

CHARACTERISTICS OF THE FAMILY ENVIRONMENT OF THE CHILDREN WITH DISABILITY

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***Abstract:** The paper presents the impacts on family functioning from the view of parents of a child born with a disability. Caring for a disabled child is a stressful situation for parents, with which they deal differently. The focus of the paper is on family preparedness and awareness, and the ability of parents to accept a child with a disability.*

***Keywords:** family, the family with a child with a disability, disability, awareness, quality of family life*

1 Introduction

The family and the comprehensive preparation for family life, represent a lifelong personalization and socialization of personal development. Within this activity, it is essential to coordinate the educational impact of the family, school and out-of-school organizations. The issues of marital, family and sexual life are part of pedagogical theory and practice.

We can compare the family to the mirror in which we can clearly see the impact of social changes and their impact on the life of an individual and the society. These changes, of course, are not reflected only in the structure of the family, but also in the relations between the individual members, the preferred and the given values, in the form of education or in the actual functioning of the family. In the past, the issues of families with the child with a disability were not the center of attention of specialists, as they focused more on the children with disability and their treatment and rehabilitation.

1.1 The family and its place in the social system and in science

The words “family” and “family education” are very concise and emotive used by each one of us and in our opinion, in these times it is important to pay attention to them. The family is the first social environment in which so-called “primary socialization” takes place, as well as the first education institution. According to Pupala (2004), education is a process of cultural transmission that ensures the transmission of values, norms, and customs of a given culture or communities, i.e. its continuity and specific features. We can conclude that the

influence of parenthood on the individual is a constant and lifelong effect on personality and its formation in all areas of development, through mutual interactions.

The role of the family in education to responsible parenthood is paramount, but practice and research show that now every family is sufficiently prepared for this function. We agree with several authors (Rozinajová, Tamášová, Hamarová, Kurincová, Helus, Potočárová, Prevendárová, Možný, Střelec and others) that the family has undoubtedly the greatest responsibility for the upbringing of the child. It follows not only from the society tradition but also from the legal forms set out in the Family Code, which perceives the family as the basic cell of the society that arises from the marriage foundation, and points to the fact that from a legal point of view, no alternative forms of partnership are allowed. The code further characterizes the family as an institution that builds a common history based on diverse and shared experiences and contributes to the sense of reciprocity between family members by their uniqueness and meaningfulness (The Family Code No 36/2005 Journal of laws).

In domestic and foreign scientific literature, there are many definitions of “the family”, from philosophical, pedagogical, sociological, but also a psychological point of view. From all of them, we choose those that the best match the given problem.

For a long time, the family has been considered stable and essentially unchanging morphotactic institution that, unlike the opaque and evolving public world, protects its members, does not alter its shape, internal organization or habitus, and changes in its surroundings balance quickly (Možný, 2006). Social expectations of family practices are changing, norms and ideas about what is and is not included in the female roles are changing and the views on the upbringing of children and its model are changing as well. In the 20th century, the institution of the family was challenged by its traditional form and undergone changes that redefined its basic characteristics.

Průcha (In Průcha, Walterová, Mareš, 2009), adds in the pedagogical encyclopedia that the family is the oldest social institution that performs socializing, economic, sexual-regulatory, reproductive and other functions. It creates a certain emotional atmosphere, shapes interpersonal relationships, values, and attitudes, the foundations of ethics and lifestyle.

We also find a similar definition of the family by Beňa et al (2006), that perceives the family as a basic social group linked by a bloodbath. The family thus provides its members with protection, community, security and correspondingly with specific patterns and traditions with socialization (Beňo, Šimčáková, Herich, 2006).

The sociological view of family and relationships between relatives is characterized as follows: *“a family is a form of long-term solidarity coexistence of persons who are connected by parentage, at least parents and children. Other family features are sociocultural. These include common housing, belonging to a common family line, joint production and consumption of the goods, etc.”* (Jandourek, 2002).

Family relationships are based on love and mutual care and are a basic criterion for the household's formation, and the task performance related to biological and social reproduction in everyday life. The family is never an isolated institution, rather it is a part of wider social processes, cultural patterns, and political systems.

Similarly, the psychologist Plaňava (1998), describes the family as a structured unit (system), whose purpose, ambition and content are to a relatively safe, stable place and environment for sharing, reproduction and production of people's lives. The author understands the family as a system that is much more plastic and flexible. It points to the dynamics of the family as a system that evolves, changes whose purpose, ambition and content is to form (not to create at once) a safe and stable space, it is, therefore, a process that is dynamic that develops over time and requires some effort for the system to work and fulfill its mission.

We can conclude that the wide variability of definitions of the defined term merely proves that it is almost impossible to do a uniform and universally acceptable definition of the term “family”. However, one fact is common to all; the family's mission is the most important institution for society and individuals. Opinions about family changed and shaped for many years but have remained unchanged in something. The recognition that the family is a very conservative social body remains stable. This is evidenced by the fact that, unlike the widespread perceptions of the disintegration and a crisis of the traditional family, they show that certain traditional norms, values, and principles of coexistence are preserved in present-day families and are guided by education (Potočárová, 2003).

1.2 Lifecycle of a family with a disabled child

When defining the concept of “family”, we used the theoretical concept of the most comprehensive definition, which defines the family as a “natural (primary) social group composed of individuals of different gender and age, who are interdependent and are interconnected by relationships for satisfying basic biological, psychological and social needs” (Prevendárová, 1998). In the above-mentioned concept, we can conclude that the family is a dynamically

formed body whose significant feature is the process of constant change, which we can call the cycle of the family with different development stages. The lifecycle of a family with a disabled child has its life cycles, which are very specific in each stage. The scientific sources often mention six stages (Plaňava, Matoušek, Rozinajová, Seidler, Kurincová, Prevendárová, and others). In our view, it is not necessary to consider all the stages, but we want to highlight the particularity of one stage when the new child comes to the family. Expectations of the birth of a child are always a big family event. This event is preceded by preparation and adaptation to the child's presence. The responsibility of a child is a very intense feeling. The difficult situation is when a baby is born with serious health problems; the third stage of the family's cycle can be very influential. At present, medicine offers us a wide range of diagnostic prenatal techniques that allow detecting abnormalities from the child's development standards before the birth of a child. Based on various examinations (withdrawal of amniotic fluid, blood exams, sonography, morphological ultrasound, and others), doctors can often detect developmental abnormalities. The verdict of the diagnosis can be defined over a different period of time, the length of which also affects the parents' reaction and how this information is processed (Vágnerová, 2014). According to Vágnerová (2014), as mentioned above, the parent's reactions to the situation of the birth of a child with a disability, according to Seidler and Kurincová (2005), parents go through the following phases:

- The phase of shock and denial- The parents have lost their expectations of their child, they do not want to accept the situation. It is a time when the family learns the unpleasant fact that their child is disabled. Shock is a defensive mechanism which is manifested by an inappropriate response to the situation, feeling of confusion and chaos;
- The acceptable phase and coping with the problem- The family gradually try to cope with reality. Part of this phase is to blame each other and looking for a guilty person that is responsible for their difficult situation. Support from the family, friends, professionals, and doctors is necessary.
- The phase of reconciliation – The family becomes aware of reality and its acceptance, they begin to perceive the situation more realistically and they start to focus on their child, his prognosis and the possibilities for its further development. The family also needs to re-evaluate their values.

After going through these phases, it is important to be informed about the type, degree, and nature of the child's health disadvantage (Slowík, J., 2007). Parents also have other tasks, such as providing a child with a quality life, such as ensuring the child financially. The family of the child with a disability requires

complex psychological, medical, social and pedagogical care. The family must understand the situation they find themselves in as soon as possible and they must be familiar with the actual state of the child, its prognosis and the possibilities of its future development. After understanding all the information, it is necessary to evaluate them, and the role of the parents is to choose an appropriate but beneficial educational approach (Prevendárová, 1998). Fitznerová (2010) introduced educational models that are identical to the errors described by Seidler (2008), whose parents commit to bringing up their child. It is an anxious, perfectionist, hyper protective, and dismissive upbringing. Already in older literature, Fišer (1968) mentions that “parents who give birth to a child with a disability are required to spend twice as much energy to accompany the child’s development and education as when working with an intact child.” (Fiser, et al. 1968, In Prevendarova, 1998). The last phase of mature parenting is:

- accepting the child is disabled,
- accepting the child as he/she is,
- accepting yourself as a parent of a disabled child, as well as a person with all other life roles, personality traits, experiences, attitudes.

It is not easy to reach this phase. This fact is also shown by Turzák, Kurincová (2016) that the experience of parents confirms that it is crucial, especially in this period, to gradually accept the idea that their child is disabled. Acceptance of this fact by parents means for the child himself a huge contribution to his life, it is so-called “the test of unconditional parental love.” Few parents go through such a life spontaneously; many of them need support from professionals, psychological, medical, educational or social institutions and services. Frania (2010) which examined the level of parent’s education has an influence on forming the child’s attitude. The level of education is strictly connected with the social status and with knowledge values which are or are not respected by parents.

2 Preparedness and awareness of the family in in the context of research

2.1 Research problem, goals, questions and methods

In the context of the theoretical background, many research investigations are being carried out, addressing the problems of families with a child with a disability. Some of the researched are given as an example. Interesting is, for example, research by Václavíková (2012), which examined the families living with a disabled child and focused on economic- social sphere. It has also addressed the quality of life of these families as well as the ability of the parent to accept a disabled child like any other. She pointed out that this issue was

also among the public in the period around the second half of the 20th century. By examining this issue, she has found that the birth of a child with a disability is stressful for the family affecting wider social structures. Further, she has concluded that the relationship to a disabled child does not depend on the level of education of the parents, but on their values (<https://www.pulib.sk/web/kniznica/elpub/dokument/Balogova6/subor/Vaclavikova.pdf>).

Repková (2006) conducted a similarly oriented research focused on the social and economic area of the family with a disabled child. She examined the perception of the changes that occur in the families in the monitored areas (<http://www.ceit.sk/IVPR/images/IVPR/vyskum/2006/ZPRZPC.pdf>). We can confirm that several studies have been carried out on this issue not only in our country but also abroad.

The subject of our investigation is the preparedness and awareness of the family that expects the arrival of a disabled child. In the context of the research, the goals were set:

- Goal 1 – To find out if the parents have enough information about the situation they are in and whether it helped them to handle this situation.
- Goal 2 – To decide whether the family has a positive impact on the success of the social integration of a disabled child.

Based on the theoretical background and research goals we have set the following research questions:

1. Do the parents at the birth of their disabled child have enough information as some time after?
2. Do the parents who have not been prepared in advance for this situation acquire enough information about disability and its consequences during the social integration?

The choice of the research group was deliberate. The sample was made up of 81 respondents, parents of a disabled child. Out of all the respondents, 24 were parents of a child with a physical disability, accounting for 29.6%. The second largest group consists of parents with a child with a hearing impairment, and it consists of 23 respondents, i.e. 28.4%.

The third largest group with 22 responses was with a child with a mental disability (the borderline of mental disability), i.e. 27.2%. The “Other” includes responses of 10 respondents, which is 12.3 %, with a child with a combination of physical and visual impairment, a child with Asperger syndrome, a child with physical impairment and a child with metabolic disorders. The smallest group was made of parents with a visually impaired child, only in two cases, i.e. 2.5% of the respondents.

The aim of the research was to find out the status of the families with a disabled child. We examined whether they have enough information to help them cope with their situation.

The following research methods were used for the research:

- literary- historical method,
- questionnaire,
- the method of statistic data analysis.

The term *literary- historical method* means to understand the issues of the subjects. By studying the literature, we have gained a more comprehensive view of the problem. Literature helped us to carry out research and based on that we could get, process and evaluate the data.

Another method that we used for data collection, is a method of exploratory nature, and that is a *questionnaire*. According to Švec (1998), a questionnaire is a research, development and evaluations tool for relatively rapid and massive way of data collections on knowledge, attitudes, and opinions of people interviewed. In our case, it was essential to find out the opinions and attitudes of the interviewed families. The type of research we have carried out is a natural part of data processing using quantitative and qualitative methods. We used standard mathematical and statistical methods for the evolution of the research.

The questionnaire had several constructs and in the context of the topic of our paper, we focused only on those parts that are relevant to the issue. We chose only the part that helped us to decide whether parents had enough information and how this information influenced them in the situation of having a disabled child. We also wondered whether parents think that a positive and stimulating environment affects the social integration of the child.

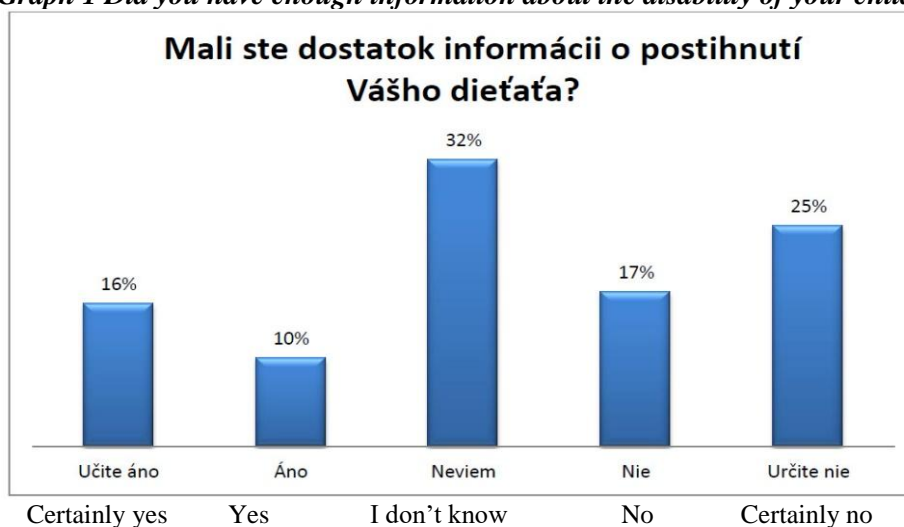
1.2 Interpretation of research results

1) Did you have enough information about the child's disability?

On this issue, parents can express whether they had enough information about their child's disability, using the scale. Most of them, 26 respondents, representing 32,1%, were unable to comment whether they had, or they did not have enough information, therefore their statement was neutral. 13 respondents, i.e. 16% of a total number of respondents, answered: "Certainly yes." Up to 20 respondents, i.e. 24,7% answered that they certainly did not have enough information.

Eight respondents replied that they had enough information, which is 9,9% of the respondents. On the other side, 17,3 %, corresponding with 14 respondents, said they had a little information.

Graph 1 Did you have enough information about the disability of your child?

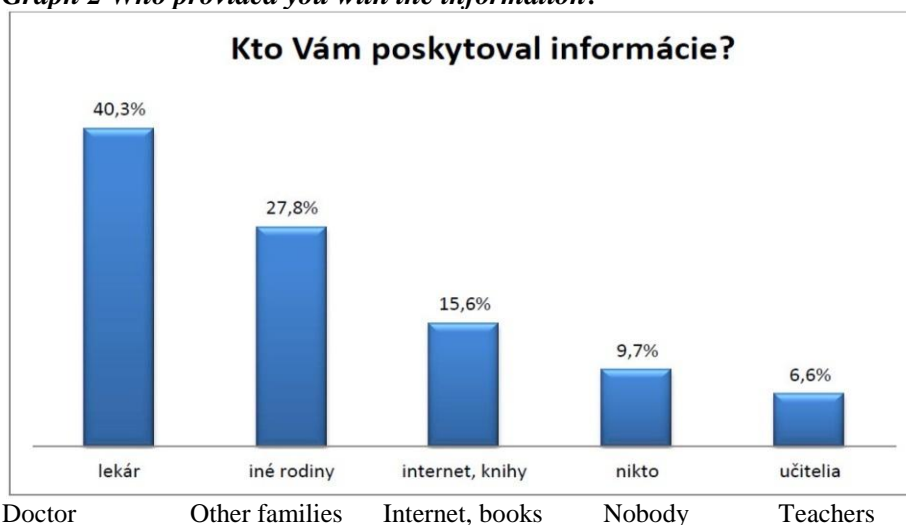


2) Who provided you with the information?

There are different answers to this question. The question was open, parents had to express their opinion on who provided them with the information. Most of the parents answered that doctors provided them with information, then the Internet or they studied books or asking for help the families with a similar problem. The most common answer was the internet, including the advice between mothers. Many parents report that they obtained information from a physiotherapist. One answer is information obtained from the Internet, self-studies, and help from the doctors from the USA, because they could not get help from doctors in Slovakia. Others obtained information from specialists in Bratislava.

To summarize that, according to many answers, parents were given the first information from the doctor. Others were either from the specialists of the ENT (Examination and treatment unit), the neurologist, specialist teacher for hearing problem, the speech therapist, the physiotherapist, the social organizations, the various foundation and then they sought the other information that was emerging either by doctors, but most often through books, the Internet, various organizations, that deal with specific issues, and mothers and families who were in a similar situation, helping and supporting each other.

Graph 2 Who provided you with the information?

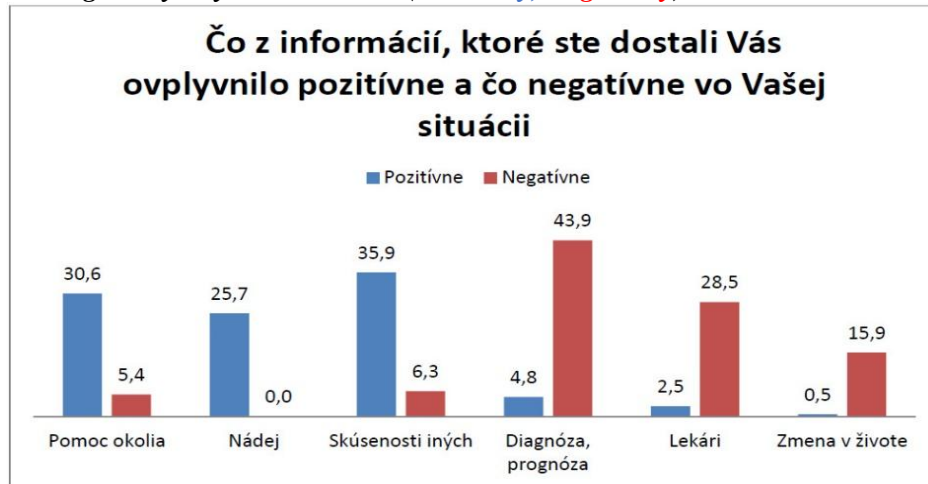


3) What information have you received has influenced you positively and negatively in your situation?

We found out the views and attitudes of the parents answering the open question: What information you have received has influenced you positively and negatively in your situation? Graph 4 draws attention to the negatives and positive sides of problematic situations that parents must face. We have summed up the answers to key areas that were most frequently encountered. Here are some examples:

- ✓ “Many things were negative because I learned this information too late but after it became positive, when I learned to appreciate other values in life and to enjoy the trifles and the fact that I must take care of my son is like a mission to help others.”
- ✓ “The positive side for me was meeting with other families, who have already undergone a given situation and were able to give me hope.”
- ✓ “It negatively affected us when they told us that our son would never be able to sit. We have been positively affected when our son started to sit and integrate after years of exercising and rehabilitation.”
- ✓ “I was negatively affected by the fact that I received the information too late and I thought my child would no longer be able to integrate, but we were able to do it with the help of doctors in Brno.”
- ✓ “Negative thinking is inadmissible.”
- ✓ “Everything affects us positively because our child is alive.”

Graph 3 What information you have received has influenced you positively and negatively in your situation? (Positively, Negatively)



Help from the others Hope Experience Diagnosis Doctors Changes in life

Conclusion

The goal of the aliquot part of our research was to find out how parents cope with their situation. By research questions, we have concluded that parents do not have enough information about disability during treatment and rehabilitation of their child. We can evaluate that, despite the early diagnosis, the access of doctors and specialists is very important during the treatment and rehabilitation of a disabled child.

Parents would appreciate accurate and clear information about their child's health. To express themselves in a professional but also human way depending on the situation which is a shock to the parent. It is important for parents to have unrestricted access to information about their child's disability, different ways of help and support. There should be more laical literature to for parents. It would be appropriate to promote different organizations that exist and often parents do not know about them and those might be able to help them.

Another issue is that parents often do not have enough information, and that is why they begin to explore the opportunities for a child to be able to continue to exist in society. There is no possibility to receive such a fact with no emotions, without the shock phase, rejection, because every parent would like his/her child to be born healthy and to stay healthy. Unfortunately, such situations as not to be influenced or planned and, therefore, a person is basically never quite ready and informed that the situation in which he finds himself in, can be overcome in an easier way. It depends on the personality of

each parent, his resilience and psyche, how they can accept the situation, how fast they cope with this situation, starting to search for information on how to help a child and be a child's lifelong support.

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