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Pediatric Palliative Care – Guidelines for the Development of Evidence-Based Public Policies

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Pediatric palliative care - Guidelines for the development of evidence-based public policies¹ is a document aimed at improving pediatric palliative care in the Republic of Croatia. According to international documents², pediatric palliative care refers to the active overall care of a child's body, mind, and spirit, which also includes family support. It starts with the diagnosis and continues regardless of whether the child receives treatment directly related to its disease or not. It requires a multidisciplinary approach and uses available resources from the community. The basic starting point of the Guidelines is the position that palliative care is the ethical responsibility of health systems and a key component of universal health coverage. An additional reason for choosing pediatric palliative care as the content of the Guidelines is that even though the past two strategic documents in the field of palliative care (the Strategic Plan for the Development of Palliative Care in the Republic of Croatia 2014-2016 and the National Program for the Development of Palliative Care for the Period 2017-2020) recognized the importance of paying special attention to pediatric palliative care, the set indicators, the developed standards and guidelines in pediatric palliative care and

¹ Available here: <https://zdravstveniopservatorij-krijesnica.hr/dokument/smjernice-o-pedijatrijskoj-palijativnoj-skrbi/>

² See: Connor, S., Morris, C. & Brennen, F. (2020). Introduction. In Connor, SR. (Eds.). *Global Atlas of Palliative Care*. 3rd edition. London: WHPCA - Worldwide Hospice Palliative Care Alliance (pp. 10-16).

the identified needs and ensured capacities in palliative care for children, were not achieved. Reports by the Ombudsman for Children of the Republic of Croatia from 2016 to 2020 confirm the giving attention to pediatric palliative care by highlighting that children who need palliative care do not receive the necessary level of support.

The guidelines were created as part of the Health Observatory (HO) project led by Firefly - an association for helping children and families facing malignant diseases, within the framework of the Thematic Network for Socio-Economic Development and the promotion of social dialogue in the context of improving working conditions. HO prioritizes equal access to quality healthcare for citizens and aims to preserve and enhance the public health system by involving various stakeholders in shaping policies through a participatory approach. Information collected by the author between January and May 2022 was used as the basis for the preparation of the Guidelines³. The information included an analysis of national strategic documents in the selected area of social and health policy, an analysis of local strategic plans for the development of palliative care, an analysis of reports on the work of significant organizations, an analysis of statistical reports and available statistical data, a review of research at the national and international level, as well as interviews with key the stakeholders in pediatric palliative care in the Republic of Croatia. The community readiness model, which enables the assessment of the level of readiness to solve specific problems on nine levels (from lack of awareness to professionalization) through five dimensions (community knowledge of existing activities, leadership, community climate, community knowledge of the problem, resources) was used for conducting interviews. Additional information was also collected through an online questionnaire on pediatric palliative care which followed the areas of IMPaCCT standards for pediatric palliative care in Europe. The collected information was presented in participatory group meetings/workshops to members of the HO project and additional stakeholders between January and May 2023. At the meetings, the main areas that needed to be emphasized in the Guidelines were agreed upon. Individual consultations were also made when necessary. The first version of the Guidelines was upgraded with recommendations obtained through feedback from the participatory process and an analysis of their social impact. Analysis of the proposed interventions in the Guidelines was carried out by an external independent expert. The analysis included desk research and a focus group composed of experts and users in the field of pediatric palliative care.

The guidelines are primarily intended for public policymakers and decision-makers at the national and local levels, but also at the institutional level, to contribute to

³ See: Šimunković, G. (2023). *Mogućnosti razvoja pedijatrijske palijativne skrbi u zdravstvenom sustavu Republike Hrvatske*. Završni specijalistički rad. Zagreb: Medicinski fakultet, Poslijediplomski specijalistički studij Javno zdravstvo.

quality decision-making and improve public policies in the field of pediatric palliative care. They are also intended for all other stakeholders in pediatric palliative care: experts, citizens, civil society organizations, etc. The guidelines are organized into five main areas: *The basic context of pediatric palliative care*; *Existing strategic and legislative framework*; *Readiness for further development of pediatric palliative care*; *Presentation of strengths, weaknesses, opportunities, and threats for the further development of pediatric palliative care*; and *Conclusions and recommendations*.

The Basic context of pediatric palliative care document emphasizes the existence of pediatric palliative care standards at the European level (IMPACT standards revised through the GO-PPaCS project⁴) and the categorization of conditions by which children and families are considered for pediatric palliative care. A portion of the requirements for pediatric palliative care in Croatia is shown. This includes tracking the number of children registered in primary healthcare, hospitalized, and listed in the *Register of Persons with Disabilities* based on specific diagnoses. The presentation of the average annual number of children who die from all types of causes in the Republic of Croatia is also given. It was highlighted that the count of children and families receiving pediatric palliative care in Croatia is still undecided, pending an agreement on which diagnoses to prioritize.

The part of the Guidelines that focuses on the existing strategic and legislative framework emphasizes that the topic of pediatric palliative care is present in a small number of strategic documents of the Republic of Croatia, without a separate strategic or action document that focuses exclusively on pediatric palliative care. Some findings of the in-depth analysis conducted as a basis for the creation of a Croatian National Action Plan for the implementation of the European Guarantee for Children are underlined. It's emphasized that although there's a universal and technically cost-free healthcare system for children in Croatia, obstacles exist in accessing healthcare and exercising their right to health, especially in remote islands and less developed regions due to challenging accessibility and isolation, and a lack of pediatricians and doctors. This discovery in the guidelines stresses the importance of expanding services for all children, with a special focus on the singled-out groups.

The *Readiness for the further development of pediatric palliative care* chapter presents parts of the research, in which the level of readiness of the Republic of Croatia for the continued development of pediatric palliative care is quantitatively determined, and elements for moving readiness to a higher level are identified through thematic analysis. Five areas/dimensions were evaluated through readiness: Knowledge

⁴ See: Benini, F., Papadatou, D., Bernad , M., Craig, F., De Zen, L., Downing, J., etc. (2022). International Standards for Pediatric Palliative Care: From IMPACT to GO-PPaCS. *J Pain Symptom Manage*, 63(5), e529-e543. doi: 10.1016/j.jpainsymman.2021.12.031

of activities (*How much does the community know about current activities for the development of pediatric palliative care?*), Leadership (*What is the attitude of leadership towards pediatric palliative care?*), Climate in the community (*What is the community attitude about pediatric palliative care?*), Knowledge of the problem (*How much does the community know about pediatric palliative care?*), and Resources (*What resources have been used or could be used to further develop pediatric palliative care?*). Each areal dimension could be followed through nine levels of readiness. The Leadership area has the lowest level of readiness for further development of pediatric palliative care (Level 4). The acknowledgment stems from this low level of readiness, highlighting that taking on leadership roles within individual institutions, both locally and nationally, is a crucial requirement for advancing pediatric palliative care. The general level of readiness is set at the level of Preparedness, which means that some members of the community have heard about the issue of pediatric palliative care and believe that action is necessary. Parts of the research are presented alongside information from international researchers and examples of good national practices.

The presentation of strengths, weaknesses, opportunities, and threats for the development of pediatric palliative care offers selected findings from the analysis of strategic documents in the selected area of social policy, the analysis of reports on the work of significant organizations, the analysis of statistical reports, the research on readiness for further development of pediatric palliative care, the participatory meetings and consultations conducted in the process of creating guidelines organized in the tables.

In the final part of the Guidelines, three main directions are proposed to ensure the improvement of the pediatric palliative care system in the Republic of Croatia, i.e. to increase the level of readiness for the further development of pediatric palliative care:

- 1) Improve the management system for the development of pediatric palliative care.
- 2) Strengthen the professional knowledge and information of the community about all aspects of pediatric palliative care.
- 3) Improve the management of resources needed for the development of pediatric palliative care.

All three directions are presented in a table format, displaying goals alongside related measures, activities, indicators, potential activity carriers, and the implementation level.

In addition to the above, the Guidelines contain three attachments and a list of used information sources (49 references). The summary of the findings of the Assessment of the social impact of interventions proposed within the Guidelines for the development of public policies in the field of pediatric palliative care is the first

attachment. The summary contains information on the assessment of the relevance of the Guidelines, their coherence with EU and national policies, effectiveness, and efficiency. This is followed by an attachment that contains a part of the Questionnaire on pediatric palliative care in the Republic of Croatia that was created based on the standard for pediatric palliative care in Europe. Part of the Questionnaire has been adapted to serve the leadership as a tool for thinking about the development and linking of resources at the national, local, and institutional levels. The third attachment is the Pediatric Palliative Care Standards document: IMPaCCT standards created at the European level, revised in 2022 through the GO-PPaCS project, so that they provide standards for wider implementation at the world level.

The guidelines for shaping evidence-based public policies in pediatric palliative care offer a distinctive solution tailored to the field's needs. Their innovation lies in integrating various participants at the heart of the HO project itself: civil society and the academic community, empowering users, citizens, healthcare professionals, and researchers to contribute to health-related political decisions. The Guidelines provide a comprehensive analysis of issues in pediatric palliative care, merging diverse data sources and methods—an invaluable addition. They address previously unexplored areas, offering recommendations with clear goals, measures, activities, and indicators. These suggestions can seamlessly integrate into the action plan for advancing pediatric palliative care, recommended as the next phase. Consequently, the Guidelines serve as a robust tool for advancing pediatric palliative care, aiding leadership responsibilities, and benefiting all those involved.

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