

PARENTAL ACCESS TO ONLINE HEALTH INFORMATION FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES: EXPLORING THE ROLE OF SOCIAL WORK

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Abstract: The aim of this study is to examine how parents of children with developmental disabilities acquire and use health information about therapies and treatments for their children. The research focuses on various information sources, including online sources, and the role they play in the information-seeking process. A questionnaire was distributed to 71 mothers of children enrolled in preschool programs with an Individualized Education Plan or receiving additional support between October and December 2024 in Serbia, most of whom were highly educated, lived in urban areas, and had one child. The findings revealed that mothers were generally satisfied with information from health professionals but often turn to additional sources of information: personal contacts, the internet, and printed materials, while showing varying levels of trust in these sources. The study emphasizes the significance of online health information, with a focus on professional sources such as doctors, pediatricians, and psychologists. When searching for more detailed insights online, mothers seek and use information from reliable resources, such as official websites and professional blogs. Finally, the study reflects on the role of social work in supporting parents in navigating this complex landscape of online health information and ensuring access to credible resources.

Keywords: children with developmental disabilities, parental information seeking, health information, digital health literacy, social work.

1. INTRODUCTION

When parents of children with developmental disabilities receive their child's diagnosis, they are confronted with complex information they may struggle to understand, emotions they may not know how to handle, and are uncertain about their child's immediate and long-term future. This situation can be overwhelming, especially when finding reliable information to navigate the path ahead.

Modern healthcare policy worldwide emphasizes the need to empower individuals to participate in decision making process regarding their health and the health of their loved ones [1]. This is especially critical for parents of children with developmental disabilities, as they are tasked with making decisions about their child's treatment, therapies, and overall well-being. Technological advancements have altered the way parents access health information, and enabled greater self-education but also introduced new challenges due to the sheer volume of often contradictory and unreliable information. In addition to traditional sources, parents increasingly turn to digital platforms such as search engines, social networks, and forums to seek guidance on their children's health and development [2]. Digital sources of information are attractive to parents due to their convenience, availability, and easy access. They allow parents to complement or clarify information received from healthcare professionals, especially when explanations from doctors are brief or unclear. These platforms enable parents to network with others in similar situations and offer a sense of anonymity, and make it easier for parents to explore different options and seek advice. While these digital platforms offer new opportunities for sharing experiences, they also carry the risk of spreading inaccurate or even harmful health information. As Arsenijević and Andevski pointed out, "media inform, entertain, and educate us, as well as persuade, indoctrinate, guide towards wrong judgments and actions, and even intellectually pollute us" [3, p. 241]. In this context, parents are often faced with dilemmas regarding the trustworthiness of sources.

Social workers have important role in early intervention for children with developmental disabilities. Their focus is on family-centred care and the provision of the necessary resources and skills for parents to support their children's development [4]. While their primary function has been in direct family support, social workers should expand their role in guiding parents toward reliable health

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resources. This expanding role is supported by findings from recent studies, which indicate that social workers can indeed help parents better navigate the digital landscape and access trustworthy health information and that community-based social interventions can significantly improve parents' ability to navigate these challenges, particularly by enhancing their health literacy and digital skills [5-7].

The aim of this study is to explore parental practices in online health information seeking for children with developmental disabilities. It focuses on parental satisfaction with available sources, trust in various formats, and preferences for online resources, while providing a reflection on the role of social services in supporting parents in this process.

2. RESEARCH METHODOLOGY

The aim of this research is to explore how parents of children with developmental disabilities acquire and use health information regarding their child's therapies and treatments, with a particular focus on the sources of information, the roles played by online and traditional sources in this process, and the challenges parents face in this context. The study also examines parents' attitudes toward alternative therapies and their trust in various information sources. A questionnaire was distributed to mothers of children with developmental disabilities, who completed it between October and December 2024 in Serbia. The questionnaire included questions with categorical answers (options to select one or more responses), numerical answers (rating scale from 1 to 5), and open-ended questions.

2.1. Sample Overview

The sample consisted of 71 mothers of children enrolled in preschool programs with an Individualized Education Plan (IEP) or who were receiving individualized instruction from their teachers. The criterion for inclusion in the study was the assessment by preschool teachers, who were first-year master's students at the Preschool Teachers' Training College in Kikinda (15 students), that the child required additional support in the form of individualized instruction, whether included in an IEP or as part of individualized teaching within regular classes.

Table 1: Child's age by gender

		Gender:		Total
		Male	Female	
Child's age		4	1	5
	37-48 months	13	2	15
	49-60 months	12	5	17
	61-72 months	15	4	19
	73-84 months	12	3	15
Total		56	15	71

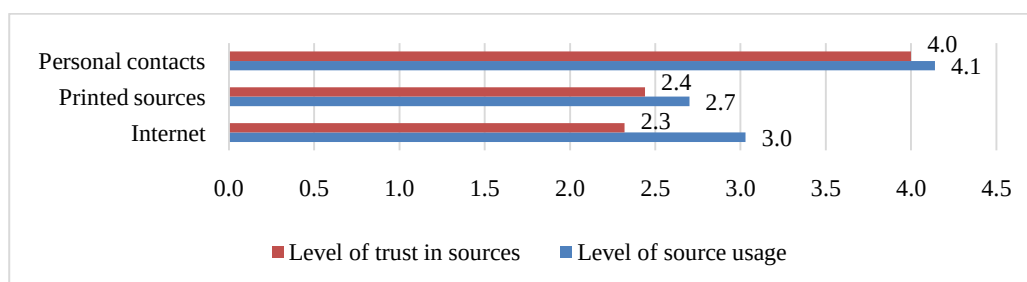
Most responses in the sample were collected in the Autonomous Province of Vojvodina (98.6%). Most mothers live in urban areas (87.3%), with fewer residing in rural areas (12.7%). Respondents were aged between 25 and 48 years, with an average age of 35.52 years (SD = 5.48). Most mothers in the sample were either highly educated (57.7%) or had completed secondary education (36.6%). The largest number of respondents had one child (40.8%), followed by those with two children (36.6%), three children (15.5%), and four or more children (5, 7%).

3. RESEARCH RESULTS

The first research question focused on mothers' satisfaction with the amount and accuracy of information regarding their children's conditions and potential treatments. On a 1 to 5 response scale, the average score for the entire sample was 3.7 (moderately high), with a standard deviation of 1.2. This indicates that certain expectations remain unmet, while standard deviation suggests differences in levels of satisfaction. The findings align with previous research, which showed that although parents

trusted official sources, they often feel that the information is neither sufficiently accessible nor detailed [8]. The results highlight the logical need for parents to further expand their knowledge and understanding of their children's conditions and therapies. Therefore, the next goal of this research is to examine the extent to which mothers utilize additional online information sources and the level of trust they place in them (also on a 1 to 5 response scale).

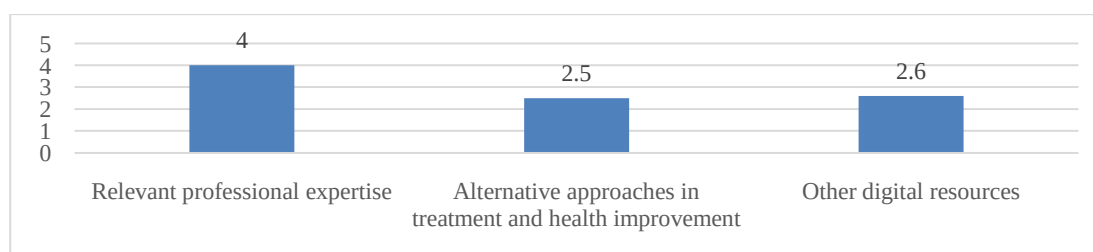
From the Graph 1, it can be observed that when mothers seek additional information outside the healthcare system, they predominantly rely on personal sources of information, such as family and friends. The level of trust in these sources is almost equal to the extent of their use. Mothers use the internet moderately, but less frequently than personal contacts as a source of health information and printed sources even less so. Furthermore, although mothers partially use the internet as an additional source of health information, they have reservations about the accuracy and reliability of these sources, as indicated by the lower level of trust in them. In fact, the gap between the frequency of use and the level of trust in these sources is the greatest for the online sources.



Graph 1. Comparison of the use and trust in additional information sources

On the other hand, while printed sources of information are the least utilized, the trust in these sources is higher than in internet sources, suggesting that mothers are willing to rely on information from various sources if they are verified (Graph 1). Similar findings were obtained in the study conducted in Melbourne in 2016, which focused on parental behaviour when seeking information about children's health. According to this study, parents largely use websites, blogs, and forums as sources of information, but at the same time, only a third of them trust these sources [9].

The gap between the frequency of use and the level of trust in online sources indicates the need for a more detailed examination of the structure of online sources to understand which specific types of digital content contribute most significantly to parents' search for information. The analysis focuses on the structure of online information sources to gain insight into usage patterns of online information. Previous research shows that the main reasons parents use the internet for health information are the lack of adequate medical support [10], the absence of suitable information from healthcare professionals [11], or their desire to explore alternative forms of treatment [12].



Graph 2. Structure of online information sources

Mothers moderately highly use online information when it comes from relevant professionals (doctors, pediatricians, special education teachers, psychologists, etc.), as shown in the Graph 2 and presented numerically on a scale from 1 to 5. These results confirm previous findings from the literature indicating that parents tend to place the highest trust in online sources coming from health professionals [1]. Therefore, mothers focus on sources that provide reliable and verified information, which points to a desire to minimize uncertainty regarding the information they find online. On the other hand, online sources of alternative approaches to treatment and health improvement, as well as

other digital resources (search engines, websites, blogs, forums, social networks), are used much less – on the borderline between moderately low and partially low usage (Graph 2).

The gap between the frequency of use and the level of trust in different online information sources (Graph 1), as well as the dominant role of additional professional sources outside the health system (Graph 2), highlights the need for a better understanding of parents' preferences regarding the format and presentation of information from relevant professionals. The following research question focuses on identifying the formats that parents consider most useful and acceptable for further information.

Table 2. Preferred forms of online information from relevant professionals

	Frequency	Percent
Official websites and portals for parents managed by professional organizations (development support centres)	36	19,4
Individual posts and blogs by professionals (doctors, therapists, psychologists)	33	17,7
Official websites of health organizations and clinics (World Health Organization, official hospital and clinic portals)	31	16,7
Video lectures, recordings, and tutorials with advice from doctors	24	12,9
Scientific studies and research	23	12,4
Written articles and guides (professional texts, manuals, blogs)	19	10,2
Instructions and brochures for parents (infographics, manuals)	17	9,1
None of the above	2	1,1
Other	1	0,5
Total	186	100

As shown in the Table 2, mothers prefer online information from official websites for parents managed by professional organizations, followed by individual posts and blogs by professionals, and then from official websites of health organizations and clinics. Interestingly, online instructions and brochures for parents are the least preferred form of information (Table 2). These results confirm previous findings in the literature, which suggest that parents often seek confirmation from professionals via online resources, including blogs and scientific papers, allowing them to gain deeper insights into specific therapies and treatment strategies [8]. They also seek evidence-based health information online, indicating a demand for more accessible, objective, and scientifically grounded health information, which is equally accessible, practical, and understandable as well as the information offered on social media [10]. The results of this paper show that, although mothers are moderately highly satisfied with information from the official healthcare system, they often turn to additional sources, which include personal contacts, the internet, and printed materials, with trust varying depending on the source (Graph 1). A preference for information provided by professionals is obvious, whether through official websites, blogs, or other digital platforms, while they are less inclined to rely on unverified sources (Table 2).

4. DISCUSSION OF RESULTS

Parents often face the challenge of finding accurate and relevant information about health and therapies for their children. While they are moderately highly satisfied with the information from official health sources, they often seek additional sources for additional information and further explanations (Graph 1). Personal contacts are the most trusted, but the internet also plays a significant role, despite concerns about its credibility and trustworthiness (ibidem). Although mothers frequently use online resources, they tend to place more trust in content from health professionals or institutions, especially official websites and posts by experts (Graph 2). In particular, they prefer online information coming from relevant professionals such as doctors, pediatricians, and psychologists (ibidem). On the other hand, alternative health approaches and digital resources like search engines, blogs, and social networks are used less frequently, with usage falling between moderately low and

partially low (*ibidem*). This reflects a clear distinction in how mothers engage with online information, and value professional input while remaining cautious about less formal sources. While the internet can contain unreliable information—especially on social networks—studies indicate that digital resources can also offer valuable support systems, enabling peer-to-peer interactions and shared experiences. These platforms can serve as spaces that help parents learn from each other and cope with the challenges of raising children with developmental disabilities [13]. Peer support through online networks is important for meeting emotional and social needs. However, to navigate both helpful and harmful aspects of online information, it is crucial for parents to possess digital literacy—to critically evaluate the resources they encounter, distinguishing between trustworthy advice and potentially misleading content.

It is important to highlight that the mothers who took part in this study are mostly highly educated, live in urban areas, and have one or two children. Highly educated mothers are more likely to use online sources, as they are more digitally literate and have greater trust in scientifically based information. Urbanization may contribute to better access to quality health information and resources, while having one or two children may provide more time to engage with online information. Previous research showed that educated parents possess better skills in identifying and selecting reliable sources [10, 14].

In the context of this study, social services play a critical role. The primary mission of social work is to support individuals, families, and communities in enhancing their well-being and addressing life challenges. For parents of children with developmental disabilities, this involves providing resources and education to help them navigate complex support systems. Social workers facilitate access to and understanding of available information, including health-related resources, through tailored advice, training, and guidance. Acting as intermediaries between parents and professional health services, social workers contribute to improving digital literacy and the critical evaluation of online health information. This effort empowers parents—especially those with lower education levels or from marginalized backgrounds—to make informed decisions. Moreover, social workers can organize and promote online peer support groups as valuable platforms for emotional support and shared experiences from other parents in similar situations. These groups address parental emotional needs, help them organize themselves and exchange information. Social work should also address disparities in digital literacy: social workers should collaborate with policymakers to design digital platforms that integrate trusted expert advice with peer-to-peer interaction. Such platforms can ensure that parents have access to reliable, professional content and benefit from the community aspect of online support as well. Furthermore, social workers can advocate for the inclusion of multilingual resources to bridge gaps for families from diverse backgrounds. Social workers contribute to public health objectives and work towards building fairer systems that ensure all families, regardless of their situation, have access to the necessary tools and information to effectively support their children.

In practise, social workers in hospitals have already demonstrated involvement in enhancing health literacy among parents of children with special health care needs, which included emotional support, counselling, and helping families navigate medical information [15]. In fact, findings from recent systematic reviews point out how important social workers are in this area. A study by Belfrage et al. [7] highlighted that community-based health literacy interventions for parents significantly improve their capacity to make informed health decisions for their children. Such interventions are effective in enhancing parents' understanding of health information, and in their health management and decision-making. Moreover, social workers can collaborate with policymakers to support for the development of digital resources tailored to the needs of underprivileged families. This collaboration can help bridge gaps in information access and ensure that all parents have the required tools and knowledge to support their children's health effectively. This approach would lead to the improved public health outcomes and a stronger connection between families and health professionals.

5. CONCLUSION

Mothers, apart from personal contacts, use digital sources moderately to gather information about their children's health, although online information is often unreliable and unverified. Mothers are generally satisfied with the information they receive from official health sources, but there is a need

for better quality and form of digital resources. While they consider official health organizations and medical sources the most reliable, they remain sceptical of informal sources such as social media, blogs, forums, and others. This indicates an obvious need to improve digital health communication and to ensure that parents have access to accurate, verified health information online.

Given that parents seek reliable sources, more effort must be invested in creating and promoting professional medical content, especially in the digital space. This is a key direction for future research and development of digital health resources. Social workers are important mediators between families and health systems and can play a central role in educating parents about navigating digital information and selecting credible sources. Moreover, they should advocate for policies that support equitable access to digital health tools and resources, particularly for vulnerable families. Improving digital literacy could significantly contribute to better selection and application of health information. This research clearly highlights the need to develop more efficient tools and platforms that will enable parents to confidently use online resources and trust expert and official sources. Furthermore, social policies should add digital health education and critical thinking and skills for selecting reliable sources, to create a stronger support system for parents and ensure they can make informed decisions about their children's health.

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