantages and opportunities in the lives of children with DD and their parents in the city of Vukovar and the third section refers to the support of the Vukovar community to children with DD and their parents.

RQ 1. What challenges do parents of children with DD face?

The first research question pointed out several problems and challenges which relate to the subjective feelings of parents related to parental care of a child with DD. However, some problems relate to the mismatch between work and childcare, and the lack of information about rights and services for parents and their children with disabilities.

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[41] *Ibid.*

[42] Bognar, L., *Kvalitativni pristup istraživanju odgojno-obrazovnog procesa*, Pedagoški fakultet Osijek, Osijek, 2000.

Parents' knowledge of the child's developmental disabilities and ignorance of the disability

After the diagnosis of the child's developmental disability, parents face new challenges such as acceptance and lack of knowledge about the child's disability. Five parents stated that they initially felt lost, but very quickly accepted the truth and continued to fight.

"After that diagnosis and the first hospitalization, it was clear that the struggle would be difficult and long-lasting, but nothing can prepare you for the reality of a sick child, believe me" (P1). "...First it was, impossible, and then it was we will fight no matter what." (P2).

Lack of understanding and support

According to parents' answers, one of the biggest challenges is the lack of understanding and lack of support in the community, including family members. Five out of eight parents state that at the very beginning they did not receive any formal or informal support, or it was only provided by their partners. One parent stated that in the beginning there was support, but as the child grew up, the support decreased:

"My life changed completely...the environment and family hurt me the most… that misunderstanding" (P3). "A small child, great understanding from the profession and the whole environment. As the child grows, that understanding and support weakens, and over time you become more and more left to yourself and the small circle of people who stayed by your side." (P1).

Fear for the future

When asked how they deal with challenges and fears related to the future, all eight parents state that they do not want to think about the future.

"Sometimes it's easier, sometimes you barely survive the day, but what's hardest is precisely the uncertainty of the future. We all fear what will happen to our children in a system like this, which is not prepared for even minor challenges in relation to the care of a person with disabilities after the death of a parent... The only thing the system offers is nursing homes, sedation with drugs and isolation. This must be changed urgently... and I am afraid that everything will again fall on the backs of already tired parents. The obligation to do our best to organize communities for our children while we are alive where they will be able to maintain, at least approximately, the quality of life they are used to." (P1). "I don't think about it, I ignore it." (P8).

Lack of leisure time

When asked about the parents' leisure time, six parents stated that they adjusted all their time to the child and lived that way.

"We have adapted to the child...we live according to him." (P3). "After the surgery, I had no recovery days. The stitches give way, but who cares. Even if you can pay a person to help, it is difficult to find a person who can or wants to take care of a child with disabilities." (P1).

Balance between professional life and caring for a child with DD

Five parents are employed and have no problems with work because they managed to organize themselves. Three parents are unemployed to take care of a child with DD. One parent uses the right to work part-time.

"One mom told me about the possibility of working part-time and then I submitted a request and got the right to work part time" (P8). "I had to quit my job, stop my studies and devote myself completely to my child. I want to realize the right to my own life and work... The system is obliged to provide medical and social care for the child so that life can continue normally after the diagnosis appears in the family. This is in the interest of the whole family. I am sure that the number of divorces would be lower if the system were better organized" (P1).

Right to information about rights

All eight parents highlighted the problem of not knowing their rights. They said that no one informed them about their rights and that they got their first information from other parents of children with DD.

"I learned the first information from parents who before me had the experience of caring for a family member with disabilities." (P2). "Where to go, who to go to, who to contact, the mother of a child with disabilities gave me the most information about my rights, followed by a social worker from the social welfare centre." (P8).

RQ 2. What are the disadvantages and opportunities in the lives of children with DD and their parents in the city of Vukovar?

The second research question pointed out the number of problems and challenges which relate to the lack and inefficiency of public services for parents and their children with DD in city of Vukovar.

Lack of services and professionals

All eight parents cited a lack of certain services or professionals. The absence of health services and professionals in the city of Vukovar affected the late diagnosis. All the parents were forced to go to another city and finally to Zagreb so that the child could be diagnosed. Five out of eight parents state that there is a lack of therapy in Vukovar. Three parents stated that health professionals were unfriendly or uneducated.

“The child was 8 years old when the diagnosis was made” (P3). “The child was diagnosed when he was 5 years old.” (P5). “ The physician in Vinkovci gives us information that our child’s EEG is extremely …. After that, he lets us go home so that we can order ourselves to one of the Zagreb hospitals.” (P1). “We spent the first years of the child’s life in the car driving the child to therapy sessions all over Slavonia, from Đakovo to Osijek and Vinkovci. From the beginning, we are oriented towards Zagreb...we have been on the route Vukovar - Zagreb for 15 years...” (P2). “The diagnosis was made at the Faculty of Education and Rehabilitation in Zagreb” (P4, P8). “We treated the child in Osijek until he reached puberty, then we transferred to Zagreb” (P7); “The support of the system is weaker as the child gets older...” (P1). “In Vukovar, we never received any therapy, except for those that we paid for privately.” (P2). “We were separated for three years because the child was in another city for therapy with his father, and I was at home with the younger child.” (P5); “There is no speech therapist, and we have been waiting for sensory therapy for two years” (P8). “Doctors are not familiar with the syndrome, so they are a little scared...uneducated.” (P6); “Doctors are not accommodating.” (P4)

Challenges of education

All parents have encountered challenges in the educational environment. Two parents cite problems with their child’s inclusion in early and preschool education. Six out of eight research participants had problems involving their children in regular primary school education.

"We were among the first to fight for our girl to attend kindergarten. Admittedly, during those years, I was in the group with her, but at least the girl was among her peers." (P1). "When it came time for primary education... there were no assistants, there was no support whatsoever. However, we overcame this with our own strength and inexhaustible will for our child to be involved in education. The first year, without an assistant, I was constantly with the child at school. From the second year, the child got an assistant, but we still encountered various challenges, for example, the school has a strange habit of constantly changing teachers and assistants... that did not suit the child. We still struggle with it today." (P1) "The biggest challenge I encountered was the lack of understanding and expertise of the school staff." (P4). "We constantly had to justify why the child couldn't do something, why he couldn't, for example, carry a table and other heavier things. " (P7).

RQ 3. Is the support of the Vukovar community to children with DD and their parents satisfactory?

The third research question pointed out the lack of financial support as well as community services in Vukovar that are necessary to parents and their children with DD.

Financial support and community services of the city of Vukovar

All parents state that financial support and community services of the city of Vukovar is not at a satisfactory level.

"Well, not nearly satisfactory." (P2). "It could be bigger." (P3). "It is not enough... For an individual, it is almost non-existent, and weak for civil society associations, for groups of parents." (P4). "It depends on the policy that is in power." (P5); "Only with the help of civil society associations in the city, we try to be at a satisfactory level." (P6). "Our family has an organized life in Vukovar, but realistically, we have achieved little in our city for the benefit of a child." (P2); "Today, when the child is older, there is nothing again, but we are starting from scratch to provide them with some opportunities... That is what the civil society organizations and day-and-night work is for, in order to provide children with some kind of life outside the walls of their own homes." (P3).

Recommendations of parents of children with DD for public policy in the city of Vukovar

All parents uniquely state that CSO should be encouraged to provide services, which is otherwise an obligation of the state that is absent. Four parents state that more services should be organized for children, especially adolescents, so that they can have useful time, but also so that parents can have leisure time for themselves. One parent state that it is necessary to work on employing persons with disabilities and securing the future of children with DD. One parent points out that work should also be done on the development of society's empathy towards children with DD.

"The first thing that would help is that we are not seen as a burden or a stumbling block. Civil society organizations are organized in the city, which do what the state system should do, and it would help a lot to provide support for the easier organization and implementation of the necessary services." (P1). "Civil society organizations that gather and help children with difficulties should be supported." (P6).

6. DISCUSSION

The conducted research indicated the following challenges faced by parents of children with DD living in the city of Vukovar: late diagnosis, lack of public and community services and professionals, lack of understanding and support in the family and community, lack of information about the rights of children and parents, challenges in the field of education, absence of parents' right to balance professional and private life, lack of leisure time for parents and fear of parents for the future of the child.

It could be seen that the parents of children with DD in Vukovar spent a lot of time looking for physicians, psychologists and other experts in order to get answers to their questions and diagnosis. The results of this research coincide with the research conducted by Laklija et al. (2016) on the experiences of mothers of premature babies regarding social support in the health system. This research also shows that early information about diagnosis, as well as treatment and services for children are lacking in Croatia.[43]

Learning that a child has a disability causes grief in parents that is like the experience of people who grieve after the death of a loved one.[44] In addition to the problems of lack of services, professionals and information, parents face the problem of lack of support in the community. Most parents of children with DD in Vukovar

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[43] Laklija, M. *et al.*, *Socijalna podrška u sustavu zdravlja – iskustva majki nedonoščadi*, Revija za socijalnu politiku, Vol. 23, No. 2, 2016, pp. 261-282; Milić Babić, M. *et al.*, *Iskustva s ranom intervencijom roditelja djece s teškoćama u razvoju*, Ljetopis socijalnog rada, Vol. 20, No. 3, 2013, pp. 474.

[44] Jerić, B. *et al.*, *Obiteljski odnosi u kontekstu pojave invalidnosti*, in: Miljenović, A. (ed.), Socijalne usluge u zajednici za osobe s invaliditetom – Priručnik za početnike, Društveni centar Kostajnica, Zagreb, 2015, p. 61-65.

had neither formal nor informal support, except possibly mutual partner support. Leutar and Buljevac stress that support is important for the whole family. A family whose member is a person with a disability often identifies with that disability.[45]

According to the results of the research, parents in Vukovar, after the first information they receive from the physicians, find another source of information on the Internet. Just as in this research, parents do not effectively exercise their right to information about the rights of children with DD. As a rule, the source of information is other parents who had the same experience. This is consistent with the research conducted by Mamić[46] and Milić Babić *et al.* (2013).[47]

Parents pointed out the lack of leisure time as a challenge in Vukovar. Their life is completely adapted to the child and his needs. If it is a matter of greater difficulties and parents who have the status of parent carers, leisure time is almost non-existent. This is not good for either the parents or the child. This research also pointed to the needs of parents of children with DD in Vukovar for work and time for themselves. The psycho-physical health of parents who care for a child with DD is often neglected. The parent of a child with DD is perceived only as the parent of a child with disabilities, forgetting about all other roles and needs that a person has in life The absence of parental leisure time leads to the impossibility of entering into an employment relationship, which can lead to parental isolation, as well as household financial problems. This is consistent with the research conducted by Lučić et al. (2017).[48]

The fear for the future of the child is constantly present among the parents of children with DD in Vukovar, which coincides with the research conducted by Ombla et al. (2023)[49] according to which parents do not want to think about the future because they cannot control what it brings with them, and this represents an additional emotional burden.

The next challenge comes from the educational environment. Parents encountered numerous obstacles in realizing the right of children with DD to education starting from kindergarten to high school in city of Vukovar. Inadequacy of the

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[45] Leutar, Z.; Buljevac, M., *Osobe s invaliditetom u društvu*, Sveučilište u Zagrebu, Zagreb, 2020, p. 157-161; Jerić *et al., loc. cit.*, note 44.

[46] Mamić, P., *Usluge rane intervencije: perspektiva obitelji djece s odustupanjima u psihomotoričkom razvoju (diplomski rad)*, Edukacijsko-rehabilitacijski fakultet Sveučilišta u Zagrebu, Zagreb, 2016, p. 87. Available [https://urn.nsk.hr/urn:nbn:hr:158:490231].

[47] Milić Babić *et al.*, *op. cit.*, note 43, p. 471.

[48] Lučić, L. *et al.*, *A comparison of well-being indicators and affect regulation strategies between parents of children with disabilities and parents of typically developed children*, Hrvatska revija za rehabilitacijska istraživanja, Vol. 53, Supplement, 2017, pp. 38-46.

[49] Ombla *et al.*, *op. cit.*, note 7, p. 85-86.

system, misunderstanding of school staff, i.e. teachers, lack of assistants, isolation of children, are just some of the challenges. Misunderstanding often occurs in the community where children live. This is consistent with the research conducted by Ured UNICEF-a and Pučko otvoreno učilište "Korak po korak".[50]

Finally, the parents in this research show that they have adapted to life in the city of Vukovar and do not have high expectations of the community in which they live. They state that the support of the Vukovar community is not at a satisfactory level. Parents know what their and their children's needs are. Therefore, they founded a CSO in which they realize various projects. It is a CSO "Vukovarski leptirići" that provides social services of psychosocial support, however, they also struggle with the lack of specialists in relation to the large number of children with DD. In other words, the parents took matters into their own hands. They are only asking the city of Vukovar to support them in this. They have ideas, desire and will, but they cannot do everything by themselves. They expect that the procedures for developing the necessary services in the community will be simplified, so that their lives and the lives of their children with DD will be equal to the lives of other children and their families. The parents gave the following recommendations to the city of Vukovar: providing support for the organization and implementation of necessary services in the community, more services in the community for children, especially adolescents with DD, employment of people with disabilities, raising empathy and respect for diversity.

When observing the results of the research, certain limitations should be considered. Limitations of the research include the lack of heterogeneity of participants in terms of gender, given that only one male participant took part in the research, as well as the inclusion of parents of children with DD who are not members of the CSO. Future research should include a larger number of parents, and it should include categorization, not only by type of difficulty but also by degree of DD, to get a clearer insight into the challenges and what affects them.

7. CONCLUSION

Despite all the problems faced by children with DD, their position in society at the global level is changing for the better, which is influenced by the increase in the number of these children, progress in diagnostics, as well as greater awareness of parents, experts and society about the rights of children with DD. Despite this, children with DD will always represent one of the most vulnerable groups of society subject to discrimination.

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[50] Bouillet, *op. cit.*, note 2, p. 105-106.

Children with DD and their parents go through various challenges and obstacles in almost all spheres of life, from accepting the diagnosis, through inclusion in education, growing up, employment and inclusion in community life. Therefore, children with DD and their parents need support from their families, professionals, and the community in which they live. In this context, one of the important roles is played by social workers who should work with the family from the first to the last stage of accepting the difficulties in the child's development. It is an important obligation of social workers to inform parents about rights and services, to provide them with support, counselling, but also to advocate positive social changes in society. In order for social workers to be able to fulfil their role in social work with children with DD and their families, it is necessary to identify their needs and challenges they face in a dialogue with them. Therefore, the goal of the conducted research was to gain an insight into the challenges faced by parents of children with disabilities in the city of Vukovar, to identify their problems and to get to know the professional public and public policy makers in Vukovar. It is up to us experts, community and society to listen to them, provide support and work together to realize the rights of children with DD as well as the rights of their parents.

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