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# The dimensions of quality of healthcare of children/adolescents with disabilities

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## Abstract

**Research Question (RQ):** Which factors have a positive respectively a negative impact on parental satisfaction with the quality of healthcare of children and adolescents with disabilities?

**Purpose:** The aim of the study is to identify the dimensions of satisfaction with the quality of healthcare based on the findings of different authors, and, at the same time, to define the factors that influence the extent to which parents of children and adolescents with disabilities are satisfied with the quality of healthcare provided to their children and adolescents.

**Method:** The research is based on a systematic review of the existing literature. A search for peer-reviewed and open-access scientific articles was conducted in SpringerLink, Science Direct, ProQuest, PubMed, and Scopus. The time frame of the search was publications between 2012 and 2023 with the exception of relevant literature in the field of research. The search offered 106 such articles. For further consideration we included articles in which different authors reported factors that positively or negatively influence parents' satisfaction with the healthcare of their child and adolescent with disabilities. The criteria were met in 57 articles. The results of the main findings are shown in the tables.

**Results:** The perceived factors that have a positive impact on parental satisfaction are communication and cooperation between the parties involved, stress reduction activities, knowledge and skills of healthcare professionals, use of modern technologies, measurement of user satisfaction of healthcare services, approaches to healthcare and patient-centred care. Among the negative factors perceived are disadvantages in the healthcare process, lack of communication and cooperation between healthcare professionals and parents, lack of patient-centredness, insufficient quality of healthcare services, no user satisfaction measurements and lack of knowledge of healthcare professionals.

**Organization:** The findings of the research may help the management of healthcare institutions to find solutions to improve the satisfaction of parents of children and adolescents with disabilities.

**Society:** This article contributes to the understanding of the importance of monitoring the satisfaction of parents of children and adolescents with disabilities who are users of healthcare services. The results of our research show positive impacts on children and adolescents, their parents and the healthcare professionals involved in the healthcare process. The negative impacts shown give an idea of how to think ahead to improve the quality of work.

**Originality:** It is the first study of its kind in Slovenia. Its originality lies in the fact that it looks at a very relevant social issue of children and adolescents with disabilities and their parents, who have both positive and negative experiences while being in the process of healthcare.

**Limitations / further research:** The research is limited to a review of existing literature in electronic databases. The results of the survey provide an idea and a basis for further research, where the results obtained in our study could be implemented in a healthcare facility and a survey on satisfaction with the healthcare of this population could be conducted there.

**Keywords:** disabilities, handicap, children and adolescents, healthcare, quality, satisfaction, parents, patient-centred-care.

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# 1 INTRODUCTION

Data show that 15 % of the world's population has some form of disability (World Health Organization, 2011 in Vovk, 2020, p. 2), in the European Union 87 million people are estimated to have some form of disability (European Commission, 2021, p. 4), while in Slovenia 170,000 of the total population is estimated to live with a disability (Ministry of Labour, Family, Social Affairs and Equal Opportunities, 2021, p. 3). Their ability to contribute to the success of society is no different from the rest of the population, and they are not always able to fulfil their potential due to various disabilities, barriers and reduced accessibility. This is not a homogeneous group of people, as they have different functional limitations such as intellectual disabilities, sensory impairments (vision, hearing), mobility impairments, etc. (Ministry of Labour, Family, Social Affairs and Equal Opportunities, 2021, p. 4). It is assumed that each type of disability has specific, complex problems and needs in the area of health, rehabilitation, education, social life and support. It is important to recognise that not even two people have exactly the same experiences and needs (World Health Organization, 2011 in Vovk, 2020, p. 2). Attitude towards people with disabilities is extremely important, as they face many difficulties (Khan, Umar, Naeem, & Marryam, 2016, p. 18).

In 2006, the United Nations Convention on the Rights of Persons with Disabilities was adopted (United Nations, 2006). The Slovenian translation of the Convention is The Convention on the Rights of Invalid Persons and according to Zaviršek (2018a, p. 143), the translation is inappropriate as "disability" is properly translated as "handicap, hindrance"; "invalidus" (Latin) means dependence, infirmity (Zaviršek, 2014a, p. 124). In Slovenian law and also in the public domain (e.g. in healthcare institutions), the term "invalid" is still being used, suggesting that these people are considered helpless, weak, frail, unable to do their jobs. It would be more appropriate to use the term "handicapped persons" or "persons with various types of disabilities" (Gosenca, Lipovec Čebron, & Zaviršek, 2016, p. 59).

Mental crises and distresses, physical, sensory and intellectual disabilities, as the concept of disability or handicap emphasises, limit individuals in their normal functioning, but become a problem when the individual is confronted with a society or environment that represents a deviation from his or her normality (Zaviršek, 2014b, p. 134). As Rutar (2018, p. 23) states, a disability is always associated with suffering, and a person is bound to suffer as a result. The Action Programme for People with Disabilities 2022-2030 (Ministry of Labour, Family, Social Affairs and Equal Opportunities, 2021, p. 3) states that the Constitution of the Republic of Slovenia, in its chapter on Human Rights and Fundamental Freedoms, in Article 14 on equality before the law, states that human rights and freedoms are guaranteed to everyone, regardless of personal circumstances, with disability being considered as a personal circumstance. Thus, the right to equality before the law for people with disabilities is explicitly emphasised here, as no one should be disadvantaged because of their disability. In this context, the specific needs of persons with disabilities must be taken into account and they must be treated equally and guaranteed the enjoyment of all human rights. In this context, the State is committed to taking effective and appropriate measures to enable persons with disabilities to achieve and maintain maximum independence, physical, mental, social and vocational capacities, and to achieve full inclusion and participation in all areas of life. Furthermore, the Law on Patients' Rights (2008), in the chapter on patients' rights, in Article 7, under the right to equal access to and treatment in healthcare, states that a patient »shall have the right to equal treatment in healthcare irrespective of sex, nationality, racial or ethnic origin, religion or belief, disability, age, sexual orientation or any other personal circumstance«. The Code of Ethics in Healthcare of Slovenia (2014, p. 2) states in Principle I that »Healthcare providers shall take care to preserve human life and health. They are obliged to carry out their work in a humane, professional, high-quality, safe, compassionate, responsible and conscientious manner and to respect the needs, values and beliefs of the patient. Factors such as race, ethnicity, religion, political beliefs, social status, age, gender, sexual orientation, medical condition, disability must not in any way influence their attitude towards the patient. The patient must be treated individually and holistically. Not only his physical needs, but also his psychological, social and spiritual needs must be taken into account and his culture and personal beliefs respected. «

A person needs to be treated as a unique being, according to Rutar (2018, p. 23-26). When treating a patient, healthcare professionals need to take into account the cultural and social factors that affect the patient, as well as act in accordance with the individual's needs (Jelenc, Keršič Svetel, & Lipovec Čebron, 2016, p. 21). Openness to accepting differences is important in coexistence (Rutar, 2018, p. 23-26). Despite differences in many areas, people share basic needs and desires, human dignity, security and, above all, an equal position in society, to which we all have an equal right. A nurse is a person who must, in addition to professional competence, also possess certain personal qualities that are manifested by an internal acceptance of the values of the profession (Mlinšek, 2012, p. 20-21).

The aim of the study is to identify the dimensions of satisfaction with the quality of healthcare based on the findings of different authors, and at the same time to define the factors that influence the extent to which parents of children and adolescents with disabilities are satisfied with the quality of healthcare provided to their children and adolescents.

While preparing this paper, we have encountered problems with the naming of people with disabilities - it ranges from special needs, disability, handicap, impairment to handicap. For children and adolescents, the Institute of Education of the Republic of Slovenia defines criteria for classification (Institute of Education of the Republic of Slovenia, 2015, p. 4), but for adults there are no such criteria. As the terms are sometimes complementary in the course of the paper, it has made sense to use one of the above-mentioned descriptions in certain places.

## 2 Theoretical framework

The first records of disabled, according to Veronique Dasen (1993 in Zaviršek, 2000, p. 187-188), come from Egypt. Descriptions of illness, mental retardation, epilepsy, blindness and the first known mention of deafness are given in the Eber papyrus of 1550 BC. One also reads that the blind was best treated by the priests who taught them music, art and massage, because the priests saw the loss of sight as a positive religious sign; the blind thus took part in religious ceremonies, temples, funerals, and were harpists and singers in aristocratic households, as the aristocrats did not consider them a danger to their women. People with mental disorders were treated less favourably because they were considered to be possessed by the souls of the dead and were therefore not allowed in the temples. People with physical disabilities were depicted in Egypt in a similar way to and alongside children.

There is no reliable information on the treatment of people with disabilities in antiquity, but various sources record that all those who were unable to care for themselves were put to death. For Sparta, Athens and Rome, information on the treatment of those persons is known for the 4th and 5th centuries BC. In Sparta and Athens, the educational systems forbade the education of handicapped persons because it was believed that they would not be able to achieve what was required in the educational system of that time. In Sparta, these children were dumped in the Taygetos mountains and in Athens they were left to die by the roadside. In Rome, handicapped children were placed in baskets and thrown into the Tiber River (Novljan, 1997).

In the 2nd century AD, the Romans began to value the handicapped as an object of amusement, because in special markets you could buy such a person and have him as a pet fool (there was no humanity here, of course) (Winzer, 1997 in Zaviršek, 2000, p. 192). Natural scientists studied various pathological phenomena as far back as antiquity, proving that disease was not the result of supernatural forces, but rather a disorder in the development of the organism. At the same time, they stressed that the development of handicapped persons is specific. At the beginning of the Middle Ages, the influence of the Church on the situation of handicapped people was very negative, since it was proclaimed that maldevelopment was a sign of an "evil spirit", and the Inquisition demanded that all handicapped children are removed from social life, regardless of class. The Renaissance period that followed changed the way people thought about their goals and the meaning of life. Man, with his intellect and strength, became important, and at the same time the position of people with disabilities began to change. The first beginnings of education and training for people with disabilities also belong to this period (Novljan, 1997).

There are many barriers and obstacles to quality patient care, as Ilkhani states (2013, p. 7-8): lack of sufficient knowledge and clinical skills, disrespectful attitudes towards health professionals and accusations that their condition is the result of unprofessional work, inadequate nursing care plan, lack of empathy and understanding from hospital staff, lack of trust in health professionals, which is likely to lead to mistrust and negative opinion of both patients and their families, dependence on caregivers, inadequate equipment and accessories, negative attitudes towards people with disabilities, lack of effective communication skills and reassurance from nurses, insufficient time to provide care, reduction in quality of care, lack of information sharing, problems with the admission process, inadequate coordination between different service providers, inaccessibility of health services and unwillingness to provide care and support.

Admission to hospital, whatever the reason for the admission is, is stressful for everyone involved, both the patient and their loved ones. People are unfamiliar with the environment around them and, of course, the language that is being used in the hospital. Being unwell and ill makes them all more vulnerable, and this is even worse when it comes to a person with a disability. There are communication difficulties, problems with expressing discomfort, pain, problems with self-management, problems due to comorbid conditions (e.g. epilepsy, intellectual disability) (Guidelines and Audit Implementation Network, 2010 in Vovk, 2020, p. 18).

Aston, Breau, & MacLeod (2014a, p. 301-302; 2014b, p. 221), Ilkhani (2013, p. 2015) and Sharkey et al. (2014, p. 748) state that nurses need to improve their knowledge and gain experience to work with patients with barriers, as working with these patients is challenging for nurses, and frustration and discomfort arise. They stress the need for nurses to establish a positive relationship with both patients and their parents. The establishment of a positive therapeutic relationship between the care providers and the users, i.e. the patients, is of great importance for a positive treatment outcome (Aston, Breau, & MacLeod, 2014b, p. 221).

Jelenc, Keršič Svetel & Lipovec Čebron (2016, p. 26) have developed recommendations to help all health professionals, not just nurses. They recommend that:

- healthcare must always go back to basics, to conscious care and preserving the dignity of the human being as a psycho-physical whole;
- the time pressure of working in healthcare is huge, but the time invested in understanding others is never lost and contributes significantly to the effectiveness of the work;
- the two basic questions that an individual can be asked are: »Tell me, please, what do you need? How can I help you?";
- each individual has to be understood as a unique person, his or her needs, wishes, beliefs, understandings and perceptions taken into account as much as possible, and care tailored accordingly to all of those;
- healthcare professionals must be aware of one's own personality, perceptions, beliefs and understandings, both personal and professional, and always take into account the impact of the wider environment on the individual;
- it is necessary to show our affection for the user and to build a relationship of trust with them;

- we should take into account the user's wishes and the needs of those close to him/her to be involved;
- we should strive for respectful relations and communication within the team and create an atmosphere of trust, regardless of the differences between team members;
- we should see one's own work, helping and caring for others as enriching and, moreover, as offering personal and professional growth and personal satisfaction.

Good communication skills are essential for nursing practice and patient-centred care and are an important part of nurses' competencies (Boykins, 2014, p. 40).

Based on the examined literature we formulated the following research questions in the theoretical part of the article:

RQ1: Which factors have a positive impact on parental satisfaction with the quality of healthcare of children and adolescents with disabilities?
RQ2: Which factors have a negative impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities?

## 3 METHOD

The research is based on a systematic review of the existing literature. A search was conducted in Springerlink, Science Direct, ProQuest, PubMed and Scopus. Based on the research questions, we identified the keywords shown in Table 1.

Table 1. Key words

| **Key words** |
|---|
| »disabilities« |
| »handicap« |
| »special needs« |
| »children + adolescents + disabilities« |
| »children + adolescents + handicap« |
| »children + adolescents + special needs« |
| »children + disabilities + healthcare« |
| »children + handicap + healthcare« |
| »children + special needs + healthcare« |
| »adolescents + disabilities + healthcare« |
| »adolescents + handicap + healthcare« |
| »adolescents + special needs + healthcare« |
| »child + family centred healthcare« |
| »child + patient centred healthcare« |
| »parental satisfaction + hospital« |
| »quality + healthcare« |

In order to narrow down the number of hits, we used the following inclusion criteria:

- peer-reviewed original and reviewed scientific articles,
- open-access articles,

- articles available in Slovene, Serbo-Croatian or English,
- topical relevance (articles dealing with children and adolescents with disabilities, handicap or special needs); and
- age of the literature up to 10 years (with the exception of relevant peer-reviewed literature in the field of research).

The exclusion criteria were:

- the article's irrelevance to the topic,
- articles in a foreign language other than English or Serbo-Croatian,
- repetitive articles,
- availability of the abstract only; and
- literature more than 10 years old (with the exception of relevant literature in the field of research).

The search returned 106 such articles. In each of the articles, we looked at the abstract and the results. Out of those 57 articles met the criteria. The results of the main findings are shown in the tables.

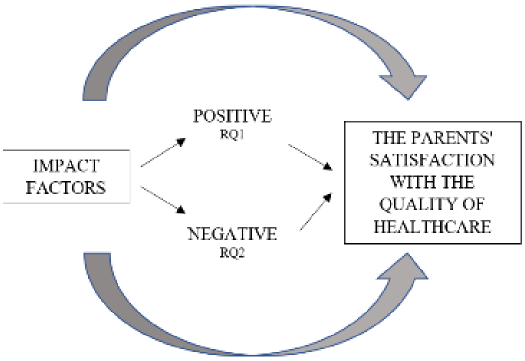

*Figure 1.* The research model

The reliability of the results was checked with a repeatability step of seven days, and there was no difference between the two examinations. The key findings were based on inductive inference conclusion.

# 4 RESULTS

## 4.1 Factors with a positive impact on parental satisfaction with the quality of healthcare of children and adolescents with disabilities

Table 2 shows the key findings of different authors, identifying factors that have a positive impact on parental satisfaction with the quality of healthcare of children and adolescents with disabilities, relating to the first research question (RQ1). The authors' views are presented in a review of 29 articles.

Table 2. Factors that have a positive impact on parental satisfaction with the quality of healthcare of children and adolescents with disabilities

| Authors | Findings |
|---|---|
| Arcuri et al. (2015) | **The importance of parents and health professionals working together** in the process of health care of children. |
| Bayat et al. (2022) | **Measuring parental satisfaction** is an important factor in paediatric healthcare because parents play a central role in their children's lives. Parents' decisions are the basis for success or failure in large-scale cases of child treatment. |
| Birkett, Liddle, Jones, & Paulson (2022) | **Individualized care plans** are an innovative method of providing care for children and adolescents with developmental disabilities, who face many challenges in the course of their care. |
| Bock et al. (2022) | **Individualised dental hygiene training** improved plaque status in hospitalised children and adolescents with mental disorders, but self-monitoring by children and adolescents did not improve. |
| Brannon, Ray, Lark, & Kindratt (2022) | **The importance of good communication and time** for the child and his/her parents when it comes to a child with special needs or a chronically ill child. |
| Jannes et al. (2020) | **Promoting parent-infant interaction** through the provision of developmentally supportive care and **non-intermittent visits** for parents whose babies are hospitalised in the NICU contributes significantly to parental satisfaction. |
| Johnson et al. (2022) | **Introducing a new conceptualisation** and **interdisciplinary approach** to the management of adolescents with chronic pain. |
| Kruszecka-Krówka et al. (2019) | **The age of the child, the type of admission** and **the educational level of the respondents** are factors that influence parental satisfaction with health care. |
| Lee & Korczak (2014) | **Parental satisfaction with their visit to the paediatric psychiatric emergency room** (time between referral and admission, feeling listened to, amount of psychoeducation received and duration of visit). |
| Leroy & Declerck (2013) | **Taking care of dental health and visiting the dentist regularly.** |
| Liddle & Sonnentag (2020) | **Applying an individualized care plan** to children and adolescents (patient-centred) with developmental disabilities. |
| Martins, Aldiss, Taylor, & Gibson (2022) | **The key role of the case coordinator** in paediatric oncology care. Coordination, consistency and continuity of care mean better outcomes for the whole family. |
| Mayland et al. (2022) | **The circumstances and care at the end of a child's life** can have a profound impact on parents and siblings. **Measuring experiences and outcomes** during this period is challenging but extremely important to ensure high quality. |
| McAnuff, Boyes, & Kolehmainen (2015) | **The importance of appropriate communication** and **interactions** between family members and health professionals. Two types of interaction: relational (listening, empathy, respect) and collaborative (sharing, planning, problem solving). |
| McGill & Rea (2015) | A key factor determining whether healthcare services are provided or whether their needs are adequately met is based on **communication between all partners in the healthcare system**, and in particular between the child/adolescent and their parents/guardians. |
| McPherson et al. (2018) | The importance of **appropriate communication** in the healthcare process of children with and without disabilities and their parents. |
| McPherson, Oake, & Stinson (2020) | **Mobile applications** can empower young people with disabilities and provide them with adapted support for a healthy lifestyle. |
| Miller & Harris (2012) | **Introducing an instrument** to measure the involvement of children and adolescents in decisions related to their chronic illness. |
| Moonen, Festen, Bakker-vanGijssel, & Vervoort-Schel (2022) | **The introduction of a specialist doctor for children with special needs,** working with a multidisciplinary team to support the child and his/her family. In addition to behavioural, physical and mental health problems, specialists should also focus on the context of the child's family and the associated social determinants of health. |
| Morris, Muskat, & Greenblatt (2018) | **Involving the social worker** in the healthcare of children with autism in the context of hospital treatment (crisis intervention, counselling, collaboration, advocacy, information resource for patients and their parents). |

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| **Authors** | **Findings** |
|---|---|
| O'Connor, Brenner, & Coyne (2019) | All health professionals caring for children need to be aware of **patient-centred care**, which can benefit the child, their family, healthcare professionals and the organisation. |
| Ong et al. (2020) | **The importance of continuing education** and **professional development of** healthcare professionals working with children with developmental disabilities. |
| Schmidt, Reis, Schulte, & Fricke (2022) | **Introducing a curriculum** for the dental care of children and adolescents with special needs into dental training. |
| Shafer et al. (2018) | **Lower parental anxiety** and **better social integration of children** predicted higher parent satisfaction scores with perioperative care (anaesthesia). There is a need to work on **reducing parental anxiety in** parents of children requiring anaesthesia. |
| Sukhov, Asante, & Ilizarov (2020) | **Telemedicine** can reduce health inequalities and increase access to care for children with disabilities. Further research is needed to demonstrate the effectiveness of telemedicine in cases of complex medical conditions in children. |
| Taylor, Kong, Foster, Badawi & Novak (2022) | Health professionals need to take **an individualised approach** to parents and their children, especially in cases where parents have no one close by to support them or where there is social isolation. |
| Thunberg, Johnson, Bornman, Öhlén, & Nilsson (2021) | **Use of a unified communication system, including pictorial aids and easy-to-read texts,** as an aid to patient-centred communication and the healthcare process. |
| Top (2022) | **Sexual health education** for adolescents with disabilities and their mothers leads to more effective sexual health management for this group of adolescents. |
| Woodman, Simon, Hauari, & Gilbert (2020) | **Involving parents** in their child's healthcare. |

*Note.* *NICU – Neonatal Intensive Care Unit

Factors that have a positive impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities:

- communication and cooperation between the parties involved (healthcare professionals, children and adolescents with disabilities, parents and other family members);
- stress reduction activities (reduction of parental anxiety when the child is hospitalised, positive circumstances and care at the end of the child's life, no restrictions on visits to the child, etc.);
- the knowledge and skills of healthcare professionals (continuous training of healthcare professionals and professional development, recruitment of healthcare professionals specialised in working with children and adolescents with special needs);
- the use of modern technology (use of mobile applications, use of telemedicine, etc.);
- measurement of user satisfaction of healthcare services (children and adolescents, their parents, etc.);
- approaches to healthcare (introduction of a new conceptualisation of healthcare and an interdisciplinary approach, identification of the involvement of children and adolescents in decisions regarding their own illness, introduction of a case coordinator, parental satisfaction with healthcare in terms of accessibility, duration of treatment and sense of acceptance, etc.);

- patient-centred care (patient-centred care and individualised approach, the use of personalised care and nursing care plans, use of a single communication system, including pictorial aids and easy-to-read texts, etc.).

## 4.2 Factors with a negative impact on parental satisfaction with the quality of healthcare of children and adolescents with disabilities

Table 3 shows the key findings of different authors identifying factors that have a negative impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities, which relate to the second research question (RQ2). The views of the authors of the review of 28 articles are presented.

Table 3. Factors that have a negative impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities

| Authors | Findings |
|---|---|
| Alle, Akenaw, Seid, & Bayable (2022) | **Parents' sex, place of residence, hospital stay, birth weight and gestational age of the baby** were factors associated with parental satisfaction in the ICU*. They were most satisfied with the organisation of work. |
| Chua & Cyna (2020) | Satisfaction in **paediatric perioperative care (anaesthesia)** is not considered a priority or a primary outcome. |
| Culnane et al. (2020) | **Differences in transition planning, systemic disconnection between health and and disability, lack of services and expertise, high levels of parental anxiety about transition, high levels of dissatisfaction and unmet needs during transition to adult care** are barriers to ensuring an optimal transition from adolescence to adulthood. |
| Eichinger et al. (2022) | **Participation** is **an important dimension** of children's healthy development and is linked to better self-rated health, educational attainment and social inclusion. Many children with disabilities are not able to participate in health care and are therefore at **risk of adverse events.** |
| Engelen, Knoll, Rabsztyn, Maas-van Schaaijk, & van Gaal (2019) | Adolescents with chronic diseases and health professionals find it difficult to start a discussion on **adolescent sexual health. Discussions on adolescent sexual health** should become part of the routine, healthcare professionals should be properly trained in the field, and sexual health should be integrated into education and hospital policy. |
| Fergus, Zambeli-Ljepović, Hampson, Copp, & Nagata (2022) | Failure to meet the health needs of adolescents with disabilities - **inadequate health education.** |
| Gauthier-Boudreault, Couture, & Gallagher (2018) | **Inconsistency** in the transition from adolescence to adulthood **and poor communication between different institutions.** |
| Hand, Boan, Bradley, Charles, & Arnstein Carpenter (2019) | **Due to poor diagnosis** and **unmet health needs** adolescents with ASD and/or a mental disorder are more likely to use emergency services, leading to higher health care costs. |
| Hart, Van Deusen, & Gonzaga (2017) | **Lack of knowledge among healthcare professionals** on the transition from adolescence to adulthood**, need for recommendations on the appropriate age** to start the transition process to adulthood. |
| Heron et al. (2019) | **Inadequate support** for adolescents with disabilities from healthcare professionals during the transition to adult healthcare. |
| Hinton & Kirk (2014) | **Exposure to the risk of sub-optimal healthcare and support** because children and adolescents **lack a medical diagnosis.** |
| Khanlou et al. (2022) | **Nurses play a key role in tackling health inequalities** in the treatment of patients with developmental disabilities, but they **lack specific education and training** to work in this field. |
| Kruszecka-Krówka et al. (2021) | There is a need to **optimise nursing care, especially in the area of parental involvement.** A plan to **improve the quality of care** in paediatric wards should focus in particular on early childhood patients and their parents, who are the most critical in assessing satisfaction. |

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| Authors | Findings |
|---|---|
| Lung et al. (2021) | **Discussing sexuality with healthcare professionals** is important for positive adolescent development, including for adolescents with special needs or chronic medical conditions. There is a perceived **deficit** in this area, especially when it comes to adolescents with special needs and/or chronic medical conditions. |
| MacNeill, Doucet, & Luke (2022) | **Lack of support, lack of continuous care, need for participation and difficulties in the transition from adolescence to adulthood.** The need for early and coordinated planning between collaborating health teams, team communication throughout the transition process and coordination between health, education and social institutions. |
| Madeo, O'Brien, Bernhardt, & Biesecker (2012) | **Uncertainty** about an undiagnosed genetic condition of a child. |
| Malapela, Thupayagale-Tshweneagae, & Ibitoye (2020) | **The need for a strong supportive healthcare system** to enable a successful transition from adolescence to adulthood. **Nurses** play a key role in helping individuals and their families with the health care challenges of the transition from adolescence to adulthood. |
| Menezes, Robinson, Harkins, Sadikova, & Mazurek (2021) | **Unmet health needs** and **poorer quality of care** for children and adolescents with ASD** with and without a mental disorder. |
| Mol, Argent, Paed, & Morrow (2018) | **Lack of communication and support for parents of children in intensive care by health professionals and parental involvement in healthcare.** |
| Muskat et al. (2015) | Communication difficulties, increased sensory sensitivity due to an overload of sensory experiences, waiting for treatment, and transitions between treatment for children and adolescents with autism spectrum disorder and their parents. **The need for adaptation to the situation by the healthcare workers.** |
| Nguyen, Nguyen, Phan, van Eeuwijk, & Fink (2020) | When **the hospital stay was prolonged** and **the newborn's health deteriorated, parental satisfaction** with the quality of care in the healthcare facility decreased. |
| Ong et al. (2017) | **Lack of skills of healthcare workers** to work with children with disabilities. |
| Park, Jang, Lee, Kim, & Park (2020) | Greater efforts are needed to **provide quality healthcare services** to respond to the health problems of children with ADHD*** and to improve their health care when needed. |
| Semovski, King, & Stewart (2021) | **Late access to mental health services** for children and adolescents is associated with **increased risk of harm and non-attendance** at planned appointments. |
| Shanahan, Ollis, Balla, Pate, & Lang (2020) | **Lack of continuity in adolescents' healthcare** as they transition to adulthood. Lack of planning, consistency, availability of care leads to feelings of anxiety, poor treatment outcomes, reduced support and, for some patients, non-adherence to care. |
| Siuba, Patel, Guilonard, & Pratt (2020) | **Providing health care** for children and adolescents with chronic illness requires the coordinated work of **a multidisciplinary team**. Children and adolescents and their families face many challenges in a complex health system. |
| Soltau, Biedermann, Hennicke, & Fydrich (2015) | **Feelings of irresponsibility** and **lack of knowledge** of mental healthcare professionals when dealing with children with disabilities. |
| Srivastva et al. (2021) | **Standardised protocols for analysing parental satisfaction need to be developed.** This will help to better understanding parents' expectations and improve patient care in intensive care units. |

*Note.* *ICU – Intensive Care Unit; **ASD – Autism Spectrum Disorder; ***ADHD – attention deficit hyperactivity disorder; ***

Factors that have a negative impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities include:

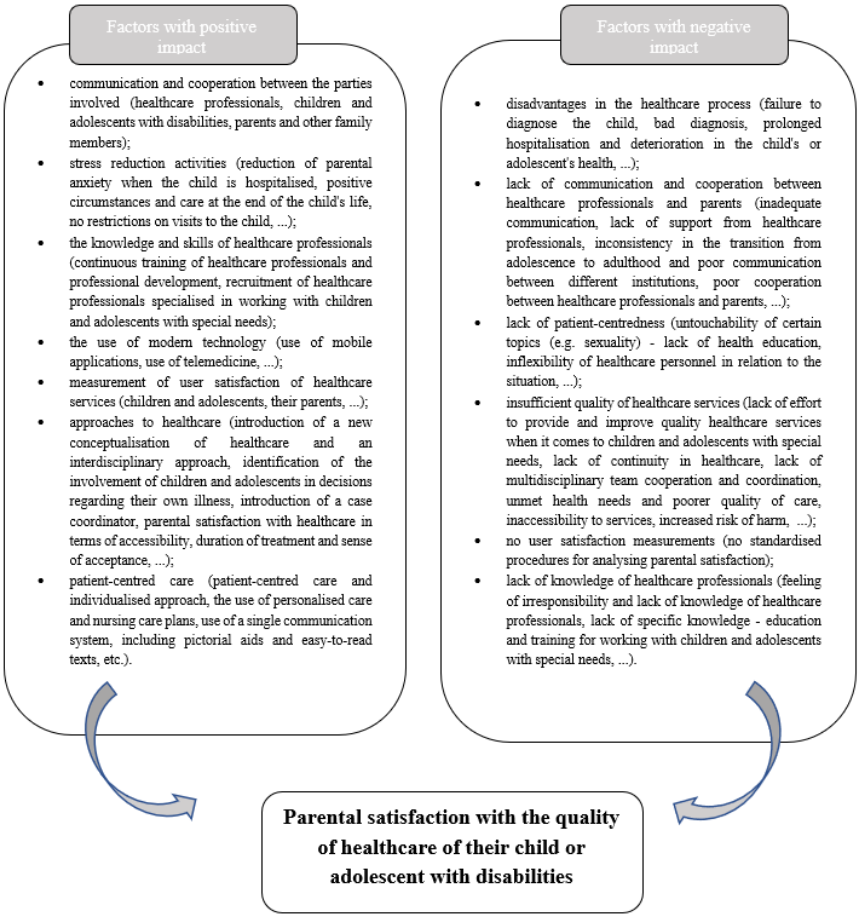
- disadvantages in the healthcare process (failure to diagnose the child, bad diagnosis, prolonged hospitalisation and deterioration in the child's or adolescent's health, ...);

- lack of communication and cooperation between healthcare professionals and parents (inadequate communication, lack of support from healthcare professionals, inconsistency in the transition from adolescence to adulthood and poor communication between different institutions, poor cooperation between healthcare professionals and parents, etc.);
- lack of patient-centredness (untouchability of certain topics (e.g. sexuality) - lack of health education, inflexibility of healthcare personnel in relation to the situation, etc.);
- insufficient quality of healthcare services (lack of effort to provide and improve quality healthcare services when it comes to children and adolescents with special needs, lack of continuity in healthcare, lack of multidisciplinary team cooperation and coordination, unmet health needs and poorer quality of care, inaccessibility to services, increased risk of harm, etc.);
- no user satisfaction measurements (no standardised procedures for analysing parental satisfaction);
- lack of knowledge of healthcare professionals (feeling of irresponsibility and lack of knowledge of healthcare professionals, lack of specific knowledge - education and training for working with children and adolescents with special needs, etc.).

## 5 DISCUSSION

The answer to the first research question "Which factors have a positive impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities?" is presented on Figure 2. The perceived factors that have a positive impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities are communication and cooperation between the parties involved (healthcare professionals, children and adolescents with disabilities, parents and other family members), stress reduction activities (reduction of parental anxiety when the child is hospitalised, positive circumstances and care at the end of the child's life, no restrictions on visits to the child, ...), the knowledge and skills of healthcare professionals (continuous training of healthcare professionals and professional development, recruitment of healthcare professionals specialised in working with children and adolescents with special needs), the use of modern technology (use of mobile applications, use of telemedicine, ...), measurement of user satisfaction of healthcare services (children and adolescents, their parents, ...), approaches to healthcare (introduction of a new conceptualisation of healthcare and an interdisciplinary approach, identification of the involvement of children and adolescents in decisions regarding their own illness, introduction of a case coordinator, parental satisfaction with healthcare in terms of accessibility, duration of treatment and sense of acceptance, ...) and patient-centred care (patient-centred care and individualised approach, the use of personalised care and nursing care plans, use of a single communication system, including pictorial aids and easy-to-read texts, etc.)

The answer to the second research question "Which factors have a negative impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities?" is shown on Figure 2. The perceived factors that have a negative impact on parental satisfaction with the quality of healthcare for children and adolescents with disabilities are the disadvantages in the healthcare process (failure to diagnose the child, bad diagnosis, prolonged hospitalisation and deterioration of the child's or adolescent's health, ...), lack of communication and cooperation between healthcare professionals and parents (inadequate communication, lack of support from healthcare professionals, inconsistency in the transition from adolescence to adulthood and poor communication between different institutions, poor cooperation between healthcare professionals and parents, ...), lack of patient-centredness (untouchability of certain topics (e.g. sexuality) - lack of health education, inflexibility of healthcare personnel in relation to the situation, ...), insufficient quality of healthcare services (lack of effort to provide and improve quality healthcare services when it comes to children and adolescents with special needs, lack of continuity in healthcare, lack of multidisciplinary team cooperation and coordination, unmet health needs and poorer quality of care, inaccessibility to services, increased risk of harm, ...), no user satisfaction measurements (no standardised procedures for analysing parental satisfaction) and lack of knowledge of healthcare professionals (feeling of irresponsibility and lack of knowledge of healthcare professionals, lack of specific knowledge - education and training for working with children and adolescents with special needs, ...).



- communication and cooperation between the parties involved (healthcare professionals, children and adolescents with disabilities, parents and other family members);
- stress reduction activities (reduction of parental anxiety when the child is hospitalised, positive circumstances and care at the end of the child's life, no restrictions on visits to the child, ...);
- the knowledge and skills of healthcare professionals (continuous training of healthcare professionals and professional development, recruitment of healthcare professionals specialised in working with children and adolescents with special needs);
- the use of modern technology (use of mobile applications, use of telemedicine, ...);
- measurement of user satisfaction of healthcare services (children and adolescents, their parents, ...);
- approaches to healthcare (introduction of a new conceptualisation of healthcare and an interdisciplinary approach, identification of the involvement of children and adolescents in decisions regarding their own illness, introduction of a case coordinator, parental satisfaction with healthcare in terms of accessibility, duration of treatment and sense of acceptance, ...);
- patient-centred care (patient-centred care and individualised approach, the use of personalised care and nursing care plans, use of a single communication system, including pictorial aids and easy-to-read texts, etc.).

- disadvantages in the healthcare process (failure to diagnose the child, bad diagnosis, prolonged hospitalisation and deterioration in the child's or adolescent's health, ...);
- lack of communication and cooperation between healthcare professionals and parents (inadequate communication, lack of support from healthcare professionals, inconsistency in the transition from adolescence to adulthood and poor communication between different institutions, poor cooperation between healthcare professionals and parents, ...);
- lack of patient-centredness (untouchability of certain topics (e.g. sexuality) - lack of health education, inflexibility of healthcare personnel in relation to the situation, ...);
- insufficient quality of healthcare services (lack of effort to provide and improve quality healthcare services when it comes to children and adolescents with special needs, lack of continuity in healthcare, lack of multidisciplinary team cooperation and coordination, unmet health needs and poorer quality of care, inaccessibility to services, increased risk of harm, ...);
- no user satisfaction measurements (no standardised procedures for analysing parental satisfaction);
- lack of knowledge of healthcare professionals (feeling of irresponsibility and lack of knowledge of healthcare professionals, lack of specific knowledge - education and training for working with children and adolescents with special needs, ...).

*Figure 2.* Presentation of positive and negative factors influencing parental satisfaction with the quality of healthcare for their child and adolescent with disabilities

McAnuff, Boyes, & Kolehmainen (2015) see adequate communication and interactions between family members and healthcare professionals as a positive factor of satisfaction with the quality of care. They highlight two types of interaction: relational (listening, empathy, respect) and collaborative (sharing, planning, problem solving). The importance of appropriate communication between all participants in the process is also discussed by Brannon, Ray, Lark, & Kindratt (2022), McGill & Rea (2015) and McPherson et al. (2018), with Thunberg, Johnson, Bornman, Öhlén, & Nilsson (2021) suggesting the use of a unified communication system, including visual aids and easy-to-read texts, as an aid to patient-centred communication and the healthcare process. Furthermore, O'Connor, Brenner, & Coyne (2019) write about patient-centred care, of which communication is an important part, stating that it can have benefits for the child, the family, the healthcare professionals and the organisation. In this context, an individualized treatment plan is important for children and adolescents with disabilities (Birkett, Liddle, Jones, & Paulson, 2022; Bock et al, 2022; Liddle & Sonnentag, 2020), which is particularly necessary in cases where parents have no one close by to support them or where there is social isolation (Taylor, Kong, Foster, Badawi & Novak, 2022), as well as when topics are not part of the routine (e.g. sex education for adolescents with disabilities) (Top, 2022). Collaboration during the healthcare process is important both between providers and children/adolescents and their parents (Arcuri et al., 2015; Woodman, Simon, Hauari, & Gilbert, 2020), involving professionals from different disciplines has an impact on treatment success (Morris, Muskat, & Greenblatt, 2018). Parental involvement in care and the possibility of unrestricted visits with the child also have an impact on increased satisfaction with healthcare (Jannes et al., 2020; Shafer et al., 2018), which also contributes to reduced parental anxiety. Adequate knowledge and training of healthcare professionals are also among the positive factors for parental satisfaction (Moonen, Festen, Bakker-vanGijssel, & Vervoort-Schel, 2022; Ong et al., 2020), and the use of certain innovations in the treatment, such as the introduction of an instrument to identify the involvement of children and adolescents in decisions related to their chronic illness (Miller & Harris, 2012), the use of mobile applications that can empower adolescents with disabilities and provide them with tailored support for healthy lifestyles (McPherson, Oake, & Stinson, 2020), the use of telemedicine that can reduce health inequalities and increase access to care for children with disabilities (Sukhov, Asante, & Ilizarov, 2020), new conceptualisations and interdisciplinary approaches in the management of adolescents with chronic pain (Johnson et al., 2022) and the introduction of a case coordinator, e.g. in the case of paediatric oncology care, where coordination, consistency and continuity of care mean better outcomes for the whole family (Martins, Aldiss, Taylor, & Gibson, 2022). Of course, all of this is facilitated by monitoring parental satisfaction through various tools (surveys, focus groups, etc.) that give feedback to staff on the work done and its performance (Bayat et al., 2022; Kruszecka-Krówka et al., 2019; Mayland et al., 2022).

What about negative factors? Several articles address the problem of knowledge deficits, in particular specific knowledge for working with children and adolescents with disabilities (Hart, Van Deusen, & Gonzaga, 2017; Khanlou et al., 2022; Lung et al., 2021; Ong et al., 2017; Soltau, Biedermann, Hennicke, & Fydrich, 2015). A lot has also been written about the difficulties of the transition from adolescence to adulthood, as there is a lack of communication between providers, and healthcare professionals lack knowledge in this area and therefore do not provide support that adolescents and their parents need, there is no continuity of care (Culnane et al., 2020; Gauthier-Boudreault, Couture, & Gallagher, 2018; Heron et al., 2019; MacNeill, Doucet, & Luke, 2022; Malapela, Thupayagale-Tshweneagae, & Ibitoye, 2020; Shanahan, Ollis, Balla, Pate, & Lang, 2020). Uncertainty about a child's failure to receive a genetic diagnosis and the resulting risk of suboptimal healthcare and support is also an issue (Hinton & Kirk, 2014; Madeo, O'Brien, Bernhardt, & Biesecker, 2012), and due to poor diagnosis and unmet health needs, adolescents with Autism Spectrum Disorder (ASD) and/or a mental disorder are more likely to use emergency services, leading to higher healthcare costs (Hand, Boan, Bradley, Charles, & Arnstein Carpenter, 2019). There is a lack of communication and support to parents of children by healthcare professionals and a lack of parental involvement in Intensive Care Unit management (Mol, Argent, Paed, & Morrow, 2018). There is a need to optimise healthcare, particularly in the area of parental involvement. A plan to improve the quality of nursing care in paediatric wards should focus in particular on patients in early childhood and their parents, who are the most critical in assessing satisfaction (Kruszecka-Krówka et al., 2021). Authors also cite delayed access to child and adolescent mental health services (Semovski, King, & Stewart, 2022), unmet health needs and poorer quality of care in children and adolescents with and without ASD (Menezes, Robinson, Harkins, Sadikova, & Mazurek, 2021) and attention deficit hyperactivity disorder (ADHD) (Park, Jang, Lee, Kim, & Park, 2020) as risk factors. Many children with disabilities are unable to participate in medical treatment and are therefore at risk of adverse events (Eichinger et al., 2022), there is also the problem of unmet health needs of these adolescents - inadequate health education (Fergus, Zambeli-Ljepović, Hampson, Copp, & Nagata, 2022), especially in the area of adolescent sexuality education (Engelen, Knoll, Rabsztyn, Maas-van Schaaijk, & van Gaal, 2019), and the lack of adaptation to the situation by healthcare personnel (Muskat et al., 2015). Authors also report that healthcare facilities do not monitor the satisfaction of parents whose child is undergoing medical treatment using standardised questionnaires (Chua & Cyna , 2020; Srivastva et al, 2021); and in follow-up cases, longer hospitalisations and deterioration in the child's health, parental gender, parental residence, parental hospital stay, birth weight and gestational age have been found to affect parental satisfaction (Alle, Akenaw, Seid, & Bayable, 2022; Nguyen, Nguyen, Phan, van Eeuwijk, & Fink, 2020). Children and adolescents and their families face many challenges in a complex healthcare system that could be addressed through coordinated collaboration of a multidisciplinary team (Siuba, Patel, Guilonard, & Pratt, 2020).

Parental satisfaction with the quality of healthcare for children and adolescents with disabilities is of paramount importance for the child or adolescent and his or her whole family, as well as for the healthcare professionals involved in the process of care.

## 6 Conclusion

We believe that the quality of healthcare for children, adolescents and their parents is equivalent to the feeling of satisfaction with the care. One of the most important objectives of modern healthcare management is to take a progressive approach to solving the health problems of children and adolescents, especially in the case of deprived persons, including children and adolescents with special needs. Satisfaction with healthcare, which includes nursing care, is a multidimensional concept that depends on the relationship between the expectations of the child or adolescent and his/her parents and family and the perception of the healthcare he/she receives. It is the parents of the child or adolescent who have the right to be present during the treatment, to participate in the process and to make decisions about the treatment. Other factors may also influence parental satisfaction, such as the child's or adolescent's state of health, the impact of the situation on the family's functioning, the child's or adolescent's emotional state, the maintenance of the continuity of the treatment process. Determining parental satisfaction is an important part of holistic or patient-centred care. The assumption is that a satisfied patient, in our case a child or young person with special needs and his/her parents, will follow the instructions of healthcare professionals more consistently, cooperate during the treatment and come back later if necessary. Satisfaction with the treatment reported by parents of children and adolescents has an impact on the whole healthcare team and works in a motivational sense.

The survey was conducted to identify factors that influence parental satisfaction with the quality of healthcare for children and adolescents with disabilities, based on a review of the views of different authors. We identified factors that positively respectively negatively influence parental satisfaction.

This article contributes to the understanding of the importance of monitoring the satisfaction of parents of children and adolescents with disabilities who are users of healthcare services. The results of our research show positive impacts on patients, i.e. children and adolescents, as well as on their parents and healthcare professionals involved in the healthcare process. The negative impacts shown are those that give an idea for reflection on how to move forward in order to improve the quality of the work. The findings may help the management of healthcare institutions to find solutions to improve the satisfaction of parents of children and adolescents with disabilities.

The research is limited to a review of existing literature in electronic databases. We believe that the results provide an idea and a basis for further research, when the results obtained in our study could be applied to an actual healthcare facility and a survey about satisfaction with the healthcare of this population could be conducted there.

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## Povzetek:
## Dimenzije kakovosti zdravstvene obravnave otrok/mladostnikov s posebnimi potrebami

**Raziskovalno vprašanje (RV):** Kateri dejavniki imajo pozitiven in kateri negativen vpliv na zadovoljstvo staršev s kakovostjo zdravstvene obravnave otrok in mladostnikov s posebnimi potrebami?

**Namen:** Namen raziskave je opredeliti dimenzije zadovoljstva s kakovostjo zdravstvene obravnave na podlagi ugotovitev različnih avtorjev in hkrati definirati dejavnike, ki vplivajo na to, v kolikšni meri so starši otrok in mladostnikov s posebnimi potrebami oz. oviranostmi zadovoljni s kakovostjo zdravstvene obravnave njihovih otrok in mladostnikov.

**Metoda:** Raziskava temelji na sistematičnem pregledu obstoječe literature. Iskanje strokovnih in znanstvenih člankov odprtega tipa je potekalo v iskalnih bazah Springerlink, Science Direct, ProQuest, PubMed in Scopus. Časovni okvir iskanja so bile objave v obdobju med leti 2012 in 2023 z izjemo za področje relevantne literature. Iskalni niz je ponudil 106 takšnih člankov. V nadaljnjo obravnavo smo vključili le članke, v katerih različni avtorji prikazujejo dejavnike, ki pozitivno oziroma negativno vplivajo na zadovoljstvo staršev z zdravstveno obravnavo njihovega otroka in mladostnika s posebnimi potrebami. Kriterijem je ustrezalo 57 člankov. Rezultati glavnih ugotovitev so prikazani v tabelah.

**Rezultati:** Zaznani dejavniki, ki pozitivno vplivajo na zadovoljstvo staršev, so komunikacija in sodelovanje med vpletenimi stranmi, dejavnosti za zmanjševanje stresa, znanje in veščine zdravstvenih delavcev, uporaba sodobnih tehnologij, merjenje zadovoljstva uporabnikov zdravstvenih storitev, pristopi k zdravstveni oskrbi in na pacienta osredotočena oskrba. Med zaznanimi negativnimi dejavniki so pomanjkljivosti v procesu zdravstvenega varstva, pomanjkanje komunikacije in sodelovanja med zdravstvenimi delavci in starši, pomanjkanje osredotočenosti na pacienta, nezadostna kakovost zdravstvenih storitev, odsotnost merjenja zadovoljstva uporabnikov in pomanjkanje znanja zdravstvenih delavcev.

**Organizacija:** Podane ugotovitve so lahko v pomoč vodstvu zdravstvenih ustanov pri iskanju rešitev za izboljšanje zadovoljstva staršev otrok in mladostnikov s posebnimi potrebami.

**Družba:** Članek predstavlja doprinos k razumevanju pomembnosti spremljanja zadovoljstva staršev otrok in mladostnikov s posebnimi potrebami, ki so uporabniki zdravstvenih storitev. Rezultati naše raziskave prikazujejo pozitivne vplive tako na otroke in mladostnike, na njihove starše kot tudi na zdravstvene delavce, ki sodelujejo v procesu obravnave. Prikazani negativni vplivi pa dajejo idejo za razmislek, kako naprej, da bo delo še bolj kakovostno opravljeno. Podane ugotovitve so lahko v pomoč vodstvu zdravstvenih ustanov pri iskanju rešitev za izboljšanje zadovoljstva staršev otrok in mladostnikov s posebnimi potrebami.

**Originalnost:** Gre za prvo tovrstno raziskavo v Sloveniji. Njena izvirnost je v tem, da obravnava zelo aktualno družbeno problematiko otrok in mladostnikov s posebnimi potrebami ter njihovih staršev, ki imajo v procesu zdravstvene obravnave tako pozitivne kot negativne izkušnje.

**Omejitve/nadaljnje raziskovanje:** Raziskava je omejena na pregled obstoječe literature v elektronskih podatkovnih bazah. Rezultati raziskave podajajo idejo in osnovo za nadaljnje raziskovanje, kjer bi lahko v naši raziskavi dobljene rezultate implementirali na zdravstveno ustanovo in tam izvedli raziskavo o zadovoljstvu z zdravstveno obravnavo te populacije.

**Ključne besede:** posebne potrebe, oviranost, otroci in mladostniki, zdravstvena obravnava, kakovost, zadovoljstvo, starši, na pacienta osredotočena zdravstvena obravnava