

## **Exercise of children's participatory rights in the healthcare system of the Republic of Croatia**

### **Abstract**

The most suitable approach to children as a vulnerable group is to combine protection and assistance based on information shaped through their participation according to age and cognitive abilities. Such an approach is not adequately reflected in the practices of different countries, including Croatia, despite being established in documents such as the Convention on the Rights of the Child. By observing children in the healthcare system, it has been established that their vulnerabilities intersect, i.e. different areas of vulnerability support one another and consequently increase the vulnerability. This paper deals with the exercise of children's participatory rights in the Croatian healthcare system by giving an overview of children's status and their vulnerabilities, as well as an overview of the relationship between protection and participation. Based on such a review and the results of the first research on the children's participation in the healthcare system in Croatia, this paper provides recommendations for fostering children's participation in the Croatian healthcare system.

### **1. Introduction – Vulnerability of children**

A child's development can be seen as the outcome of a dynamic process during which an individual is formed through the interaction of his or her genetic heritage and the experience with the environment. In this dynamic process, an individual encounters are among the factors that can positively or adversely affect him or her. Predisposition, tendency or susceptibility to stress and a subsequent negative outcome may

be considered vulnerability, despite the fact that vulnerability is a dynamic concept without a uniquely accepted definition.<sup>1</sup>

Vulnerability is contextual and socially conditioned and depends on the specific culture and society, but also on the dominant political ideology. Singh, Eghdami and Singh define vulnerability as the consequence of social inequalities rooted in gender, race, social class, culture, nationality, age and other power relationships.<sup>2</sup> Also Pitkin Derose, Escarce, Lurie point out that vulnerability is shaped by multiple factors, including political and social marginalization and lack of socio-economic and social resources.<sup>3</sup> Larkin argues that the concept of vulnerability may entail danger, risk, threat, potential problems, feeling of helplessness, need for protection and support;<sup>4</sup> while some authors make a distinction between ethical vulnerability – defined from the outside, i.e. attributed by others; and emic vulnerability – experience of vulnerability defined from an individual's perspective.<sup>5</sup>

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<sup>1</sup> Annelies Heijmans, Benfield Greig: Vulnerability: a matter of perception. Disaster Management Working Paper 4. London 2001, here pp. 1–17; Pranee Liamputtong: Researching the Vulnerable. A Guide to Sensitive Research Methods. London 2007; Mary Larkin: Vulnerable groups in health and social care. London 2009; Georg Frerks, Jeroen Warner, Bart Weijs: The Politics of Vulnerability and resilience. In: *Ambiente & Sociedade Campinas* 14 (2011), pp. 105–122; Paul Shitangsu: Vulnerability Concepts and Its Application in Various Fields: A Review On Geographical Perspective. In: *Journal of Life and Earth Science* 8 (2013), pp. 63–81; Maria de Lourdes Peroni Manzoni, Alexandra Timmer: Vulnerable groups: The promise of an emerging concept in European Human Rights Convention law. In: *International Journal of Constitutional Law* 11 (2013), pp. 1056–1085; Christina Zarowsky, Slim Haddad, Vinh-Kim Nguyen: Beyond »vulnerable groups«: contexts and dynamics of vulnerability. In: *Global Health Promotion* 20 (2013), pp. 3–9; Kate Brown: Vulnerability and Young People – Care and Social Control in Policy and Practice. Bristol 2015; Benjamin Wisner: Vulnerability as Concept, Model, Metric, and Tool. In: *Oxford Research Encyclopedia of Natural Hazard Science* 2016, pp. 1–51; Dearbhail Bracken-Roche, Emily Bell, Mary Ellen Macdonald, Eric Racine: The concept of »vulnerability« in research ethics: an in-depth analysis of policies and guidelines. In: *Health Research Policy and Systems* 15 (2017), <https://doi.org/10.1186/s12961-016-0164-6>.

<sup>2</sup> Sapam Ranabir Singh, Mohammad Reza Eghdami, Sarbjeet Singh: The Concept of Social Vulnerability: A Review from Disasters Perspectives. In: *International Journal of Interdisciplinary and Multidisciplinary Studies* 1 (2014), pp. 71–82.

<sup>3</sup> Kathryn Pitkin Derose, José J. Escarce, Nicole Lurie: Immigrants and Health Care: Sources of Vulnerability. In: *Health Affairs* 26 (2007), pp. 1258–1268.

<sup>4</sup> Larkin: Vulnerable groups (Note 1).

<sup>5</sup> Judith Spiers: New perspectives on vulnerability using etic and emic approaches. In: *Journal of Advanced Nursing* 31 (2000), pp. 715–721; Larkin: Vulnerable groups (Note 1); Mary de Chesnay: Vulnerable Populations: Vulnerable People. In: Mary de

The dynamic relative concept of vulnerability has brought up the difficulty of determining which groups are vulnerable or more vulnerable than others; however, when it comes to children, there is a clear consensus. Vulnerability has been associated with children for centuries, and has only relatively recently emerged as the key concept in developmental childhood studies.<sup>6</sup> Children are generally perceived as the most vulnerable social group, as they are more dependent on the help and care of others than adults.<sup>7</sup> Their vulnerability is the outcome of the interaction of individual, i.e., cognitive, emotional and physical capabilities, personal circumstances, and environmental factors, i.e., factors within family and within community, that compound dynamically over time<sup>8</sup>. On the level of individual factors – such as age, disability, ethnic minority, immigrant background etc. – different ages contain different needs that require the support of adults to a greater or lesser extent. Infants depend on caregiving while middle school age children can benefit from education away from the home environment. In this sense, Masten and Gewirtz argue that vulnerability can also change as a function of development, as there are general periods of increased vulnerability during development.<sup>9</sup> On the level of environmental factors – such as material deprivation, exposure to violence, child care services etc. – childhood cannot be seen as a universal category, even when it entails the same time period and similar geographical space. For example, growing up and childhood can be a completely different experience for children living in rural and urban settings, for children from poor and rich families. Such, almost endless, variations in individual childhood experiences lead to different possibilities, priorities and limits of what is possible,

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Chesnay, Barbara Anderson (Eds.): *Caring for the Vulnerable. Perspectives in Nursing Theory, Practice and Research*. Burlington 2016, pp. 3–19.

<sup>6</sup> Kate Brown, Kathryn Ecclestone, Nick Emmel: The many faces of vulnerability. In: *Social Policy and Society* 16 (2017), pp. 497–510.

<sup>7</sup> Liamputtong: *Researching the Vulnerable* (Note 1); Ann S. Masten, Abigail H. Gewirtz: *Vulnerability and Resilience in Early Child Development*. In: Kathleen McCartney, Deborah Phillips (Eds.): *The Blackwell Handbook of Early Childhood Development*. Malden, Oxford, Melbourne 2006, pp. 22–43; Larkin: *Vulnerable groups* (Note 1); Brigid Daniel: *Concepts of Adversity, Risk, Vulnerability and resilience; A discussion in the context of the child protection system*. In: *Social Policy and Society* 9 (2010), pp. 231–241; Brown: *Vulnerability and* (Note 1).

<sup>8</sup> OECD: *Changing the Odds for Vulnerable Children: Building Opportunities and Resilience*, OECD Publishing, Paris, 2019, <https://doi.org/10.1787/a2e8796c-en>.

<sup>9</sup> Masten, Gewirtz: *Vulnerability and Resilience* (Note 7).

appropriate or expected. Speaking of variations, it should be pointed out that certain vulnerability factors overlap, support one another and/or lead to additional factors, thereby increasing the initial vulnerability, which is also referred to as intersections of vulnerability.<sup>10</sup>

Vulnerable individuals and groups are often denied or hindered – or not enabled – to participate fully in public and political, and often private life.<sup>11</sup> If we see children as weak, immature and incompetent, i.e., more vulnerable, which has been the dominant experience of children for a long time, then we will necessarily focus more on protection and help, and less on encouraging self-determination, self-regulation and participation. In modern western societies, the image of the child is changing, and child is perceived more through his potential and competence, which also affects the reduction of the general experience of vulnerability.<sup>12</sup> The preoccupation with the assumption of children's vulnerability – and consequently the focus on protection – reduces the opportunities for children to experience challenges and to develop coping strategies. In this way we can deprive them of acquiring certain competencies and deny them the active exercise of their rights.<sup>13</sup>

This paper focuses on children in the healthcare system in Croatia, i.e. children who are faced with health challenges, whereby children are considered persons from 0 to 18 years of age in accordance with the Convention on the Rights of the Child. Children in healthcare is one of the groups that are experiencing low levels of participation.<sup>14</sup> It is estimated that children account for 19 %, according to the authors' calculation based on data for the 0–19 age group,<sup>15</sup> in the total share of population in 2020 in the Republic of Croatia, i.e.

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<sup>10</sup> Yochay Nadan, Jill E. Korbin: Cultural Context, Intersectionality, and Child Vulnerability. In: *Childhood Vulnerability 1* (2018), pp. 5–14; Zarowsky, Haddad, Nguyen: *Beyond »vulnerable groups«* (Note 1).

<sup>11</sup> Larkin: *Vulnerable groups* (Note 1).

<sup>12</sup> Brown: *Vulnerability and* (Note 1).

<sup>13</sup> Tony Newman, Sarah Blackburn: *Transitions in the Lives of Children and Young People: Resilience Factors*. Scottish Executive Education Department, Edinburgh, 2002.

<sup>14</sup> Ivana Jeđud Borić: *Evaluation of legislation, policy and practice on child participation in the European Union (EU). Country report: Croatia*. European Commission, Directorate-General for Justice and Consumers 2015. <https://data.europa.eu/doi/10.2838/52052> (accessed on 7.2.2023).

<sup>15</sup> Croatian Bureau of Statistics: *Population estimates (2020)*. [https://www.dzs.hr/Hrv\\_Eng/Pokazatelj/Procjene%20stanovnistva.xlsx](https://www.dzs.hr/Hrv_Eng/Pokazatelj/Procjene%20stanovnistva.xlsx) (accessed on 7.2.2023).

approximately 740,000 people, which is a decrease compared to previous years. According to the last available census, in 2011 there were 896 605 children aged 0–18 (DZS, 2013) in Croatia, which accounts for approximately 20 % of the total population in the same year. Through primary, secondary and tertiary healthcare, their coverage in the health system can be monitored by number of visits and/or hospitalizations. Thus, in the preventative protection of infants and preschool children, a total of 243,523 children and a total of 299,346 screenings<sup>16</sup> were recorded for 2019 in the area of healthcare protection of infants and preschool children, with acute upper respiratory tract infections being dominant when it comes to diseases and conditions in the area of healthcare protection of infants and preschool children. Primary health care for sick school-age children is carried out by general/family medicine physicians, while preventative and specific healthcare is carried out by school medicine physicians as part of the activities of the Institute of Public Health.<sup>17</sup> According to the authors' calculation based on the data for the last five years, an average of 316,662 children attend primary schools per year, while 155,119 children attend regular secondary schools.<sup>18</sup> At the same time, 118,319 primary school pupils and 38,757 secondary school pupils are covered

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<sup>16</sup> Croatian Institute of Public Health: Croatian Health and Statistical Yearbook for 2018. Zagreb 2020.

<sup>17</sup> Croatian Institute of Public Health: Croatian Health (Note 16).

<sup>18</sup> Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2019/2020 and start of school year 2020/2021. Zagreb 2021; Croatian Bureau of Statistics Communication 8.1.2. Primary schools end of school year 2018/2019 and start of school year 2019/2020. Zagreb 2020; Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2017/2018 and start of school year 2018/2019 Zagreb 2019; Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2016/2017 and start of school year 2017/2018. Zagreb 2018; Croatian Bureau of Statistics: Communication 8.1.2. Primary schools end of school year 2015/2016 and start of school year 2016/2017. Zagreb 2017; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2019/2020 and start of school year 2020/2021. Zagreb 2021; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2018/2019 and start of school year 2019/2020. Zagreb 2020; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2017/2018 and start of school year 2018/2019 Zagreb 2019; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2016/2017 and start of school year 2017/2018. Zagreb 2018; Croatian Bureau of Statistics: Communication 8.1.3. Secondary schools end of school year 2015/2016 and start of school year 2016/2017 Zagreb 2017.

by physical examinations.<sup>19</sup> Among residential care recipients, children accounted for around 1 % in 2019 (total N = 826 for ages 0 to 19; among which 45 % with limited mobility; 34 % bedridden, 1 % dying; 20 % other).<sup>20</sup> In the total number of examinations in permanent and temporary specialist offices, according to the authors' calculation, children accounted for 14 % (N = 1,525,428 for ages 0 to 19),<sup>21</sup> and 15 % in total hospital morbidity and hospitalizations (N = 96,886 for ages 0 to 19).<sup>22</sup> In the total hospital morbidity and hospitalization of children, respiratory diseases and certain perinatal conditions were dominant, with the trend applying equally to the previous two years. The data are provided in order to gain insight into the population, which is the topic of this paper.

The aim of this paper is to answer the question of how participatory rights of children in the healthcare system, especially in the healthcare system of the Republic of Croatia, are exercised. It will be shown that with the existence of international and national policy frameworks and the recognition of the importance of participation, in the desire to protect the most vulnerable, participation is not sufficient in its balance for protection. In the further text, after information about method and materials, an overview of the status of children's participation in basic policy documents were given. First is given an overview of the basic policy documents for child participation from international level and on the level of Republic of Croatia. Afterwards is given an overview of the basic policy documents relevant to the child participation in the healthcare system. Separate chapter discuss relationship between protection and participation of children to which is followed by a chapter with an overview of international research on the topic of children's participation in the healthcare system and the chapter with review of the study on participation of children in the Croatian healthcare system.

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<sup>19</sup> Croatian Bureau of Statistics (Note 15).

<sup>20</sup> Croatian Institute of Public Health: Croatian Health and Statistical Yearbook for 2019. Zagreb 2021.

<sup>21</sup> Croatian Institute of Public Health: Croatian Health (Note 16).

<sup>22</sup> Croatian Institute of Public Health: Croatian Health (Note 16).

## 2. Method and materials

In order to answer to the aim of the paper, a review of secondary data was made. The secondary data included researches on the topic of participation for the Republic of Croatia and for the international level. Special attention is given to the first wider research on the participation of children in the healthcare system in the Republic of Croatia as part of a larger research on participation of children from vulnerable groups. Also, the review of policy documents relevant to the participation, especially in the field of health, was made.

## 3. Participation of children

Basic principles of participatory rights of children are embedded in international policy documents and in the policy documents of the Republic of Croatia giving a framework in which the participatory rights of children in the healthcare system are built upon. The starting points for participatory rights can be found in the Convention on the Rights of the Child, where the defined rights of children are generally divided into three groups.<sup>23</sup> Children's participatory rights are defined in the most straightforward way in Article 12, which states that »the child has the right to express [his or her] views freely in all matters affecting [him or her]«. In addition to Article 12, which is considered »synonymous with child participation« by authors such as Hart<sup>24</sup> and Verhellen<sup>25</sup> and the UN Committee on the Rights of the Child, children's participatory rights also refer to other key civil rights such as the right to freedom of expression (Article 13), the right to freedom of thought, conscience and religion (Article 14), the right to freedom of association (Article 15), access to information (Article 17) and the right to protection of privacy (Article 16). The UN's Committee on the Rights of the Child in their General Commentary

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<sup>23</sup> UN General Assembly: Convention on the Rights of the Child (20.11.1989). <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child> (accessed on 7.2.2023).

<sup>24</sup> Roger A. Hart: *Children's Participation: From Tokenism to Citizenship*. New York 1992.

<sup>25</sup> Eugene Verhellen: *Children's rights: Education and academic responsibilities*. In: Philip D. Jaffé (Ed.): *Challenging Mentalities: Implementing the United Nations Convention on the Rights of the Child*. Ghent 1998.

of Article 12 of the Convention on the Rights of the Child defines child participation as a:

(...) widespread practice which appeared in recent years, and which has been broadly conceptualised as participation, although the term itself is not used in Article 12. The expression has evolved and is now widely used to describe a continuous process which involves the sharing of information and dialogue between children and adults based on mutual trust, in which children can learn how their views and the views of adults are both taken into account and form the outcome of this process.<sup>26</sup>

Based on the Convention on the Rights of the Child, the Recommendation of the Committee of Ministers to member States on the participation of children and young people under the age of 18,<sup>27</sup> contains recommendations for implementing right to be heard. The Recommendation stated that the right to be heard and taken seriously is fundamental to the human dignity and healthy development of every child and young person. The European Commission's recommendations on investing in children and breaking the vicious circle of disadvantaged children recognize the participation of children as one of the three pillars on which action strategies should be based in order to be successful.<sup>28</sup> Furthermore, participation of children is first of the six thematic areas in the EU Strategy on the Rights of the Child<sup>29</sup> presented as participation in the EU's political and democratic life.

Evaluation of legislation, policy and practice on child participation in the European Union shown that the legislative arrangements relating to child participation vary considerably across the EU and that

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<sup>26</sup> UN Committee on the Rights of the Child (CRC): General comment No. 12 (2009): The right of the child to be heard (20.7.2009). <https://www2.ohchr.org/english/bodies/crc/docs/advanceversions/crc-c-gc-12.pdf> (accessed on 7.2.2023).

<sup>27</sup> Council of Europe: Committee of Ministers, Recommendation CM/Rec(2012)2 of the Committee of Ministers to member States on the participation of children and young people under the age of 18 (28.3.2012), <https://www.refworld.org/docid/506981802.html> (accessed on 7.2.2023).

<sup>28</sup> European Commission: Commission Recommendation of 20 February 2013 – Investing in children: breaking the cycle of disadvantage. <https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX%3A32013H0112> (accessed on 7.2.2023).

<sup>29</sup> European Commission, Directorate-General for Justice and Consumers: EU strategy on the rights of the child, Publications Office, 2021, <https://data.europa.eu/doi/10.2838/313794> (accessed on: 7.2.2023).



gap between legislation and practice often exists<sup>30</sup>. Croatia has a good legislative framework for respecting children's rights in general,<sup>31</sup> but it has been noted that there is a lack of systematic investment in children in accordance with the needs and international guidelines.<sup>32</sup> It is the same with participation of children. Participatory rights are reflected in Family Law Act, Law on Education in Primary and Secondary Schools and Social Welfare Act. The most common forms of child participation are consultation in decisions affecting children and collaboration in shared decisions with adult<sup>33</sup>. Children's right to participation is one of the special goals of the National Plan for the Rights of the Children in the Republic of Croatia for the 2022–2026.<sup>34</sup> Some of the measures related to the participation includes education for experts in the educational system, creation of a procedure for the inclusion of children in the development and adoption of public policy and establishing children's cities councils. We can expect that the new one currently in developmental stage will also nurture that direction. While improvement of children's participation in Croatia<sup>35</sup> and good standardization of participation through legislative and strategic documents are evident,<sup>36</sup> there is also a lack of clear mechanisms for their monitoring, as well as a lack

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<sup>30</sup> Laurie Day, Barry Percy-Smith, Sandy Ruxton, Katharine McKenna, Katy Redgrave, James Ronicle, Tricia Young: Evaluation of legislation, policy and practice of child participation in the European Union (EU) – Final Report. Luxembourg 2015. <https://data.europa.eu/doi/10.2838/45596> (accessed on 7.2.2023).

<sup>31</sup> Paul Stubbs, Siniša Zrinščak: Ulaganje u djecu – kako nadvladati zamku deprivacije – Hrvatska [Investing in children – how to overcome the deprivation trap – Croatia]. Brussels 2014.

<sup>32</sup> Zdenko Babić: Ulaganje u djecu kao visokoisplativa socijalna investicija [Investing in children as a highly profitable social investment]. In: Paediatrica Croatica 64 (2020), pp. 53–62.

<sup>33</sup> Jedud Borić: Evaluation of legislation (Note 14).

<sup>34</sup> Ministry of Labour, Pension System, Family and Social Policy: The National Plan for the Rights of the Children in the Republic of Croatia for the 2022–2026 period. Zagreb 2022.

<sup>35</sup> Paul Stubbs, Siniša Zrinščak: ESPN Thematic Report on Progress in the implementation of the 2013 EU Recommendation on »Investing in children: Breaking the cycle of disadvantage – Croatia«. Brussels 2017.

<sup>36</sup> Ivana Jedud Borić, Anja Miroslavljević, Nivex Koller-Trbović, Ana Širanović, Sandra Car, Barbara Kušević: Poštujmo, uključimo, uvažimo. Analiza stanja dječje participacije u Hrvatskoj [Let's respect, include, and honor. Analysis of child participation in Croatia]. Zagreb 2017.

of sanctioning mechanisms for non-compliance with provisions and measures, and a lack of or an insufficient number of child-friendly legislative information concerning children.<sup>37</sup>

#### 4. Participation of children in healthcare

When we look at the healthcare system, we can notice an increasing focus on inclusion and participation of children observed in public policies at international level but also at national levels.<sup>38</sup> At the level of the Republic of Croatia basically coverage of participation of children exist within the documents relevant for the patients in general without special emphasis on children. Participatory rights are embedded in the Guidelines of the Committee of Ministers of the Council of Europe on child-friendly healthcare, where »child-friendly healthcare« refers to »healthcare policy and practice that are centered on children's rights, needs, characteristics, assets and evolving capacities, taking into account their own opinion«. The Guidelines define participation as:

(...) the right to be informed, consulted and heard, to give their opinions independently from their parents and to have their opinions taken into account. It implies the recognition of children as active stakeholders and describes the process by which they take part in decision making. The level of child participation depends both on his or her age, evolving capacities, maturity and on the importance of the decision to be taken.<sup>39</sup>

Furthermore, the Guidelines also state how child participation in the healthcare system can be achieved through three levels of par-

<sup>37</sup> Jeđud Borić, Miroslavljević, Koller-Trbović, Širanović, Car, Kušević: Poštujmo, uključimo (Note 36).

<sup>38</sup> Jenny Baston: Healthcare decisions: a review of children's involvement. In: Paediatric Nursing 20 (2008), pp. 24–26; Adam Davies, Duncan Randall: Perceptions of Children's Participation in Their Healthcare: A Critical Review. In: Comprehensive Pediatric Nursing 38 (2015), pp. 202–221; Ingrid Larsson, Carin Staland-Nyman, Petra Svedberg, Jens M Nygren, Ing-Marie Carlsson: Children and young people's participation in developing interventions in health and well-being: a scoping review. In: BMC Health Services Research 18 (2018), <https://doi.org/10.1186/s12913-018-3219-2>.

<sup>39</sup> Council of Europe: Guidelines on child-friendly health care (21.9.2011). <https://r.m.coe.int/168046ccef> (accessed on 7.2.2023).

ticipation: 1. Individual decision making, whether this be lifestyle choices or involvement in medical decision making. Implementation will require accessible information, clinical staff able to communicate with children and measures for mediation when differences occur; 2. Children should be given the opportunity to provide feedback on their experience after they have used services. Implementation will require the development of assessment of both patient-reported outcome and patient-reported experience and different methods of involving them in the process individually and with peers; 3. With increasing maturity and capacity, children should be involved in the policy/planning process for the services they use. Implementation will require appropriate training/learning opportunities to enable them to participate in this process, for example understanding priority setting.

The Council of Europe Strategic Action Plan on Human Rights and Technologies in Biomedicine 2020–2025<sup>40</sup> provides specific consideration on children and pediatric population, underlining that changes in the perception of the decision-making capacity in children are prompting reconsideration of the balance between protection and respect for autonomy. A specific session is dedicated to strengthen children's participation in the decision-making process on matters regarding their health.

In the Croatian healthcare system, fostering the idea of participation can be observed indirectly, especially in the Law on the Protection of Patients' Rights and also in the principles of protecting patients' rights, such as the principle of humanity, which includes ensuring respect for the patient as a human being, and ensuring the right to physical and mental integrity of the patient and protection of the patient's personality, including respect for his or her privacy, attitudes, and moral and religious beliefs. Therefore, integrity cannot be respected while participation is neglected. Provisions of the Law on the Protection of Patients' Rights, which are focused on the right to co-decide, the right to information, and the right to accept or refuse a particular procedure, will be the most conducive to fostering participation, while, in the context of this paper, it should be noted that the right to information is emphasized separately »with regard to age, education and mental abilities« without special emphasis on

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<sup>40</sup> Council of Europe: Strategic Action Plan on Human Rights and Technologies in Biomedicine 2020–2025. <https://rm.coe.int/strategic-action-plan-final-e/1680a2c5d2> (accessed on 7.2.2023).

children. Healthcare provider codes of conduct, e.g. the Code of Ethics of Nurses,<sup>41</sup> the Code of Medical Ethics and Deontology,<sup>42</sup> have incorporated elements of participation also without specific emphasis on children. It has been more than a decade since it was observed that the Law on the Protection of Patients' Rights was not harmonized with the Convention on the Rights of the Child, failing to emphasize the possibility and need for the active role of minor patients in health decisions.<sup>43</sup>

## 5. Relationship between protection and participation of children

In the light of the aforementioned policy documents which, among other things, exist to protect children, it is important to consider the relationship between protection and participation. The balance between protection and participation would be the best solution than can rich the whole society for a long term but it seems that we are still struggling with that balance in everyday practice. Increased focus from society in order to ensure adequate protection of children is reasonable given the fact that children are not responsible for their vulnerability and are more dependent on the help and care from others. Contrary to the dominant perception of children as immature and incompetent, which leads to a significant focus on protection and assistance, we seek to perceive children through their potential and competencies, which helps encourage their self-determination, self-regulation and participation. Tisdall notes that children who are perceived as vulnerable are often prevented from participating

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<sup>41</sup> Assembly of the Croatian Chamber of Nurses: The Code of Ethics of Nurses. Zagreb 2005.

<sup>42</sup> Code of Medical Ethics and Deontology, Official Gazette of Croatia No 55/08; Amendments to the Code of Medical Ethics and Deontology, Official Gazette of Croatia No 139/15.

<sup>43</sup> Gordana Pelčić, Anamarija Gjurjan-Coha: UNESCO, bioetika i dijete [UNESCO, bioethics and the child]. In: *Jahr 1* (2010), pp. 63–68.; Gordana Pelčić, Neda Aberle, Goran Pelčić, Inge Vlašić-Cicvarić, Darko Kraguljac, Ivica Benčić, Anamarija Gjurjan Coha, Silvana Karačić: Croatian Children's Views towards Importance of Health Care Information. In: *Collegium antropologicum* 36 (2012), pp. 543–548.

precisely under the guise of their protection.<sup>44</sup> Thus, it seems that children are sometimes overprotected in the name of their best interests, but essentially at the expense of their interests, presenting an ethical and a professional challenge. In modern society, especially in Western countries, public discourses emphasize the perspective and the »voices« of vulnerable and marginalized social groups, such as ethnic and racial minorities, people with disabilities, children, etc.<sup>45</sup> On the other hand, Aldridge states that while declaratively a lot of attention is paid to hearing children's voices' in everyday practice, children's perspectives are still not considered a priority, nor are they given the same importance as the perspective of adults.<sup>46</sup> Children who are perceived as more vulnerable, e.g., children with disabilities, children who are patients, children in alternative care, do not have the same access to services nor the same opportunities to participate, preventing them from accessing social, educational, political and cultural life. Furthermore, children are often perceived only as passive beneficiaries of various interventions created and carried out by adults, and their opinion is generally not taken into account in policy and intervention development.<sup>47</sup> Children's vulnerability, related with the scope of protection and participation, stems not only from their lack of competence but from the lack of power and the social position through which they can exercise their rights. Participation itself can make children vulnerable – which again requires protection – as they expose their perspective, i.e., their opinions, ideas and suggestions to adults who still hold more power and are able to punish them if they express opposing views. Lansdown argues that continuous

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<sup>44</sup> E. Kay M. Tisdall: Conceptualising children and young people's participation: examining vulnerability, social accountability and co-production. In: *International Journal of Human Rights* 21 (2016), pp. 59–75.

<sup>45</sup> Jelena Marković: Je li etično etički istraživati s djecom? Neka etička pitanja u istraživanju folklorističkih i kulturnoantropoloških aspekata djetinjstva [Is it ethical to do research with children? Some ethical issues in researching the folkloristic and cultural-anthropological aspects of childhood]. In: *Etnološka tribina* 31 (2008), pp. 147–165.

<sup>46</sup> Jo Aldridge: *Participatory Research: Working with vulnerable groups in research and practice*. Bristol 2015.

<sup>47</sup> Faye Mishna, Beverley J. Antle, Cheryl Regehr: Tapping the Perspectives of Children-Emerging Ethical Issues in Qualitative Research. In: *Qualitative Social Work* 3 (2004), pp. 449–468; Sharon Bessell: Participation in decision-making in out-of-home care in Australia: What do young people say? In: *Children and Youth Services Review* 33 (2011), pp. 496–501.

dependence on adults, the lack of power and relative vulnerability make children more susceptible to manipulation and exploitation.<sup>48</sup> In the context of participation of children, when it comes to vulnerable groups of children, the term »seldom heard children« is used:

The term »seldom heard« refers to groups of people who do not have a collective voice and are often under-represented in consultation or participation activities. »Seldom heard young people« are young people whose voices are not heard in decisions that affect them and/or who are not benefitting from services designed to meet their needs. Seldom heard young people are not a homogenous group, and the term »seldom heard« when used in the current context, may best be seen as an umbrella term which encompasses groups of great diversity and complexity that have in common their isolation from both mainstream and targeted participatory activities.<sup>49</sup>

## 6. International researches in participation of children in healthcare

The balance between protection and participation is also the challenge in the healthcare system where we can find increased interest of the research community in the involvement of various segments of participation of children. Research covers segments from emphasizing the benefits of participation, overview of the state of children's participation in everyday healthcare practice to factors influencing participation.

Involvement in decision-making brings a range of benefits for children in the healthcare system, such as maintaining a sense of control over their own life,<sup>50</sup> a higher level of self-determination and

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<sup>48</sup> Gerison Lansdown: The realisation of children's participation rights – Critical reflections. In: Barry Percy-Smith, Nigel P. Thomas (Eds.): *A Handbook of Children and Young People's Participation. Perspectives from Theory and Practice*. London, New York 2010, pp. 11–23.

<sup>49</sup> Cathy Kelleher, Mairéad Seymour, Ann Marie Halpenny: *Promoting the Participation of Seldom Heard Young People: A Review of the Literature on Best Practice Principles* (2014). <https://arrow.tudublin.ie/cgi/viewcontent.cgi?article=1026&context=aaschslrep> (accessed on 7.2.2023), here p. 24.

<sup>50</sup> Ingrid Runeson, Inger Hallström, Gunnel Elander, Göran Hermerén: *Children's Participation in the Decision-Making Process During Hospitalization: an observa-*

power,<sup>51</sup> but also a better health outcome.<sup>52</sup> A research in Sweden has shown that children tolerate medical treatments more easily when they feel their opinions are respected.<sup>53</sup> Capurso, Di Castelbianco & Di Renzo emphasize the importance of recognizing the emotions, thoughts and concerns of children in the healthcare system, especially children admitted to hospitals for treatment.<sup>54</sup> Precisely because of this complexity of children's feelings and thoughts, the authors emphasize the importance of talking to children and respecting their perspective.

Based on research conducted in pediatric departments in the Netherlands, Schalkers et al. concluded that health professionals do not use the expression »participation of children« in everyday practice; however, the ideas on which participation is based are perceived as an essential part of their work.<sup>55</sup> The participants stated that the participation of children in decision-making in the healthcare system is complex and limited by numerous factors. They also expressed the need for greater participation of children in the evaluation of healthcare services. Gilljam et al. emphasize the importance of measuring children's participation in the healthcare system in order to provide more precise data on where investments are needed to encourage children's participation.<sup>56</sup> The authors have developed an instrument (Child participation in Health Care – ChiPaC), which was pilot-tested, and showed an adequate level of reliability and

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tional study. In: *Nursing Ethics* 9 (2002), pp. 583–598; Baston: Healthcare decisions (Note 38).

<sup>51</sup> Isabelle Aujoulat, Fabrizio Simonelli, Alain Deccache: Health promotion needs of children and adolescents in hospitals: A review. In: *Patient Education and Counseling* 61 (2006), pp. 23–32.

<sup>52</sup> Priscilla Alderson, Katy Sutcliffe, Katherine Curtis-Tyler: Children's competence to consent to medical treatment. In: *Hastings Center Report* 36 (2006), pp. 25–34.

<sup>53</sup> Runeson, Hallström, Elander, Hermerén: Children's Participation (Note 50).

<sup>54</sup> Michele Capurso, Federico Bianchi di Castelbianco, Magda Di Renzo: »My Life in the Hospital«: Narratives of Children with a Medical Condition. In: *Continuity in Education* 2 (2021), pp. 4–25.

<sup>55</sup> Inge Schalkers, Cathleen S. Parsons, Joske F.G. Bunders, Christine Dedding: Health professionals' perspectives on children's and young people's participation in health care: a qualitative multihospital study. In: *Journal of Clinical Nursing* 25 (2016), pp. 1035–1044.

<sup>56</sup> Britt-Mari Gilljam, Susann Arvidsson, Jens M Nygren, Petra Svedberg: Child participation in health care (ChiPaC)-Development and psychometric evaluation of a self-report instrument for children's participation in health care. In: *Journal of Clinical Nursing* 29 (2020), pp. 107–118.

validity to assess children's participation in the healthcare system. Four components of participation of children are measured by the instrument: involvement, trust in professionals, taking control and understanding information. The questionnaire is adapted to children aged 6–12 and the authors note it can be used both in individual work with children in the healthcare system, but also as an instrument to improve the quality of childcare at the level of the healthcare system in general.

Coyne investigated the attitudes of children, parents and nurses about the participation of children in healthcare in England.<sup>57</sup> She concluded that both children and adults understand the importance of participation and the perspective of children. Nurses say that participation of children depends on the age of the child and his or her understanding of the disease. They believe that children should be allowed to participate with the permission of the parents. Coyne underlines the importance of nurses in encouraging children to become active partners in making decisions on their own healthcare from the very beginning of treatment.<sup>58</sup> In evaluation of the legislation, policy and practice of child participation in the European Union, Day et al. state that children generally have fewer opportunities to participate in developing, planning and reviewing healthcare services.<sup>59</sup> Legislation in EU Member States is predominantly concerned with safeguarding the ability of children to give informed consent to medical procedures. Furthermore, a general view was that opportunities to participate in decisions about their care were limited, i.e. children reported that in practice doctors usually talk to their parents, while ignoring them. Also, children often are not aware of what support and activities exist in the healthcare system nor do they know how to access them.

Children are recognized as holders of rights; however, in everyday practice the participation of children in healthcare remains relatively limited.<sup>60</sup> Davies and Randall state, based on the analysis of

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<sup>57</sup> Imelda Coyne: Children's Experiences of Hospitalization. In: *Journal of Child Health Care* 10 (2006), pp. 326–336.

<sup>58</sup> Imelda Coyne: Children's participation in consultations and decision-making at health service level: A review of the literature. In: *International Journal of Nursing Studies* 45 (2008), pp. 1682–1689.

<sup>59</sup> Day, Percy-Smith, Ruxton, McKenna, Redgrave, Ronicle, Young: Evaluation of legislation (Note 30).

<sup>60</sup> Davies, Randall: Perceptions of Children's (Note 38); Noreen M. Clark, Belinda W. Nelson, Melissa A. Valerio, Z. Molly Gong, Judith C. Taylor-Fishwick, Monica



various research in the area of participation of children in the healthcare system, that many children are excluded from decision-making, among other things because of the protective role of parents, as well as the belief that a child cannot adequately decide and act on his or her own best interests.<sup>61</sup> Children's ability to make decisions and to participate in making decisions about medical care and treatment depends more on the attitudes of parents and health professionals than on the capacity of the child,<sup>62</sup> and it is important to bear in mind that children always have the right to express their views, regardless of whether adults assess the child is competent to do so.

The right to express an opinion, established in Article 12 of the Convention on the Rights of the Child, is a fundamental right of the child, irrespective of the assessment of the child's competence. The estimated lack of competence to express opinions does not invalidate the children's right to express their opinions regardless. Participation of children in decision-making in the healthcare system is a complex issue, precisely because of the primary protective role of adults, i.e., parents and health professionals, but also because of perceptions and attitudes towards children as a vulnerable group. Therefore, Coyne and Harder advocate for a situational assessment of the individual child and his or her situation, and for the decisions to be made by adults and children together, all the while respecting the children's rights and opinions.<sup>63</sup> In fact, it is about finding the balance between protecting the child and fostering autonomy, taking into account the child's best interests.<sup>64</sup> Exactly what Strategic Plan on Human Rights and Technologies in Biomedicine 2020–2025 emphasizes recogniz-

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Fletcher: Consideration of shared decision making in nursing: A review of clinicians' perceptions and interventions. In: *The Open Nursing Journal* 3 (2009), pp. 65–75; Marjo Virkki, Tarja Heino Tolonen, Tapio Koskimaa, Eija Paavilainen: Children as decision-makers in health care – An integrative review. In: *Clinical Nursing Studies* 3 (2014), pp. 47–54.

<sup>61</sup> Davies, Randall: Perceptions of Children's (Note 38).

<sup>62</sup> Eva K. Mårtenson, Astrid M. Fågerskiöld: A review of children's decision-making competence in health care. In: *Journal of Clinical Nursing* 17 (2008), pp. 3131–3141.

<sup>63</sup> Imelda Coyne, Maria Harder: Children's participation in decision-making: balancing protection with shared decision-making using a situational perspective. In: *Journal of Child Health Care* 15 (2011), pp. 312–319.

<sup>64</sup> Annagrazia Altavilla, Ritva Halila, Maria-Andriani Kostopoulou, Laurence Lwoff, Katrin Uerpmann: Strengthening children's participation in their health: the new initiative of the Council of Europe. In: *Lancet, Child & Adolescents Health* 5 (2021), pp. 237–238.

ing that balance as a challenge when considering that children's rights are situated within a larger set of parental rights and responsibilities which also focus on their best interests.

When it comes to the participation of children in the healthcare system, there are parallel perspectives: user and children's perspectives. Furthermore, changing positions and power relations between adult professionals and children who are patients – users – are also taken into account. In doing so, professionals – adults – are no longer the sole holders of knowledge and skills, and beneficiaries – children – are not solely responsible for the existing problems, but may in turn be regarded as »experiential professionals«. <sup>65</sup> In that sense we speak of »child-centred care« which entails critical consideration of the child's perspective in all situations while ensuring collaboration with the family. <sup>66</sup> Furthermore, this concept also implies changes in the attitudes of healthcare professionals and changes in everyday practice of working with children in healthcare. In this regard, investment in additional education of healthcare professionals is also needed.

Some authors also emphasize that children can participate in different ways <sup>67</sup> and that participation is multidimensional, <sup>68</sup> while it is important, especially in the healthcare system, to consider not only the child's verbal but also the non-verbal statements. It is particularly important that healthcare professionals do not judge the children who choose not to participate or who choose simply to passively

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<sup>65</sup> Gabi Čačinović Vogrinčić, Nina Mešl: Uspostavljanje suradnog odnosa u socijalnom radu [Establishing a cooperative relationship in social work]. In: Gabi Čačinović Vogrinčić, Leonida Kobal, Nina Mešl, Miran Možina (Eds.): Uspostavljanje suradnog odnosa i osobnog kontakta u socijalnom radu [Establishing a cooperative relationship and personal contact in social work]. Zagreb 2007, pp. 3–49.

<sup>66</sup> Gail Davison, Martina Ann Kelly, Richard Conn, Andrew Thompson, Tim Dornan: How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis. In: *BMJ Open* 11 (2021), <https://doi.org/10.1136/bmjopen-2021-054368>; Karen Ford, Annette Dickinson, Tineke Water, Steven Campbell, Lucy Bray, Bernie Carter: Child Centred Care: Challenging Assumptions and Repositioning Children and Young People. In: *Journal of Pediatric Nursing* 43 (2018), pp. 39–43.

<sup>67</sup> Angela A. Quaye, Imelda Coyne, Maja Söderbäck, Inger K. Hallström: Children's active participation in decision-making processes during hospitalisation: An observational study. In: *Journal of Clinical Nursing* 28 (2019), pp. 4525–4537.

<sup>68</sup> Anna Ståhlberg, Anette Sandberg, Thomas Larsson, Imelda Coyne, Maja Söderbäck: Curious, thoughtful and affirmative—Young children's meanings of participation in healthcare situations when using an interactive communication tool. In: *Journal of Clinical Nursing* 27 (2018), pp. 235–246.

observe.<sup>69</sup> In this respect, Ehrich et al. emphasize certain requirements for ensuring participation of children in the healthcare system when it comes to relevant stakeholders, i.e., healthcare professionals, parents and children: knowledge, self-confidence, imagination, and trust.<sup>70</sup> The authors state that healthcare professionals are very knowledgeable about medical conditions and diseases, but they lack the skills to enable them to communicate with children and parents. The key principle in sharing information is that such information is aligned with the child's age and capacity for understanding so that the child can understand the information and respond to it. Many adults, including those in the healthcare system, express interest and desire to involve children to a greater extent and to enable children's participation. They, however, often lack the knowledge and the tools to do so.<sup>71</sup>

## 7. Participation of children in healthcare in Croatia

Research on the participation of children in the Republic of Croatia is sparse, with a rising trend in the last five years. The research on participation of children in the healthcare system, however, is almost non-existent. Existing ones cover part of the participative elements such as need for healthcare information.<sup>72</sup> The most relevant research is the analysis of child participation in Croatia by Jeđud Borić et al.,<sup>73</sup> as well as the overview of participation in the context of the report

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<sup>69</sup> Barbara Rogoff, Ruth Paradise, Rebeca Mejía Arauz, Maricela Correa-Chávez, Cathy Angelillo: Firsthand learning through intent participation. In: *Annual Review of Psychology* 54 (2003), pp. 175–203.

<sup>70</sup> Jochen Ehrich, Massimo Pettoello-Mantovani, Simon Lenton, Lilly Damm, Jeffrey Goldhagen: Participation of Children and Young People in Their Health Care: Understanding the Potential and Limitations. In: *Journal of Pediatrics* 167 (2015), pp. 783–784.

<sup>71</sup> Imelda Coyne: Children's Experiences of Hospitalization. In: *Journal of Child Health Care* 10 (2006), pp. 326–336; Lilly Damm, Ulrike Leiss, Ulrike Habeler, Jochen Ehrich: Improving care through better communication: understanding the benefits. In: *Journal of Pediatrics* 166 (2015), pp. 1327–1328.

<sup>72</sup> Pelčić, Aberle, Pelčić, Vlašić-Cicvarić, Kraguljac, Benčić, Gjuran Coha, Karačić: Croatian Children's Views (Note 43).

<sup>73</sup> Jeđud Borić, Miroslavjević, Koller-Trbović, Širanović, Car, Kušević: Poštujmo, uključimo (Note 36).

on investments in children<sup>74</sup>. The last major research on participation of children was focused on vulnerable groups of children,<sup>75</sup> and separately covered the children in the healthcare system<sup>76</sup>. Part of the results from that recent study on participation of vulnerable groups of children in Croatia will be given as it follows to illustrate best practices. First, the overall results will be presented, followed by a more detailed presentation of the results obtained in the case study on participation of children in healthcare in Croatia.

»Participation of Vulnerable Groups of Children« is a comprehensive study undertaken by UNICEF Office for Croatia in the 2018–2020 period.<sup>77</sup> The purpose of the study was to gain extensive knowledge on the participation of children from vulnerable groups in Croatia, i.e. Roma children, children without adequate parental care, children with disabilities, children in the healthcare system, children in the justice system, refugee and migrant children, children affected by poverty and children from isolated areas, including the information on existing attitudes, opportunities, barriers and enabling factors for the participation of children. The study combined both quantitative and qualitative data within four main components, three of which are based on empirical research: 1. conceptualization and description of children's vulnerability in respect to their participatory rights; 2. attitudes of the general public and professional from education, healthcare, justice and social welfare sectors regarding the participation of children from vulnerable groups; 3. situational overview of the participation of children from selected vulnerable groups, and information on both the constraints and enabling factors identified through eight case studies; and 4. designing a model of inclusion and participation of children in the process of study implementation – research – and the development of recommendations. A total of 1,774 participants were involved in this study, 232 of which were children and 1,542 adults.

Overall results showed that vulnerability of children is a relative rather than a real, i.e. static, concept or characteristic, since it occurs

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<sup>74</sup> Stubbs, Siniša: *Ulaganje u djecu* (Note 31); Stubbs, Zrinščak: *ESPN Thematic Report* (Note 35).

<sup>75</sup> Ivana Borić, Arijana Mataga Tintor: *Participacija ranjivih skupina djece* [Participation of vulnerable groups of children]. Zagreb 2021.

<sup>76</sup> Gordana Šimunković, Marina Grubić: *Participacija djece u sustavu zdravstva* [Participation of children in the health system]. Zagreb 2021.

<sup>77</sup> Borić, Mataga Tintor: *Participacija ranjivih* (Note 75).

as a result of external, i.e. structural, factors, personal characteristics and social processes that can make people vulnerable, excluded and marginalized. Certain groups suffer from intersecting vulnerability to the extent that their vulnerability is almost general. Children from vulnerable groups are often prevented from participating precisely under the guise of their protection, so it seems that adults sometimes overprotect children in the name of their best interests, with the result being quite the opposite. Vulnerable groups of children participate to a lesser degree in various aspects of their lives, i.e. from family and school to the wider community, and mostly participate »inwards«, i.e. within their own, often closed and protected microenvironment. The scope and the reach of participation of children from vulnerable groups outside of their families is very narrow. Most of the children from vulnerable groups have no experience of participating in student councils, and the few who were included felt marginalized and perceived their participation as merely for appearance's sake. Participation of children is not truly practiced and is at best limited, more often individual, and rarely collective. Furthermore, professionals emphasize gender inequality and the disadvantaged position of girls, who have fewer rights and opportunities to participate.

»Study on participation of children in the healthcare system«, as the first wider study on this topic in the Republic of Croatia, focused on finding answers to the participation of children in the healthcare system, at the same time giving children space for participation through the expression of opinions and experiences in segments directly related to them, with the potential to influence a change in their conditions – fostering the participation of children.<sup>78</sup> The study included 74 people – 26 children, 7 young people, 21 parents, 20 professionals – from three different institutions/organizations – a clinical hospital center, a hospital, an association of citizens – who participated in interviews and focus groups. The key criterion for participation in interviews and focus groups was having a health condition that required treatment over a long period of time, thus requiring more frequent contacts with the healthcare system. The research also included an analysis of the available public data – websites and documents accessible through them – of the institutions/organizations covered. Interviews and focus groups have affected the experience of vulnerability, the exercise of children's

<sup>78</sup> Šimunković, Grubić: Participacija djece (Note 76).

rights, the participation of children in different aspects of their lives and the potential and barriers to participation. The analysis of the website and available documents included an overview of information about participation, i.e. how much it informs, how much it encourages opinions, involvement in decision-making, proposing activities, etc., and sought to understand clear and hidden values related to the field of research.

The research showed that key factors contributing to the vulnerability of the child in the healthcare system at the individual level are those related to the specific difficulty with which the child is faced, i.e. mental health difficulty and/or contributing causes for such difficulty, physical illness, and its characteristics, including symptoms and consequences. Structural factors contributing to vulnerability are the specificities regarding the organization of different systems in the community. Such factors are:

1. too slow and partially effective cooperation between systems, e.g. health and education, health and social care, which is necessary to address the cause of the problem;
2. the location of the mechanisms needed to address the causes in the domain of other systems, e.g. a mechanism which would enable the professionals in a health institution to mandate the parent of a child with mental health difficulties to go to therapy or school for parents, rather than to just advise them to do so;
3. taking over segments from the domains of other systems, e.g. social system, justice system, etc., due to their inadequate functioning, e.g. an aggressive child stays in the hospital for a longer period of time because adequate accommodation needs to be found;
4. lack of adequate supervision of professionals providing services to children;
5. insufficient number of professionals to provide services to children, e.g. to provide adequate number of individual and group therapies, to provide information and/or psychological support for physical illness;
6. lack of knowledge of individual professionals, e.g. in the school system, on how to access and assist the child;
7. lower interest of psychopharmacological companies regarding children, which means that upon arrival in the hospital the child cannot receive the first medicine of choice or that the existing

medicine must be »broken« because it is not available in the dose for children;

8. disregarding the recommendations of one system within another system, e.g. providing a teaching assistant to a child with ADHD who was recommended to stay in school, enforcing boundaries in working with such children, placing them in a separate class.

The intersections of vulnerability happen when individual factors overlap with structural factors, where children with mental health difficulties are perceived as more vulnerable and different, mostly due to the specific nature of their difficulties, but also due to the difficulties of growing up in dysfunctional families. Professionals working with children with mental health difficulties also express a higher level of vulnerability compared to the professionals caring for children with chronic physical illnesses due to the limited resources available in the work – as stated above: lack of supervision, lack of support tools for children, etc.

All participants of the research agreed on the importance of participation of children – children should be informed, listened to, asked for an opinion and involved in decision-making; however, opinions on the level of children's participation differ. Children with mental health difficulties perceive their participation as inadequate – in family, school and healthcare – while most of their parents' state that their children are overly involved and have too many rights. Professionals also emphasize the importance of the family environment in encouraging and limiting the participation of children. Children faced with a physical chronic disease do not see a greater need for participation in the healthcare system. They would like to be provided with more information, but they are satisfied with the fact that doctors mostly talk to their parents. Most research participants in proposals and recommendations for the improvement of participation in the healthcare system highlight the importance of informing children during treatment and of improving the communication skills of healthcare professionals.

Elements resulting from the study, as well as elements enabling and facilitating participation are the following:

1. the sensibility of the individual, institution/organization, system and community regarding the needs of the child and respecting the child as a significant actor in the process of growing up;
2. the use of personal and professional skills that enhance participation, e.g. communication skills;
3. the use of knowledge about the importance of participation and its position in the context of children's rights;
4. the organization of the system to provide an environment for participation, e.g. time availability, availability of human resources.

The following elements are part of good practice:

1. informing the child about a particular service within a health institution in the course of diagnosis and/or treatment, e.g. information about the condition, expectations from hospitalization, expectations from a specific procedure, elements of the diagnosis and/or treatment, expectations from the diagnosis and/or treatment, the benefits and/or risks, etc.;
2. providing the child with the space to ask questions and express opinions, e.g. providing information, having available person(s) to provide information and taking into account the child's opinion, etc.;
3. encouraging participation, e.g. via the website of the institution/organization that fosters participation, by ensuring a supportive environment, organizing a group of children/young people who will act with a specific objective, including participation;
4. providing options, e.g. order of activities, introduction of psychopharmaceuticals, use of certain types of anesthetics, topics in psychotherapeutic work, etc.

## 8. Conclusion and recommendations

In relation to the situation at the international level, the Republic of Croatia is in the process of rising in terms of children's participation in the healthcare system. In recognizing the importance of participation and the differences in levels of participation, it coincides with some international research. Participation in everyday practice is recognized up to a certain level, with its insufficient emphasis in policy documents. The healthcare system of the Republic of Croatia



generates additional factors that contribute to the child's vulnerability, disrupting the balance between protection and participation.

For children in the health system, participation has three important values: intrinsic value for the children themselves in terms of improving their competences and self-esteem; instrumental value in terms of improving interventions for children based on their actual needs and the value in terms of promoting children's rights to participate in all aspects of their lives.<sup>79</sup> In order for the participation of children in the healthcare system in Croatia to be more extensive and meaningful in accordance with the specified values, it is necessary, above all, to further invest in the promotion and education of children's rights at all levels of education. Accordingly, research by Šimunković and Grubić<sup>80</sup> indicated that the participants agreed on the importance of children's participation, but also that opinions on the level of participation differ among children, experts and adults. Information about what participation is and how it is realized should go to children and adults, where in the group of adults special attention will be given to experts from different sectors. In this way, the understanding of all parties will be achieved as to what is expected when fostering participation and enable its greater practice. This is also in accordance with the findings of research from the international level, which indicate that participation depends on the attitudes of parents and health workers.

Education on children's rights and especially the education on the exercise of children's participatory rights is particularly important when it comes to the education of healthcare professionals, among other things, also due to the intersection of vulnerability. Thereby, in addition to introducing the topics on children's rights and participation in formal education programs, additional education in the framework of lifelong education should also be provided, especially education focused on methods and ways of working with children. This is in line with expressed interest and desire of adults to involve children to a greater extent and to enable children's participation but, they,

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<sup>79</sup> Bessell: Participation in decision-making (Note 47).

<sup>80</sup> Šimunković, Grubić: Participacija djece (Note 76).

however, often lack the knowledge and the tools to do so including communication skills.<sup>81</sup>

The case study in Croatia clearly separates the factors that promote participation and factors which contribute to vulnerability. Therefore, the guidelines for the participation of children in the healthcare system, which would include the mentioned factors, should be developed in cooperation with healthcare professionals and the children who have experienced hospitalization and treatment. Such guidelines can be a good reminder for the implementation of participation, which will also strengthen the connection between policy and practice. Similar materials focused on everyday participation of children in the healthcare system are found in European countries, as stated by Wood, Turner, Shaw.<sup>82</sup> In Croatia, two similar publications have been published in the last year, both aimed at professionals working with children in different fields.<sup>83</sup> However, there are no specific guidelines for the healthcare system. The purpose and the profit of developing such guidelines is at least threefold: »value driven« in terms of promoting children's rights, children's perspective and participation in the healthcare system, »practical« in terms of creating specific tools for working with children in everyday practice, and »participatory« through the involvement and cooperation of healthcare professionals and children in the development of the guidelines.

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<sup>81</sup> Coyne: Children's Experiences (Note 71); Šimunković, Grubić: Participacija djece (Note 76); Pelčić, Aberle, Pelčić, Vlašić-Cicvarić, Kraguljac, Benčić, Gjurana Coha, Karačić: Croatian Children's Views (Note 43).

<sup>82</sup> Damian Wood, Gill Turner, Fiona Straw: Not Just a Phase: A Guide to the Participation of Children and Young People in Health Services (2010). <https://www.rcpch.ac.uk/sites/default/files/RCPC-Not-Just-a-Phase-2010.pdf> (accessed on 7.2.2023).

<sup>83</sup> Ivana Borić, Arijana Mataga Tintor: Smjernice za kvalitetnu participaciju djece u javnim politikama i odlučivanju [Guidelines for quality participation of children in public policies and decision-making] (2020). <https://www.unicef.org/croatia/media/4971/file/Smjernice%20za%20kvalitetnu%20participaciju%20djece%20u%20javnim%20politikama%20i%20odlučivanju%20.pdf> (accessed on 7.2.2023); Ivana Borić, Arijana Mataga Tintor, Davorica Osmak Franjić: Smjernice za sudjelovanje djece i mladih u savjetodavnim tijelima, radnim grupama i na sastancima. [Guidelines for the participation of children and young people in advisory bodies, working groups and meetings] (2021). <https://www.unicef.org/croatia/media/8831/file/Smjernice%20za%20sudjelovanje%20djece%20i%20mladih%20u%20savjetodavnim%20tijelima,%20radnim%20skupinama%20i%20na%20sastancima.pdf> (accessed on 7.2.2023).

Participation of children in the healthcare system in Croatia – or lack of it – should certainly be further explored through more active involvement of children, following the examples of similar research from other countries,<sup>84</sup> especially in the use of modern digital tools<sup>85</sup>.

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<sup>84</sup> Sonya Clarke: An Exploration of the Child's Experience of Staying in Hospital from the Perspectives of Children and Children's Nurses using Child-Centered Methodology. In: *Comprehensive Child and Adolescent Nursing* 45 (2021), pp. 105–118.

<sup>85</sup> Loni Ledderer, Anne Møller, Antoinette Fage-Butler: Adolescents' participation in their healthcare: A sociomaterial investigation of a diabetes app. In: *Digital Health* 5 (2019), <https://doi.org/10.1177/2055207619845448>; Stålberg, Sandberg, Larsson, Coyne, Söderbäck: Curious, thoughtful (Note 68).

