



# Early Intervention in Special Education and Rehabilitation



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## HEALTH CARE QUALITY FOR PERSONS WITH INTELLECTUAL DISABILITIES<sup>a</sup>

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### SUMMARY

*The aim of this research is to make comparison between the parents of children with disabilities and parents of typically developing children regarding the level of their satisfaction with the quality of health care provided for their children and to rank factors influencing the quality of health care for children with disabilities.*

*The sample consisted of parents of 91 children, ranging in age from 4 to 7 years ( $M=5.63$ ,  $SD=1.05$ ), 37 of which were children with disabilities ( $M_{age}=5.86$ ,  $SD=.93$ ), and 54 were children with typical development ( $M_{age}=5.48$ ,  $SD=1.11$ ).*

*In addition to demographic data collected through the specific questionnaire, the reports of parents on performance of health care for their children were also collected by recording their answers on the scale "Quality of health care for preschool children".*

*It was established that education level of parents influences significantly the level of their satisfaction with the quality of health care for their children. Significant difference between the parents of children with disabilities and parents of the children with typical development regarding their level of general satisfaction with the quality of the health care system for children was not recorded, but also regarding the perceived quality of the procedure for making appointments, waiting time to see the physician and relationship of physicians with the parents and their children.*

Key words: mobile support, children with disabilities, health care

### INTRODUCTION

Early intervention in children at risk of delayed development or in children already diagnosed with delay in development, serves the purpose of conducting general prevention of disabilities universal for all children at risk and their families, as well as individual prevention programmes designed to prevent certain developmental disorders (Fox et al., 2015). As a part of early intervention, a multidisciplinary team of professionals makes assessment of developmental level of cognitive, language, motor and adaptive skills of children, using predefined protocols and instruments (Bartolotta & Shulman, 2010). It is necessary to establish an efficient cooperation between special

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education teachers, psychologists, paediatricians and other professionals during early intervention, in order to enable sufficient accessibility, quality and stability during the process of identification, management, treatment, education and providing other services needed by children and their families. Physicians and other professionals involved in early intervention need to have access to the combined database of information relevant for child's health and preservation of family functioning. Professionals and parents alike need to have on their disposal general and specific information about child, family and unique parent-child interactions. Sensible use of support options and highly individualized support are enabled due to the availability of information about diagnosis and prognostic parameters of further child development dynamics and of the data related to specific difficulties and daily functioning of the child and the family (Guralnick, 2005).

Apart from individual professional competency and experience level, the quality of early intervention also depends on building a good rapport between professionals and family members. The empathy and care expressed by professionals who conduct diagnostic procedures and/or treatment, together with high level of expertise, constitute the basis for high quality, competent service focused on children and their families (Council on Children with Disabilities, 2007).

Despite all these facts, persons with intellectual disability (ID) constitute a vulnerable group in terms of health care deliveries. They have shorter life span and higher risk of associated diseases and disorders (Mencap, 2004), and, additionally, they are often confronted with different limitations and barriers when trying to exercise their right to health care (Green et al., 2004, Krahn, Hammond & Turner, 2006).

The right to primary health care is one of the fundamental human rights, both for persons with typical development and persons with ID (Lennox, & Kerr, 1997). According to the *Law against discrimination on the basis of disability*, refusal to provide medical service and/or setting specific requirements to do so, for a person with disability, when there is a lack of medical justification, is regarded as particularly severe case of discrimination (Article 17.) (Official Gazette of RS, no. 33/2006).

### **Behavioural difficulties of children with disabilities and the quality of health care**

Quite a number of difficulties in providing high quality health care for people with ID are caused by poor training of physicians, and also by the fact that people with disabilities are prone to stress induced problems in behaviour.

Physicians who are not properly trained for work with members of this population might sometimes cancel certain medical procedures, the reason for this being unusual behaviour of people with ID who generally show more pronounced difficulties in respecting social norms.

Untrained physicians' concern for their own safety and safety of others is often caused by peculiar walk, hand movements and gestures, cries and other patterns of behaviour of people with ID, which are not necessarily connected to aggressive behaviour (Ward, Nichols & Freedman, 2010; Wilkinson et al., 2013).

The long periods spent in the waiting room, waiting to see a doctor, can lead to elevated anxiety and outbursts in people with ID. High intensity expression of behavioural problems in people with ID can cause them to leave the medical facility and miss the scheduled appointment (Ward, Nichols & Freedman, 2010).

Waiting time can influence the perception of the quality of the obtained medical service in people with disabilities. The analysis based on information collected from 27 individuals with ID led to the conclusion that, according to participants' opinion, doctors do not devote enough time to them, while doctors themselves were of another opinion. They claim that providing service for persons with ID is much more time consuming than for persons who belong to the general population. The explanation for this analysis result is connected to a comparison between the lengths of time spent in consultation room and waiting, such that persons with ID get an impression of not being devoted sufficient amount of time (Wilkinson et al., 2013). In order to overcome these problems, it is recommended to assist people with ID when they make medical appointments and to apply positive discrimination when it comes to access to medical institutions.

### **Communication difficulties and healthcare quality**

General practitioners, who do not possess the experience of working with patients with ID, often tend to underestimate their communication capabilities so they address exclusively patients' parents or other accompanying persons during consultation. This can be humiliating for the patients with ID (Ward, Nichols & Freedman, 2010; Wilkinson et al., 2013). According to a study conducted in Australia, the most of the general practitioners included in the study, identified communication hurdles as one of the major difficulties in helping people with ID (Lennox, Diggins & Ugoni, 1997). Based on their previous experience during hospitalization, people with ID expressed a range of negative comments regarding the quality of the provided medical service. They said that medical professionals did not communicate with them and considered irrelevant the information they provided. Participants of the study stated that their difficulties underpinning their higher time consumption for daily activities (taking a bath, going to the toilette) were neglected. Based on the majority of recorded objections, the proposition could be made that nurses were not properly trained and experienced, which reflected in inadequate care provided for people with ID (Smeltzer, Avery & Haynor, 2012). Nurses who consider they don't have enough time to interpret statements of the patients with ID, tend to avoid communication with them. It was found that nurses who invest more time in communication with people with ID, and who tend to employ different strategies in order to establish communication, also have better knowledge of personal characteristics of people with ID, succeed in enhancing mutual understanding and provide health care services of the higher quality (Hemsley, Balandin & Worrall, 2012). Collecting the information from 29 persons providing support to people with ID, it was determined that people with ID who mastered the verbal communalisation could give rather reliable information on whether they feel the pain or not and indicate the part of the body which hurts, using words and patterns of behaviour familiar to the general population. Therefore, it is considered that medical professionals who conduct

medical checkups should take their statements into account. However, expressions of emotional anxiety are more idiosyncratic by its nature, and therefore their interpreting requires longer knowing of a particular person with ID (McKenzie, Smith & Purcell, 2013).

Especially challenging aspect of communication with people with ID is the need to give them the negative information about their health. A study which included people with ID, their parents and physicians, established the ambivalence in people with ID as to whether they want to be informed when their health is seriously compromised, or not. Parents' opinion is that they should be the first to obtain this type of information from doctors, in order to decide independently, later, whether they will pass this information on to their child with disability or not. On the contrary, the doctors' view is that, being their patient, a person with ID should be given this information directly. Both doctors and parents agreed that depending on the particular situation, informing people with ID about their health condition can be beneficial or disadvantageous. Whether persons with ID should actually be informed about worsening of their health, or not, depends on their ability to understand the way in which their health is compromised, on how knowledgeable they are and on their capacity to cope with negative information emotionally (Tuffrey-Wijne, 2013).

### **Support for people with disabilities in claiming their right to health care**

The investigation of Parish and others (2008) showed that people with ID who have adequate informal or formal support when accessing medical services, obtain satisfactory level of health care. These authors emphasize that education of medical professionals or volunteers who would assist or advocate people with ID in different health care related situations could compensate for the lack of formal support in these situations. The situations to which this could apply include: making appointments and conducting regular prevention checkups, appropriate for the age of the person; making appointments related to chronic and acute conditions; communication with physicians; following of the physician's instructions during consultations; dealing with fear and other negative emotions related to medical procedures and giving information to the members of the family of a person with ID who could act as support in following guidelines provided by physicians (Parish, Moss & Richman, 2008).

### **Education of medical professionals**

Investigation of physicians' opinion related to their experience in work with people with ID yielded the awareness of need for additional education of medical professionals, since physicians stated they felt inadequately informed and unconfident, sometimes even scared, when they needed to see a patient with ID. According to their opinion, this education would be efficient only if it would be based primarily on the practical work in order to gather the experience, not if it would be mainly theoretical (Wilkinson et al., 2012). Educating medical staff, including general practitioners, specialist doctors, qualified nurses and unqualified nursing staff, within the frames of their primary

and continual education, would certainly improve the quality of the provided medical services (While & Clark, 2010). The content of this type of educational programme should include the following: information about general characteristics of the functioning of people with ID, establishing a separate system of record about provided services and treatment outcomes for people with ID, providing people with ID the information about their health status in the form adapted and easily comprehensible for them, and providing people with ID information about available prevention checkups and measures through collaboration with associations for support of people with ID (Michael, 2008). In addition to work invested in increase of knowledge related to improvement of the quality of services provided for people with ID, it is also indispensable to work on changes in attitude of medical professionals towards people with ID as patients. A study by Lewis and others (2010) established that nursing staff attitude towards providing service for people with ID is more negative than for physically disabled people. Nurses opinion is that people with ID should be accommodated separately from other patients, since they are easily upset and then become aggressive, communication with them is more difficult and maintaining their personal hygiene is more demanding (Lewis & Stenfert-Kroese, 2010).

### **Description of the sample**

This study included parents of 91 child, aged 4 to 7 ( $M=5.63$ ,  $SD=1.05$ ), 37 of which were children with disabilities and 54 were children showing typical development. Children with disabilities made up a sample of the following structure: children with intellectual disabilities ( $n=4$ ), children with autism ( $n=11$ ), children with ADHD ( $n=5$ ), children with motor disturbances ( $n=2$ ), sensory disturbances ( $n=6$ ) and multiple disabilities ( $n=9$ ). The group including children with disabilities consisted of 54.1% ( $n=20$ ) boys and 45.9% ( $n=17$ ) girls, while typically developing group consisted of 48.1% ( $n=26$ ) boys and 51.9% ( $n=28$ ) girls. The distribution of male and female participants in these two samples was not significantly different,  $\chi^2(1, n=91)=.116$   $p=.734$  (Yates correction).

Also, no significant differences were established between the subsamples of children with disabilities ( $M=5.86$ ,  $SD=.93$ ) and typically developing children ( $M=5.48$ ,  $SD=1.11$ ), regarding the calendar age of participants  $t(83,41)=-1.75$ ,  $p=.083$ .

### **Instrument description**

The questionnaire for collecting demographic data included following information about children: sex, age, type of disability, frequency of visits to physicians within the last year, and about parents: education level (of the mother/father), employment status (of the mother/father), whether they take the child more often to the physicians who work in the private practice or in a public health institution and question related to the family income.

In order to determine the level of satisfaction of parents who have children with disabilities with the quality of the health care services, specific scale "Quality of health care for preschool children" was created. This scale contains 20 statements related to



procedures of appointment making, availability of health care services and satisfaction level with the cooperation with physicians.

Parents of the children with disabilities were given six statements related to particular aspects of the treatment of their child. They were asked to assign each of the statements one number, ranging from 1 to 6. 1 would be assigned to the statement about most important factor influencing the quality of health care provided to their child, according to their opinion, and 6 to the statement about the least influential factor.

### Preliminary analyses

One of the mothers of children with disability did not provide information about her education level. Therefore, the comparison of education levels was made using the available information for 54 mothers of children with typical development and 36 mothers of children with disabilities. Significantly lower level of education was established for mothers of children with disabilities ( $M=2.50$ ,  $SD=.73$ ) compared to that of mothers of typically developing children ( $M=3.02$ ,  $SD=.60$ )  $t(64.34)=3.52$ ,  $p=.001$ .

Also, one father whose child had a disability did not provide the answer to the question about highest completed education level, so this comparison was also made using the available information on education level of 54 fathers of children with typical development and 36 fathers of children with disabilities. Significant difference in the level of education was confirmed for the sample of fathers as well. Fathers of children with disabilities had a lower education level ( $M=2.42$ ,  $SD=.73$ ) than fathers of typically developing children ( $M=2.96$ ,  $SD=.73$ ),  $t(88)=3.49$ ,  $p=.001$ .

Common score representing the level of education of the family was calculated, in order to control for the influence of the parents' education level on the level of their satisfaction with the health care of their children.

No significant difference was established between the two groups of participants regarding the choice of the private practice vs. public health service. The majority (76,9%) of the parents whose children show typical development, as well as most (75.9%) of the parents whose children are with disabilities, choose more often to obtain service of the physicians who work in public health institutions  $\chi^2(1) = .000$ ,  $p=1.00$  (Yates correction).

Satisfaction with the quality of the medical services that children were offered in private practices compared to those obtained in public health institutions didn't show any difference neither over subsamples nor over the whole sample (Table 1).

Table 1 *Satisfaction with the quality of the medical service in the private practice vs. public health institution*

		Md	SD	U	Z	p
Parents of children with disabilities	private	60.00	16.01	75.500	-.077	.939
	public	55.50	12.46			
Parents of children with typical development	private	60.50	16.90	209	-.674	.500
	public	64.00	14.59			
The whole sample	private	60.00	16.63	534	-.614	.540
	public	63.00	14.04			

## RESULTS

The comparison between level of satisfaction of the parents of the children with disabilities ( $M=55.42$ ,  $SD=11.61$ ) and parents of the children of the general population ( $M=63.37$ ,  $SD=15.07$ ) with the quality of health care provided to their children, showed significantly lower level of satisfaction for parents of children with disabilities  $F(1,89)=7,181$ ,  $p=.009$ ,  $\eta^2=.08$ .

Comparison of the total scores for the questionnaire used to determine the level of the quality of healthcare provided for children with disabilities, didn't show significant difference between parents of these children ( $M=55.42$ ,  $SD=11.61$ ) and parents of children with typical development ( $M=63.37$ ,  $SD=15.07$ )  $F(1,87)=2.847$ ,  $p=.095$ , partial  $\eta^2=.032$ .

The factor analysis showed that the items are grouped around three factors: Making appointment and waiting time to see the physician, Cooperation with the physician and Information important for finding the way around in the health care institution.

Using the Levene's test, it was shown that assumption about equality of variances of the two populations was not correct,  $F(1, 88)=7.274$ ,  $p=0.08$ . Therefore, in order to establish statistically significant differences, the lower p-value was used ( $p < 0.001$ ). When the control for the influence of education level of parents of children with disabilities ( $M=15.75$ ,  $SD=4.15$ ), and parents of typically developing children ( $M=17.57$ ,  $SD=6.12$ ) was applied, significant differences were not found for the group of items used to investigate level of satisfaction with system for making appointments and length of waiting time to see a physician  $F(1,87)=.413$ ,  $p=.522$ , partial  $\eta^2=.005$ .

Since Levene's test value was significant  $F(1, 88)=8.358$ ,  $p=0.05$ , lower level of significance was applied to interpret the results of two-factor analysis of variance, so  $p < 0.001$  is considered to be a significant p-value.

Significant differences were not found for the part of the questionnaire related to the satisfaction with cooperation with physician. Level of satisfaction regarding the cooperation with physician for parents of children with disabilities ( $M=30.00$ ,  $SD=7.05$ ), was not significantly different from the level of satisfaction of parents with typically developing children ( $M=34.98$ ,  $SD=9.64$ )  $F(1,87)=3.301$ ,  $p=.073$ , partial  $\eta^2=.037$ .

Lower p-value ( $p < 0.001$ ) was used to detect statistically significant differences, since Levene's test showed unequal variance for the results in both groups  $F(1, 88)=7.274$ ,  $p=0.08$ . Significant difference was not established for items related to getting information and finding the way around the health institution facilities. For these three items, the level of satisfaction expressed by the parents of children with disabilities ( $M=9.67$ ,  $SD=2.80$ ) was equal to that of the parents of children with typical development ( $M=10.81$ ,  $SD=1.82$ )  $F(1,87)=2.839$ ,  $p=.096$ , partial  $\eta^2=.03$ .

### **Priorities influencing the quality of health care for children with disabilities**

Thirty out of 37 parents named their priorities which influence the quality of health care services offered to their children. The results are shown in detail in the Table 2.

Table 2 *Priorities influencing the quality of health care for children with disabilities*

	Priority 1 <sup>1</sup>	Priority 2 <sup>2</sup>	Priority 3 <sup>3</sup>	Σ <sup>4</sup>
	n (%)	n (%)	n (%)	
1 In addition to the information provided by the accompanying person, the children with disabilities should also communicate their feelings (show the part of body where they feel the pain and similar).	4 (13.3)	1 (3.4)	3 (10.0)	8
2 Additional time should be provided for face-to-face consultation for children with disabilities.	8 (26.7)	7 (23.3)	5 (16.6)	20
3 Physicians should not attribute new symptoms (health deterioration) of the child exclusively and in advance to a disability state and ignore them consequently, should be prepared instead to try to treat or at least relieve them.	8 (26.7)	4 (13.3)	10 (33.3)	22
4 Good communication between physicians and parents	7 (23.3)	10 (33.3)	5 (16.7)	23
5 Assure that children with disabilities follow the instructions of medical professionals during the consultation.	1 (3.3)	2 (6.7)	5 (16.7)	8
6 Assure that children with disabilities respect recommendations of physicians regarding the treatment.	2 (6.7)	6 (20.0)	2 (6.7)	10

<sup>1</sup>Priority 1 – number of parents who designated the content of particular statement as the most important for quality of the health care for their child; <sup>2</sup>Priority 2 – number of parents who designated the content of particular statement as the second most important for quality of the health care for their child; <sup>3</sup>Priority 3 – number of parents who designated the content of particular statement as the second most important for quality of the health care for their child; <sup>4</sup>Total number of parents of children with disabilities who included the content of particular statement in the first three priorities.

## DISCUSSION

General limitations and flaws of the healthcare system are often interpreted as discrimination by the parents of children with disabilities (Thompson, Linehan, Glynn & Kerr, 2013).

In spite of this observation, while controlling for the influence of socioeconomic status in our sample, we could not confirm the difference of the level of general satisfaction with the quality of health care services of parents who have children with disabilities and those whose children belong to general population. To achieve interpretation of results as unbiased as possible, it is necessary to take into account several important differences between two groups of parents detected by primary analyses. The education level and income of parents of children with disabilities was significantly lower than of the parents of typically developing children. Without controlling for the differences in socioeconomic status, the level of satisfaction of parents of children with disabilities was significantly lower compared to the parents of typically developing children.

The studies of other authors also established significant connection between the levels of social deprivation and satisfaction with the quality of health care (Croker et al.,

2015). It can be assumed that there is a connection between the influence of the level of education and income of the parents of the children with disabilities and the level of understanding of certain medical procedures. The feeling of fear is present if parents haven't got enough knowledge, experience and can't find the information needed to be able to influence the decisions important for their child's health.

The studies conducted in the USA established that parents of children with special health care needs, who belong to the socially excluded groups, have lower income and show less satisfaction with the medical services their children receive. They are of the view that physicians don't talk to them enough, do not take into consideration their objections and remarks, do not answer their questions and do not devote enough time to their children (Ngui & Flores, 2006).

The result obtained when controlling for the variable of socioeconomic status of parents, shows that parents of the children with developmental disorders are equally satisfied as parents of the children with typical development. It is believed that parents of the typically developing children with the lower socioeconomic status also have less confidence in doctors and health care system (Willems, De Maesschalck, Deveugele, Derese & De Maeseneer, 2005). Parents with higher education levels communicate with physicians more intensely, ask more questions and express their observations and suggestions more often, and, as a result, obtain more information from them (Street, 1992).

### **The procedure of making an appointment and waiting time to see the physician**

When the control for the influence of education level was performed, significant differences between the level of satisfaction with accessibility to the health care services of the parents who have children with disabilities and parents of typically developing children were not determined.

Early intervention includes identification of children at risk of being diagnosed or children already diagnosed with some type of developmental disorder, follow-up and treatment designed to mitigate already developed impairment and prevent potential secondary damage which could compromise further child development. Early intervention may comprise medical support, special education support, psychological, social and other forms of support (Marković & Arsić, 2011). In the early intervention phase, support to the parents is most often provided by the paediatricians, paediatric nurses and home care nurses. To assure the efficacy of early intervention, in addition to professional competences of medical care givers it is necessary to provide easy access to the health care services. This condition is fulfilled if a highly efficient system for making appointments exists and if waiting time to see a physician is relatively short. This process must be adjusted to the child and parents' needs. Financial status of the family of child with disability, education level and working hours of parents, distance between the family residence and health care facility and individual characteristics of the child, as well as all other factors strongly influencing access to the health care services, must be taken into account when a support plan is being made. Factors such as coordination of the medical professionals' work, child support, but also the broader

context, meaning that the support should be provided for the family as a whole, have positive influence on the child's possibilities to grow and develop in an environment best suited to its needs (Adams et al., 2013).

### **The relationship parents establish with the physicians**

In this paper, accessibility of the health care services was analyzed, but also the quality of the relationship the parents and their children with disabilities establish with the physicians. In this area, while also controlling for the influence of socioeconomic status, statistically significant differences between the parents of children with disabilities and children with typical development were not recorded.

The relationship between the physician and the parent of a child with a medical condition is rather complicated and depends on both personal characteristics of the two parties, but on the quality of the interaction between the physician and the patient as well. One study conducted in the USA showed a difference among the physicians included in the sample regarding the amount of information they were providing and the need to establish a relationship of equality with the parents. At the same time, all physicians were providing approximately the same amount of socio-emotional support. The relationship between physicians and parents may also be significantly influenced by cultural differences, manifested as different ways of expressing emotions and care for the child. It was demonstrated that parents who express their concerns more intensely obtain higher emotional support from the physicians (Street, 1992).

Understanding, compassion, acknowledging cultural differences as well as coordination of different medical service units, represent a basis for early intervention of the high quality (Sia, Tonniges, Osterhus & Taba, 2004).

The results of another study conducted in the USA demonstrated satisfaction of parents with the cooperation with paediatricians, quality and range of provided services and the level of involvement in decision-making during creation of the treatment plan. The tendency to assess the experience of an early intervention as negative was recorded for the parents of lower socioeconomic status (Bailey, Hebbeler, Scarborough, Spiker & Mallik, 2004).

### **Informing parents about their health care rights**

When controlling for the influence of socioeconomic status, no significant differences were found between parents of children with disabilities and children with typical development for the following three items: "Web site of the health care institution contains all the important information such as address, working hours of different departments and telephone numbers.", "Consultation rooms are clearly labelled by the number or the name of the doctor" and "There is information clearly posted in the waiting room that enables making contact with the patients' rights advocate".

The role of the patients' rights advocate or patients' advisors is to provide the legal advice for the patients. The objections of patients who believe they have been discriminated on a certain basis or their rights were not properly respected are submitted to patients' rights advocate (The Law on Patients' Rights, Official Gazette

of RS, no. 45/13). It is possible that the majority of parents of children with disabilities who participated in the study was satisfied with the health care services, and did not pay attention to the information provided about patients' rights advocate. The other interpretation of the obtained results could be related to the level of parents' knowledge about their rights or rights of their children within the health care system. The right to access, right to information, right to free choice and privacy of data, as well as right to objection and reparation of damage (The Law on Patients' Rights, Official Gazette of RS, no. 45/13) are some of the patients' rights that need to be respected in order to enable patients to take an active part in their own treatment or treatment of their children. If person is not aware of their own rights, they also cannot be aware of violation of these rights. Based on our results we can make a proposition that broad campaign is needed, which would provide the information for marginalized groups about their rights and the ways to claim them.

### **Communication between physicians and parents of the children with disabilities**

Statement number 4: "Good communication between physician and a parent is of highest importance for the quality of treatment your child receives", was designated by the largest number of parents, 23 of them (76.67%), as one of their three highest priorities that influence the quality of health care for their children.

Submissive patients, who do not feel equal in communication with physicians follow less closely the recommendations of physicians, compared to the patients who are active in asking for information, who give their own suggestions and whose relationship with physician has a quality of partnership (Davis, 1968). The patient seeking to be involved in treatment process is more informed, shows a higher level of knowledge and readiness to cooperate, follows regularly the indicators important for the health status and respects the physician's recommendation. This type of active, high quality communication with physician could be significant contributor to the positive outcome of the treatment.

There are three possible goals of the communication between patient and physician: creating good interpersonal rapport, exchanging information and making informed decision about application of medical procedures (Ong, De Haes, Hoos & Lammes, 1995). As a primary obstacle emerging in communication with physicians, the parents indicate insufficiently clear explanations related to the diagnosed condition and lack of empathy on the part of physicians. The use of medical terminology and jargon is stressed by parents as another obstacle for the information exchange with physicians (Korsch, Gozzi & Francis, 1968).

Both physicians and patients identified expressing empathy as an important predictor of satisfaction of the patient. Eye contact and physicians interest in patient as forms of affectionate communication, influence strongly patient's perception of the quality of received medical services (Bensing, 1991).

Socioeconomic status of the family also influences the way patients and physicians communicate with each other. Parents who belong to socially excluded groups are more prone to accepting physicians' instructions and less to participating in

communication as equal partners, asking questions, asking for additional explanations and information, and expressing their own hopes and fears (Willems, De Maesschalck, Deveugele, Derese & De Maeseneer, 2005). Patients with lower income are the least satisfied with physician-patient communication. Within this group, the highest level of dissatisfaction is present in participants who are functionally literate and engaged in claiming their own rights (Jensen, King, Guntzviller, & Davis, 2010). Within the last decade, the relationship between patient and physician gained features of a business relationship, devoid of expressions of emotions. Patients became more passive, asking fewer questions and expressing less concern, while general practitioners tend to give information related to patient treatment without expressing empathy and initiating a high quality relationship with patients (Bensing et al., 2006).

### **The time needed for face-to-face consultation for children with disabilities**

26.7% of participants in this research isolated statement number 2 (Additional time should be provided for face-to-face consultation for children with disabilities) as the most important factor influencing the quality of the treatment of their child.

A study realised in England, stresses the following factors as the most influential for the quality of health care: active participation of patients in decision-making process related to treatment and the time physicians devote to the patients (Croker et al., 2013). Almost half of participants with low income were not satisfied with the time devoted to them by a physician (Jensen et al., 2010).

The lack of time that physicians face when providing service to the patients of the typical population, constitutes one of the significant factors preventing them from conducting all the recommended screening procedures important for prevention of disease development. (Yarnall, Pollak, Østbye Krause, & Michener, 2003). General practitioners identified lack of time as one of the obstacles for providing high quality service to the people with ID (Lennox et al., 1997). The time necessary for updating medical records and lack of time that could be devoted to the patient, represent a burden for physicians and reduce the quality of their work (Webb & Rogers, 1999).

### **Possibilities for improvement of the health status of children with disabilities**

For 26.7% of participants, the most important factor for the quality of medical treatment of their children, is the prerequisite that physicians do not attribute the symptoms the children complain about, in advance and exclusively to their disability, and consequently ignore them, but to be prepared to treat or at least try to ease these symptoms.

The thrust of patients in physicians depends predominantly on the patient's impression that physicians give careful attention to their symptoms (Croker et al., 2015). Parents believe that expectations of physicians regarding the possibility of improvement of the health of children with disabilities are low, that physicians do not invest themselves too much and do not explore all the possibilities for improvement of

health condition of children with disabilities. On the other hand, physicians complain about low-information status and difficulties in communication with parents of children with disabilities (Thompson, Linehan, Glynn & Kerr, 2013).

### **Self-advocacy skills and health care for children with disabilities**

One of the statements offered in the part of questionnaire in which participants of the study were supposed to mark what they consider to be the priority in providing high quality health service for their children with disabilities was the statement that not only the information given by the parent or other accompanying person to the physician is important, but also the direct communication of children with disabilities and physicians. This communication would enable children to express how they feel, show the part of the body where they feel the pain etc., on their own. It seems interesting that small number of parents perceive the direct communication between physician and child as important for the quality of the treatment process. Only 4 (13,3%) of the parents of children with disabilities marked the content of this statement as the most important for the quality of the health care for their children, while 8 of them (26.7%) placed it among the first three most important factors that have influence on their level of satisfaction with their child's treatment.

Regardless of communication difficulties, it is important to encourage children to express in word or gestures, with support of their parents, the way they feel. This is a way to teach the children, starting at preschool age, not to be passive observers, but to interact with their surroundings. It is of the utmost importance for children or adults with ID to be able to convey their feeling of pain. For children who are able to convey this information only with considerable difficulties, it is necessary to develop ability to use alternative forms of communication. This would provide them with means to inform parents and physicians early enough that they feel the pain (Beacroft & Dodd, 2011). It happens that people with ID experience chronic pain for longer periods of time without their suffering being recognized by their parents. Long-term pain considerably reduces the life quality in these persons and influences their behaviour. Regular medical checkups and adequate communication with physicians enable timely detection of pain in children or adults with ID which is a prerequisite to eliminate or relieve this pain (Lewis, Bell & Gillanders, 2007).

It was established that advances in the domain of health care quality and respect of patients' rights could be made by implementing programmes designed to develop skills of self-advocacy in health care for adults with moderate and mild intellectual disabilities (Feldman et al., 2012). According to the Social model of disability and Normalization principle, children with disabilities are included in the decision-making process related to medical interventions, together with their parents and physicians. Their decisions are taken into consideration if they do not compromise their health. These decisions are not compulsory if certain intervention is unavoidable or if the person with ID asks for the revision herself, but it gives children with disabilities the sense of being in control and being involved in the treatment process. Children and young people with disabilities want to have basic information needed for informed decision. In addition to the information provided by physicians, experience of other patients who underwent the same or similar medical intervention is also considered as important (Mitchell, 2014).



## CONCLUSION

It was established that education level of parents shows significant correlation with level of satisfaction with health care services provided to their children. Based on results we obtained we propose that the more parents are informed, the lower their level of uncertainty is. It was also observed that if they are better informed, their expectations are more realistic and, consequently, their level of satisfaction with the quality of the health service deliveries is higher. Parents of the children with disabilities prevalently possess lower education, have lower income and often belong to socially excluded groups. This gives importance to the improvement of the system of social and medical support, which would allow them to obtain information related to health and treatment of their child in a proper way. By doing so, the feeling of confidence and higher level of trust in physicians could be experienced by the parents of lower socioeconomic status.

If the influence of the education level is controlled for, the significant difference is not recorded between the parents of children with disabilities and children with typical development regarding neither general satisfaction level with children health care system, nor perceived quality of the procedure for making an appointment, waiting time or attitude towards parent and the child.

According to parents' opinion, the factors such as: additional consultation time, good communication with physicians and commitment of physicians to alleviation of symptoms accompanying the disability of their child, would represent a significant additional improvement of the quality of health care provided for their children.

## Limitations

The results we obtained could be interpreted solely as a reflection of the quality of health care provided for children with disabilities because the sample consisted of children with different types and levels of disability. The participants with particular type of disability in the sample were not frequent enough to enable analysis of specific aspects of health care for children with intellectual disability, pervasive, motor, and sensory disorders or multiple disorders.

There is also a possibility that the study included a certain number of parents with the lowest education level who are only functionally literate, so they had difficulties to read and answer the questionnaires used in this investigation.

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