SILESIAN
UNIVERSITY
FACULTY OF PUBLIC
POLICIES IN OPAVA

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CURRENT QUESTIONS OF SPECIAL EDUCATION

PARENTAL RESILIENCE AND SUPPORT IN RAISING CHILDREN WITH SPECIAL NEEDS

OPAVA, 2023

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This monograph was prepared with the aid of long-term institutional support for research activities by the Faculty of Public Policy, Silesian University in Opava.

Abstract:
This professional publication describes aspects of the education of children with special educational needs in context of the family and school environment. It looks at the issue of parents' resilience in the context of managing developmental risks of children with disabilities and chronic illness, describes the position of siblings of children with disabilities and the impact of the family environment on the school achievements and social integration of children with special educational needs. It characterises the impact of distance learning on pupils' mental health, social and communication skills and highlights the importance of family support in preventing school failure.

Key words:
Parents' resilience, mental retardation, developmental disabilities, attention deficit hyperactivity disorder (ADHD), social disadvantage, interprofessional cooperation, special pedagogical centre, non-profit sector, department of social and legal protection of children, paediatrician, school failure, problem behaviour, risk behaviour, parental involvement in education, family-school cooperation, prisons, recidivists in prisons, family environment, education of pupils in primary school, school achievement and failure, family role in education

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ISBN 978-80-7510-567-7 (print)
ISBN 978-80-7510-568-4 (online)

TABLE OF CONTENTS

INTRODUCTION

"Every child is unique. Each has their own world that they bring into reality, and it is up to us to support them, and not to hinder their growth." John R. Wooden

The herein presented monograph is the outcome of an international conference titled Family Transformations XI, Challenges of the 21st Century for the Helping Professions. The conference was organized in cooperation with the Institute of Educational and Psychological Sciences and the Institute of Special Education of the Faculty of Public Policies at the Silesian University in Opava with financial support from the project 'Development of Education' at the Silesian University in Opava CZ.02.2.69/0.0/0.0/16_015/0002400. The aim of the conference was to highlight the transformations of contemporary families, whose members face various challenging situations in everyday life, but also new circumstances they have not encountered before (e.g. Covid-19, war conflict in Ukraine, etc.). These raise a number of issues related to the upbringing and education of children in general, and children at risk in their physical, psychological and social development in particular. Changing social conditions are expanding the base of people in need of help and support, and increased demands are therefore rightly placed on the professional competences of helping professionals. Finding ways to mitigate or eliminate the negative influences threatening the mental well-being of parents and children is becoming an increasingly urgent challenge. The presented monograph can be perceived as a platform for discussion and sharing of new knowledge in the field of special pedagogy, whose mission is to reflect on current trends in society in the field of promoting equal opportunities for people with disabilities and disadvantages in the physical, psychological and social aspects, in line with the current state of scientific knowledge in the subject areas.

The content of the monograph is divided into chapters in which attention is paid to selected aspects that significantly influence a child's development, which can also predetermine the quality of their future life. The presented aspects signal the need to promote the principles of lifelong learning across age categories, to reduce inequalities in education, and to support the subjects and objects of education and training with an emphasis on partnership cooperation between professionals, parents and other family members of the target group. In a functional family, where the needs of all family members are naturally met and undesirable educational approaches do not occur, the child has all the prerequisites for the optimum development of their potential and for achieving the expected competences for successful schooling and subsequent integration into society. However, the creation of optimal conditions for the child's upbringing and the ability to cope with adverse life situations is influenced by diverse and broad variabilities of external and internal factors inherent in particular individuals.

The determinants affecting the quality of life of individual family members include the social and political environment, the economic situation, the social groups they belong to, personality, temperament, motivation, beliefs, employment, work environment, education, health, etc. Unfortunately, a number of parents, even with good intentions, fail to create an optimal environment for their children that would prevent potential school and social failure. The search for efficient forms of support for families at risk has therefore long been a topical issue on the minds of professionals in the helping professions.

The emphasis on interdisciplinary cooperation is absolutely crucial in the whole process, as the fields of economics, health care, upbringing, education, welfare, etc. are mutually intertwined. It is often very difficult to set up a functioning cooperation between parents and specialists of the assisting professions, and the presented good examples of effective cooperation are still somewhat an exception. The partnership between parents and professionals is based on mutual trust. However, it happens more and more often that parents are not convinced of the meaningfulness of cooperation with professionals and vice versa. The level of understanding of how professionals can be truly ‘helping’ and how both parties can benefit from each other is still insufficient. The monograph provides stimuli for reflection on aspects of the upbringing of the subject group children and the need to support parents in the context of health, social and educational circumstances.

The first chapter presents the issue of families caring for a child with a disability or serious chronic disease. It pays attention to the role of parents in building the relationship between siblings, as the role of a sibling of a child with a disability is very challenging, especially in developing appropriate strategies to manage the situation of an asymmetrical relationship. In the next section, the chapter introduces the results of research in families caring for a terminally ill child and highlights the negative consequences of the child’s isolation on their overall health and the family’s quality of life. The final text of the chapter highlights the burden on the family associated with the need for intensive sensory reeducation.

The second chapter introduces the reader to the developmental aspects of education for children growing up in socially disadvantaged environments. Two introductory essays focus on the school’s collaboration with the family and other professionals to reduce risky behaviors and promote motivation to learn. The following subsection introduces the results of empirical research on the perception of the family through the eyes of recidivists with different criminal histories and describes the consequences of a negative family environment on the respondents’ behaviour and social maladjustment. The chapter concludes with a text reflecting on the issue of prevention and the application of preventive thinking in the social area. It presents reflections on the actual benefits and effectiveness of prevention and points to the absence of arguments about the effectiveness of prevention programs in the area of inappropriate social behaviour.

The third chapter presents the aspects of education that influence the development of a child manifesting risks of school failure. It presents the results of mapping the impact of distance learning on pupils’ mental health, social and communication skills and the limits of preparation for the classroom in the family environment. It reflects on the practical experience of conducting online individual speech therapy interventions in a special education centre. Through case studies, examples of the positive and negative impact of the family environment on pupils' academic achievement are also presented. The final section of the chapter is devoted to research findings focusing on relationships between parents and children in foster care.

In the text of the expert publication, current special education topics are elaborated on from various perspectives, which are intended to be an incentive for more efficient support for parents and children in crisis or long-term difficult life situation. The latter are often in a "vicious circle" due to insufficient and uncoordinated support from professionals. Timely and effective intervention is one of the ways to positively influence a seemingly intractable situation, to support the development of the child with respect for their individual needs and to strengthen the quality of life of the whole family.

On behalf of the team of authors,

Eva Zezulková and Kateřina Janků
Opava, 2023

1

ASPECTS OF EDUCATION IN THE DEVELOPMENT OF A CHILD WITH DISABILITIES AND CHRONIC DISEASE IN THE FAMILY

1.1 THE POINT OF AN INTACT SIBLING IN THE FAMILY OF AN INDIVIDUAL WITH DOWN SYNDROME

Jarmila Pipeková and Jan Viktorin

INTRODUCTION

For the socialization of an individual, the relationship between siblings is one of the most important relationships. The relationship between siblings is always different. What if a situation arises where an individual with Down syndrome appears in the sibling relationship? An intact individual can be jealous that his sibling with Down syndrome is privileged and can be a source of stress for him, or, on the contrary, an intact sibling can also become a protector of a sibling with Down syndrome and he can learn understanding, tolerance, and modesty thanks to him. For some, it is a strange, often even sensitive topic, when the whole family has to deal with and come to terms with the reality that is the result of long adaptation phases, especially on the part of the parents. Bonds and relationships in the family are always different; in families where there is an individual with Down syndrome, these bonds are usually much stronger. At the same time, life values are affected for these families, which ordinary families do not usually have to think about.

The main aim of the research study was to find out what position the intact sibling occupies with his sibling with Down syndrome and how he perceives their mutual relationship. Based on the main objective, partial objectives were set to find out how Down syndrome affected the family from the point of view of an intact sibling; how Down syndrome affected the intact sibling itself, and which factors could affect the relationship between siblings. To achieve the objectives of the research study, the qualitative method with the semi-structured interview technique was used. The research study has shown that the relationship between siblings is positive and intact siblings occupy an appropriate position in the family. This was mainly helped by parents, who created suitable conditions for building a good relationship between siblings.

THEORETICAL BACKGROUND

Down syndrome is the most widespread form of intellectual disability. It is a congenital genetic disorder that affects approximately 10% of people with intellectual disabilities. We classify Down syndrome as a so-called 'genomic disorder'. Almost all people with

Down syndrome have some degree of intellectual disability and often have typical health complications and physiological features that separate them the majority. The typical features of a person with Down syndrome include, in particular, a larger figure, shorter stature, a flattened crown, a flat round face, slanted eyes with bilateral epicanthus, and hypotonia of the entire body, including the orofacial area. Compared to the intact population, people with Down syndrome may have an increased incidence of typical health complications which can include intestinal and stomach abnormalities, congenital heart defects, myopia, congenital cataracts, nystagmus, thyroid gland disorders, conductive hearing loss, and even hearing loss. As a result of hypotonia orofacial area, intellectual disability, and pathologies in the area of the oral cavity and teeth, people with Down syndrome often have difficulties in verbal communication. Down syndrome is the most well-known and frequently described syndrome, which is caused by a change in the number of chromosomes. The cause of Down syndrome is the presence of an extra 21st chromosome in all or only some cells. Accordingly, three basic forms of Down syndrome are distinguished, namely non-disjunction (trisomy), translocation, and mosaic. The emergence of this syndrome is uncontrollable and not to blame. It is a random chromosomal mutation. Older age of parents, fathers over 50 and mothers over 35 are mentioned as the only risk factor. Since it is a congenital genetic disorder, this syndrome can be detected in the foetus during pregnancy or during prenatal development through prenatal diagnosis. Among the most common examinations in prenatal diagnostics are ultrasound or Triple test, as a non-invasive examination, and amniocentesis, as an invasive examination (Bartoňová, Bazalová, & Pipeková, 2007; Cicchetti & Beeghly, 1990; Cohen, Nadel, & Madnick, 2002; Černá et al., 2015; Nečásek, 1997; Rasore-Quartino et al., 2008; Šustrová, 2004; Švarcová, 2011).

The family is the primary, primordial, and most fundamental environment with which the child comes into contact and within which he builds an elementary perception of relationships and society and develops and learns. It is an environment that has the most fundamental influence on the development of the psyche and socialization of each individual, whether with or without a disability. The family is the most important social group in a person's life. Family relationships are characterized by mutual cohesion, emotional bonds between members, intimacy, and clearly defined roles. The family shapes a person's personality in a fundamental way, provides him with elementary social experiences, and creates very specific emotional bonds here. If a child with Down syndrome is born in the family, it is a very complex social situation that will affect the relationships, functioning and experience of the entire family. The birth of a child with Down syndrome usually results in a crisis in the way the family functions and experiences shock and frustration, which can last for a long time personally for individual family members. In the case of the birth of a child with Down syndrome, it is absolutely essential to know whether the child's disability was known before or after birth. If the syndrome is detected as part of prenatal diagnosis, the family can already go through a crisis period during pregnancy, have more time to cope with the stated fact, and decide on a possible termination of pregnancy. The child born is already expected by the family with this diagnosis, so accepting the whole situation and coming to terms with it is easier for this family. If the family expected the child to be intact and a child with a disability is born instead, the family usually goes through several stages in the process of experiencing and coping with the said traumatic life situation. The first knowledge that something is wrong with the child represents a certain shock in the ideas and attitudes of the parents. The first feeling of disappointment is usually proportional to how obvious the child's disability is and how much the parents can realize its impact on their future. If such a realization occurs soon after birth or at any time later, the entire family life will undoubtedly be affected by it. After the birth of a child with Down syndrome, the family goes through a stressful period, which is a reaction to an unexpected situation, disappointment, and fear for the future. The initial communication of the diagnosis causes sadness, anxiety, and shock in the parents and leads to the development of defence mechanisms. Parents find themselves in a completely unexpected reality, experiencing deep disappointment. The family can fulfil its main role only if the parents are able to submit to the child's needs, because they are responsible for the child, and if the adult family members also have a similarly responsible relationship with each other (Carr, 1995; Jankovský 2006; Matějček, 2001; Matoušek, 2003; Opatřilová et al., 2006; Pueschel, 1997; Selikowitz, 2011; Vágnerová, Strnadová, & Krejčová, 2009).

Having another child in the family is beneficial for the functioning of the family and the development of the child with Down syndrome. A sibling is an inseparable and stable part of life. Siblings are very important and useful to each other as they form a close and mutual relationship where they are both rivals and allies. Parents are understandably worried about having another child. There is a mix of concern for the child to be intact, but at the same time uncertainty about how they will manage to care for a child with Down syndrome and another offspring. Sibling relationships are formed between members of a sibling group that influence a person to conform to the demands of society. These relationships cannot be considered complex. It is an exclusive, interesting, and special relationship. We do not deserve it, we do not choose it, it will be given to us, one might say, by fate. It is among the closest that exists in the world, it is not talked about or discussed, it just is. It can be formed by persons of the same, but also of a different sex. Knowing that family life is psychologically more demanding and different in a certain way, an intact child can also influence parents on certain attitudes and behaviour. The child may develop positive qualities, e.g. respect for health, tolerance, responsibility, the ability to empathize with the situation of others, but at the same time the child may feel pushed away, insignificant, or blame himself for his own sibling's disability. It is very important that parents of the intact child reasonably explain the disability of the younger or older sibling. They should choose a level of explanation that will be understandable to the child. This should be simple, short, so that the child himself can repeat and explain the disability of his own sibling. An intact child in the family should understand that a sibling with Down syndrome has behavioural peculiarities and needs help, but he should not perceive any differences from those closest to him. The child must feel that he is not discriminated against, not feel that he is a burden for his parents, and at the same time have the opportunity to have free time for himself and his peers. The intact child can then gradually adopt certain practices on how to manage the relationship with the disabled child. It is desirable to support the joint pleasant activities of siblings, to appreciate and not overlook any, even if only a small sign of cooperation and good relations. An intact child has a disturbed social status. He may feel uncomfortable and embarrassed when he has to go out in public with his sibling as he may receive inappropriate comments and ridicule from peers and the wider environment.

Of course, the intact child does not tolerate it well. All children in the family should receive the same care, but if there is a child with Down syndrome in the family, the situation will be different. From an early age, an intact sibling may feel signs of the obligation to support their sibling with a disability. The older he gets, the more he gets to take care of his younger sibling at home. It is not only a negative factor because the intact sibling is enriched with new life experiences that will be useful to him throughout his life. The child acquires new social skills and experiences how to care for others. Due to this, he can often play the role of a protector who needs to protect and support his sibling with Down syndrome. In order for ideas, abilities, and relationships between siblings to be verified, it is necessary to achieve interaction, and above all a positive one. Love must be established between siblings at an early age for a positive relationship to last a lifetime. In adulthood, sometimes an intact individual has to care for up to three generations of family members, i.e. his parents, siblings with Down syndrome, and his own offspring. He is under a lot of psychological pressure, physical, and emotional fatigue, so he should not be blamed if he provides his siblings and parents with adequate, appropriate care in a social service facility (Bartoňová, 2013; Bazalová, 2014; Caspi, 2011; Cunningham, 1996; Leman, 2016; Mertin, 2004; Plevová, 2007; Vágnerová, 2014).

OBJECTIVES AND METHODOLOGY OF RESEARCH

The main objective of the research investigation was to find out what position the intact sibling takes in relation to their sibling with Down syndrome and how they perceive their mutual relationship. The partial goals of the research investigation were to find out how Down syndrome affected the family from the point of view of the intact sibling, how Down syndrome affected the intact sibling, and which factors could influence the relationship between siblings. For this, a main research question and three partial research questions were established. Main research question: What is the position of the intact sibling towards his sibling with Down syndrome and how does he perceive their relationship? Partial research questions: How did the child’s Down syndrome affect the family? How has a sibling with Down syndrome affected the life of an intact sibling? What factors might have influenced the relationship between siblings?

Qualitative research was used for the research investigation, which can be characterized as a process of seeking understanding, which is based on various methodological traditions to investigate a chosen human or social problem. The researcher creates a holistic, complex picture, informs about the opinions of research participants, analyses various types of text, and examines them in natural conditions. Qualitative research is associated with the inductive method. Induction is characterized as a method of reasoning in which the conclusion contains information exceeding the information (of empirical origin) in the starting point, i.e. thanks to it we can create general laws. The method mentioned is based on repetition, where constantly recurring cases lead to the adoption of a certain law or rule based on probability. Interview is the most widely used method of data collection in qualitative research. The mentioned method makes it not only possible to obtain facts, but to also penetrate the deeper attitudes and opinions of the informant. Semi-structured interviews were chosen for the research investigation. The goal of the semi-structured interview is to obtain comprehensive and detailed information about the phenomenon under study. The researcher prepares a range of basic topics and open questions, which he supplements during the interview with additional questions based on the informant's answers. More attention is needed at the beginning and end of the interview because it is important to break the barriers between the informant and the researcher. The conclusion of the interview is important because of the possibility of obtaining additional important information that the informant can provide when saying goodbye (Gavora, 2010; Mason, 2018; Švaříček, Šeďová et al., 2014).

Based on the set of partial research questions, a list of specific questions was created. During the interview, the questions were expanded with additional information and questions to better and more accurately express and clarify the informant's answers. If the question seemed unclear to the informant, it was reformulated in such a way that he could better understand it and be able to answer it. At the beginning, each informant was asked to tell some basic information about himself, his siblings with Down syndrome, and his parents, and then to share some information, such as his studies/occupation, and interests. The duration of all interviews is around 30 minutes. Each informant gives their informed consent for the interview. In this type of research, we will work with transcribed data from interviews, i.e. with words, i.e. text. As for the method of data analysis, qualitative data analysis and interpretation seeks semantic relationships and combines descriptive categories into logical units. In qualitative research, results are not achieved using quantification or statistical procedures, as is the case in quantitative research (Hendl, 2016).

Data collection from interviews was followed by the transcription process, which is a necessary part of qualitative research and is extremely time consuming. This research investigation used verbatim transcription, which is the exact process of converting spoken speech from a conversation into written form. For a detailed evaluation of the transcription, it was necessary to emphasize, for example, by commenting on the edge of the page, holding or comparing individual places plus the essential points. Once the transcription is done, the researcher can start analysing the data. Open coding was chosen for the research, which represents a simple but sophisticated analytical technique aimed at detailed and in-depth work with the text. Data analysis always starts with open coding, but the researcher has the possibility to lean towards another method at any time according to needs. In grounded theory, coding is an analytical operation that breaks data into fragments (indicators), which are then classified into relevant concepts. During open coding, the text was broken into fragments (units), mostly in the form of sentences, paragraphs, or words, and the researcher then gives them a new name, assigned a code (title, name). The code captures the topic of the text and at the same time considers the research questions. The goal of the coding was the thematic disclosure of the text. The codes were mostly adjectives, nouns, or verbs, which are understood as properties of the categories. The properties are read from the data, or alternatively, the researcher has to derive them himself. The analysis is followed by its interpretation, which is then complemented by direct quotations of parts of the interview (Corbin & Strauss, 2015; Flick, 2018; Miovský, 2006; Mišovič, 2019).

CHARACTERISTICS OF THE RESEARCH SAMPLE

The sample consisted of five intact siblings of children with Down syndrome in the south Moravian region, who come from full families. The intact siblings were in the 18–32 years age range. The age range of the siblings with Down syndrome was 19–31 years and the age range between siblings was a maximum of nine years. The lower limit of intact siblings was chosen on the basis of the already more mature opinions of the informants. Interviews were always conducted in person. To preserve anonymity, informants are marked with letter I and the corresponding numbers 1–5.

Table 1: The Research Sample

Informant	Gender	Age	Sibling with disability	Age	Diagnosis	Parents	Age
I1	female	18	male	27	Down syndrome (moderate intellectual disability)	father	54
						mother	47
I2	male	32	female	30	Down syndrome (severe intellectual disability)	father	58
						mother	53
I3	female	31	male	31	Down syndrome (moderate intellectual disability)	father	57
						mother	57
I4	female	29	male	21	Down syndrome (moderate intellectual disability)	father	61
						mother	56
I5	female	24	female	19	Down syndrome (mild intellectual disability)	father	57
						mother	57

ANALYSIS AND INTERPRETATION OF RESEARCH RESULTS

The data obtained from the semi-structured interviews were analysed and interpreted in the following section. Partial questions are always listed first, followed by individual categories. Using open coding, several categories were created that will attempt to answer partial research questions. The following is an interpretation of the given categories, which is supplemented by direct and authentic quotations from informants.

PARTIAL RESEARCH QUESTION 1: HOW DID THE CHILD'S DOWN SYNDROME AFFECT THE FAMILY?

Category 1: Rapprochement

Most of the informants said that Down syndrome brought the family closer and strengthened their relationships. This has a positive impact on overall family relationships, when not a single party is in need, and such a positive effect can have an effect on the better development of the personality of the individual with Down syndrome and the intact child. At the same time, it is a crucial aspect in family relations that helps to accept an individual with Down syndrome. I1: *"Well, I don't think so, as we take him normally, I would say so. That it does not affect anything, etc. But we have a strong relationship, yes."* I2 was the only one who thought that the life of the family would probably be different if his sister was intact. I2: *"Relationships probably not, but it would probably be different if she were healthy. (...) Just like a solid unit at the same time, I would say, nothing will break us apart."*

Category 2: Time

Family relationships were also supported by time spent together and activities that the family carried out according to the possibilities of the child with Down syndrome since childhood. These were mostly vacationing and social events spent together, when the family tried not to single out a child with Down syndrome and also adapted a suitable environment for this. I4: *"So every year we go on vacation in a tent with friends. That used to be really cool."* I1 added that the older her brother got, the more he had trouble adjusting to a foreign environment, which gradually led to a decrease in vacations spent together. This can have the effect of partially disrupting the integrity of family relationships, as time spent together outside the home leads to the formation of new experiences and the family makes up for the lack of time through daily responsibilities. I1: *"We travelled a lot with him. Well, about three, maybe four years ago, we were together with him for the last time. Like, you know how, maybe he was naughty, he just couldn't stand it in those restaurants or something like that."*

Category 3: Relationship

The statements of the informants gave the impression that the relationship between them and their parents was very positive. The informants did not feel that parents made differences between them and their siblings with Down syndrome. Mothers tried to give love to intact children from childhood and always tried to give them advice when they had a problem. I5: *"Mom and dad always tried to dedicate some of their time to each of us. That certainly helped with the kind of relationships I have with them. When I came to my mother with anything, she gave me advice, helped me, never said that I should go away, that she did not have time. Dad is the same, he taught me different things..."* The only exception is I3, when the interview revealed that the relationship with her parents, but especially with her mother, is disrupted due to her brother's Down syndrome. As I3 pointed out, this situation itself arose from the fact that the siblings are twins and I3 did not have the opportunity to spend some time alone only with her parents. I3 has also had very high demands placed on her by her mother, where I3 has a sense of healing her mother's unfulfilled goals. I3: *"They treated me differently all my life. I have always been the one who has to understand, he just has to back off because he has the paperwork. I am healthy, I just have to understand it. (...) That she is healing some of her complexes on me, which she was unable to do. (...) I always did what she wanted, but it was never good enough. It could always be better. In school I simply got a two, it was immediately that you couldn't learn it with a first? So, you understand, that is simply zero motivation, simply nothing."* The relationship between intact children and fathers is also very good. The informants positively agreed on their willingness to share advice and experience. For intact siblings, it is important that parents take both children equally, devote part of their time to them, and not neglect them. The informants confirmed that the relationship between parents and a child with Down syndrome is stronger and stronger. Differences are only slightly noticeable in the father-child, mother-child relationship, where I1 and I2 are of the opinion that siblings gravitate slightly more toward mothers than toward fathers. This is probably due to the fact that mothers have a slightly different function than fathers. At the same time, I2 adds that the relationship between his parents and his sister would be very similar even if she did not have Down syndrome. I2: *"Very good, both like her very much. Mom and sister may be a little more attached to each other because they are babies, but the relationship between dad and sister is also very close. After finding out that the sister would not be well, it was difficult for us to deal with it and accept the fact. But I think they would like her just as much, and that the relationship would be very similar to what it is now. (...) Our behaviour and attitude were different compared to his condition."* In contrast, the relationship between parents and the child with Down syndrome in the family of I4 strengthened when, according to I4, her brother's Down syndrome enriched the parents and gave them additional motivation in life. I4: *"A brother was born and they seemed to stick together, but with him, yes. (...) That they are still so vital, that they still have the child. And dad just goes to pick mushrooms with him, they cut wood together, mom goes to balls with him now, and so on."*

Category 4: Communication

When informants were asked whether their parents had explained to them in childhood what their sibling's Down syndrome was, the answer was mostly that the parents did not go into too much detail. Their explanation was most often that the sibling will be slightly different from the intact child. This may be understandable because the parents tried to adapt to the age of the intact child so that he could better absorb such information. In the case of I2, the parents were more open and explained to him more closely the situation regarding the development of Down syndrome in his sister. On the other hand with I3, her parents never explained what Down syndrome meant and how her brother would develop.

Category 5: Parental care

In the context of parental care for a child with Down syndrome, the informants agreed that both parents were always actively involved in the care of their siblings. This is a good role model for the intact child when he sees the parents' joint care for the individual with Down syndrome, which can influence him to participate in the support for his sibling. Only in the case of I4, because of the father's employment, there was more care for her brother on the part of the mother. This can also result in greater affection, respect, and trust for the mother. I4: *"Well, dad was almost always at work. Mom was more at home. As we always have him at home for the weekend, mom was at home with us because of dad's work."* I3 recalled her mother's greater participation in recovery stays, where she accompanied her son with Down syndrome, but in the home environment he then participated in helping with the care of the child and dad. I3: *"When my brother was little, they used to go to the spa a lot, and my mother usually went there with him, so I was with my father. But otherwise, both were involved as much as possible."*

PARTIAL RESEARCH QUESTION 2: HOW DID THE SIBLING WITH DOWN SYNDROME AFFECT THE LIFE OF THE INTACT SIBLING?

Category 1: Awareness

A very common fact with which intact siblings identify is not remembering the moment they recognized their sibling's Down syndrome during childhood. The informants noted that their sibling's condition was natural for them and they could not imagine anything else. It can be assumed that full awareness of a sibling's Down syndrome occurs only after the age of 10. The older an intact individual is, the more he is able to realize and perceive the differences between him and a sibling with Down syndrome, and thus also the consequences of this condition, when he has to cope with certain complications that will arise during his life. I3: *"I don't remember. I think it felt completely normal. This was normal for me."*

Category 2: Relationship between siblings

Current sibling relationships are at a good level from the point of view of intact siblings. The informants describe their relationship with their sibling as a normal sibling relationship, where they are fully aware of certain differences between them in the sense that, for example, they cannot communicate with their sibling on all topics as with another intact individual. I4: *"I would say that we have a good relationship. Although it is a bit affected by his Down syndrome, such as in the sense that we cannot talk to each other about all things, but I think it is good that we like each other."* It is hard for I2 and I3 to compare such sibling relationship, as they have no other intact siblings. I5 perceives his relationship with his sister as very close, where he tries to support and be close to his sister at all times.

Category 3: Enhancement (enrichment)

When the informants had to think about what their sibling's Down syndrome has enriched for them, respect for other people and especially for individuals with Down syndrome were mostly mentioned. Furthermore, intact siblings agreed that they can better empathize with the situations of others, which is a sign of empathy in intact siblings. I5: *"Certainly, as in many things. Also, the fact that I get to know a lot of other families with Down syndrome and the whole disability is so much closer to me, in such a good way, that I got to know it."*

Category 4: Current sibling contact

Since most of the informants have started to live their own personal lives, have moved away, or want to move away from their parents in the near future, they also mentioned how often they currently see their siblings. Thanks to the fact that good and friendly relations were formed between the siblings during their lives, there are often regular visits on weekends and holidays, because almost all informants (except for sisters I5) are on weekly residential service in a home for people with disabilities. On the contrary, intact siblings' study or go to work during the week. The exception is I3, who lives in Prague and visits her parents 1–2 times a month, depending on time. At the same time, she added that her brother initially had a problem getting used to her moving away and thus to less regular contact, but over time he accepted the given situation. I3: *"He simply understood that as I am in Prague, that I am away and only at home sometimes."*

Category 5: Choice of profession/study

The statements of the informants showed that the Down syndrome of their siblings had no influence on their choice of future school or future job. To some extent, I1 was interested in a school with a pedagogical focus, but the field of special education never appealed to her. In the case of I5, who studies special education, the presence of her sister with Down syndrome in the family was an advantage and an inspiration, as she could better imagine what this field would entail. I5: *"Well, of course. Yes, I don't know what it would be like without her, but it certainly encouraged me in a certain direction."* Otherwise, the intact siblings never showed interest in Down syndrome in the form of a professional focus.

Category 6: Surroundings

The environment's reaction to a child's Down syndrome affects the entire family. It can traumatize the family more or, on the contrary, positively encourage it. The informants themselves agreed that they did not encounter negative reactions regarding the siblings of Down syndrome in their immediate environment and that they were able to understand and positively accept that their siblings of Down syndrome played a certain role in their choice of friends. If intact siblings were to encounter a certain negation regarding Down syndrome, they would have no need for more intensive communication and establishing a relationship with the person in question. An interesting example was given by I4, when she did not encounter a negative reaction from the environment directly to her brother's Down syndrome, but at work she condemns the behaviour and negative attitude of a colleague in how he approaches people with Down syndrome. I4: *"I didn't have to. Like I didn't really have a brother, like no. But we have one at work. He is the same age as me. There are people who go there and I can tell that the person has Down syndrome or simply has* *some kind of disability. And he was just such a dude, he had a stupid talk about it when they left, and he started imitating them and stuff. That really bothers me a lot. I condemn such behaviour."*

Category 7: Responsibility for siblings

All informants agreed that they are thinking about the future with a sibling with Down syndrome. They have not discussed their future plans with their parents yet. Intact siblings believe that siblings with Down syndrome need to maintain relationships and feel the need to be close to them when parents cannot. It is precisely the mostly intact siblings that are the last closest persons to individuals with Down syndrome. An interesting fact was the finding that there was no difference between the gender of the informants, when a smaller initiative about planning one's future with a sibling with Down syndrome is assumed in I2. On the contrary, he showed great interest and is already planning his future life with his sister. I2: *"I'm definitely counting on it in the future. So, for now, even though we are building now, I am counting on the fact that he will live there with us. So, I adapt some things to that."* Several informants agreed that it is still premature to decide the future and that they will deal with it when it becomes relevant.

Category 8: Securing the care of the siblings

When asked if the informants think that their siblings are better off in a home environment or in a social service facility, the informants split into two groups, with I2 and I5 exclusively agreeing only with home care and I1, I3, and I4 seeing positives as well as negative aspects of care in a social service facility. The informants see the positives primarily in the frequent rich activities that social service facilities offer to their clients, as well as in the establishment of new contacts and friendships. An ordinary family cannot provide such activities for their child with Down syndrome. Informants see the negative in the fact that the siblings have been in these facilities for several years and the older they get, the more difficult it is for them to leave their home environment. I2: *"One hundred percent at home. What we give her at home, whether emotionally or materially, they cannot give him there."* I1: *"If he was at home, someone would have to be with him. And we cannot play with him as much as they do over there. So, I think things are good there, things are better there."*

Category 9: Partners of intact siblings

Relationships between partners of intact siblings and a sibling with Down syndrome are positive. The informants stated that neither in the past nor in the present did any of their partners have a problem with their sibling's Down syndrome, nor did the informants themselves limit their search for a partner by the fact that they have a sibling with Down syndrome. I1 has not yet found a partner but adds her uncertainty as to whether her brother's partner will accept her in the future. I1: *"I have not had a partner yet, so I don't know, but maybe not, we will see."* I3 does not rule out the possibility that a future partner will have a problem with her brother's Down syndrome. For intact siblings, it is important that their partners have understanding, a positive attitude, and a certain willingness for a future that will include an individual with Down syndrome.

PARTIAL RESEARCH QUESTION 3: WHAT FACTORS MIGHT HAVE INFLUENCED THE RELATIONSHIP BETWEEN SIBLINGS?

Category 1: Positive characteristics of intact siblings

It was evident in all informants that their sibling's Down syndrome had a positive impact on them in a certain way. I2, I4, and I5 confirmed that, thanks to Down syndrome, the siblings became more independent, while I4 partially admits that this acquisition of ability was also initiated by her parents, who left her and her sister room to become independent. At the same time, I5 added that the fact that she comes from five siblings contributed to her independence. I5: *"Certainly yes, otherwise it wouldn't even be possible. When you have so many siblings, you have to learn to be independent."* Independence is one of the positive traits found in intact siblings. In addition to independence, responsibility is often a typical factor that can also be included among the positive qualities of intact individuals. Intact siblings felt responsibility for themselves and their siblings with Down syndrome since childhood, when they became fully aware of the consequences of their actions and possible consequences. Too much responsibility can lead to precocious puberty, which I4 identified with. I4: *"Thanks to this, you learn responsibility. (...) We really matured earlier with that."*

Category 2: Ability to care for others

Another factor that I1, I2, I4 and I5 agreed on as positive is the ability to care for and care for other people due to their sibling's Down syndrome. Several informants have already started helping their siblings with Down syndrome in their childhood. I3 adds that this ability did not come naturally to her, but she had to adapt and learn it through the circumstances. I3: *"Yeah, I can probably take care of it, like, yeah. Everyone who knows me knows me, but they don't know my brother, so they wonder how I will be a good mother. How can I take care of everything? It is not that I wanted to, but I simply had to. That the circumstances forced me, so I had to adapt to it."* The ability to care for another person is very common and typical for siblings of individuals with Down syndrome. Due to this factor, there can be trust between siblings.

Category 3: Change of values

The statements also showed that the sibling with Down syndrome had an impact on the different creation of life values during development compared to peers. The informants add that their outlook on life has changed, they can appreciate ordinary things more, and above all, they do not take health for granted. I1: *"Um, maybe I value health more, so maybe I can empathize with others..."* For I5, it is also an enriching factor that, thanks to her sister, she had the opportunity to meet other people and their families with Down syndrome. I5: *"At the same time, due to my sister with Down syndrome, I began to value health more, and probably influenced my overall outlook on life in a certain way..."*

Category 4: Access

Informants believe that they have positive relationships with their siblings with Down syndrome, which is also reflected in the approach and attitude with which intact siblings approach their siblings with Down syndrome. They try to approach them as equals and point out that Down syndrome has no effect on these attitudes and approaches. In I3, the attitude towards his brother is somewhat undecided, as he does not know how to deal with the fact that he has a brother with Down syndrome. I3: *"So now that I am in Prague, it's kind of normal. I approach him or, rather, I treat him normally, as I do other people. (...) Sometimes I have such explicit opinions that I wish he was not there... Then again, I have the opinion that I will not put him in an institution after all, when ours is no longer here. Well, so I am sort of moving between it now and I don't quite know how to approach it, that is, how to approach it."*

Category 5: Interaction between siblings

Another positive factor that influenced the relationship between siblings is the time spent together and activities, thanks to which siblings strengthened their relationships since childhood. Common activities mainly included playing, which took place alone without other peers. I1 and I5 commented that they still play with their siblings to this day. The exception is I4, who admits that he has a low motivation to spend and engage in joint activities with his brother due to less free time. I4: *"In my childhood, I had activities together with my sister, because my brother was born when I was eight years old... Then it was school or work again, so I did not come into contact with him that much, nor did I participate in those activities she did not get involved in..."* Regarding jealousy and envy in the sibling relationship, I2, I4 and I5 positively agreed that they never had a need to be jealous and envious of their sibling with Down syndrome. I4 and I5 did not need to develop this information in detail. The only minor exception is I1 and I3, with a hint of jealousy for greater parental attention to a child with Down syndrome. I3: *"Everything just fit him. I have always been the other."* A non-jealous approach to your sibling with Down syndrome is a positive factor that serves to encourage positive sibling relationships.

Category 6: Fixation

Intact siblings can sometimes experience a situation during their lives when they feel a greater emotional dependence on the part of the sibling with Down syndrome. I1 and I3 just agreed to fixate their brothers more than they needed. I1: *"He just really depends on me a lot lately... He just listens to me sometimes, but not to us..."* Too much emotional fixation on the part of a sibling with Down syndrome can lead to a disruption of relationships between siblings and give intact siblings a sense of loss of privacy, of being tied down, and a certain feeling of guilt and regret as he tries to establish certain boundaries and limits to his sibling.

Category 7: Feeling alone

As one of the negative factors, I1 and I3 stated that they felt lonely in childhood. This feeling may have been due in part to the fact that the siblings with Down syndrome have been in a weekly residential service in a home for people with disabilities since childhood and also to the fact that they do not have another intact sibling. I3: *"Well, I'm saying that I'm a half-only child. I'm an only child during the week and a sister on the weekend."* I2, I4, and I5 never felt lonely because I4 and I5 have other intact siblings, and I2 mentioned that he had a common program with his sister in childhood and thus never suffered from loneliness. I2: *"When she was younger, as she was at home during the week. So, we had the program together. When I was older, I had my hobbies and she had already lived in that institution."*

CONCLUSIONS OF THE RESEARCH INVESTIGATION

The main research objective and three partial objectives were fulfilled by answering the main research question, for which three partial research questions were set. The interviews and their analysis provided answers to partial research questions and met the set objectives.

The first partial objective was to find out how Down syndrome affected the family from the perspective of the intact sibling. The research question led to this: How did the child's Down syndrome affect the family? Each family of informants was affected in some way by their child's Down syndrome. The informants agreed that, due to the individual's Down syndrome, the family was cemented, strengthened, very open to each other, and even gained a new motivation for life. These facts are used to assume that the family is very dependent on each other and is fixed. The parents of the informants tried not to make any differences between their children since childhood and to provide everyone with as much love and understanding as possible, to be as close as possible as needed, to spend holidays together, and to participate in family events, which led to the basis of forming positive relationships between siblings and gave the intact child the feeling that he is an equal member of the family who is not copremoised in any way. Disruption of the relationship between parents and intact child appeared only in one case, when the mother made too high demands on her daughter and felt a certain necessity to take more care of her son with Down syndrome. The informants confirmed that both parents were involved in the care of siblings with Down syndrome, only some tasks were performed more often by mothers, while at other times, in contrast, fathers were given more space. Based on the research investigation, it can be assumed that the joint care of parents of a child with Down syndrome served as a certain model for the intact sibling to start intuitively participating in helping the sibling. The statements of the informants also revealed the fact that parents, when explaining their sibling's Down syndrome, chose such examples so that intact children of the given age could understand them. In some cases, when the intact siblings were older, the situation was explained immediately after the arrival of the mother and sibling from the maternity ward, in other cases the parents had to wait several years because the intact child was younger. When expectant parents receive a prenatal diagnosis of Down syndrome, they often wonder what impact this child will have on their other siblings. Researchers from the Netherlands (Korenromp, Page-Christiaens, van den Bout, Mulder, & Visser, 2007) surveyed 71 women who had terminated their pregnancy based on a prenatal diagnosis of Down syndrome, and nearly three quarters of them reported that the "burden" would be too big for their next child or children.

The second partial aim was to find out how Down syndrome affected the intact sibling itself. This led to a research question: In what way did a sibling with Down syndrome affect the life of an intact sibling? The life of an intact sibling alone can be challenging but also very rewarding, thanks to a sibling with Down syndrome. The first signs of awareness of the difference between siblings can only be expected after the 10th year of an intact child's life, when he is already able to better understand and perceive the Down syndrome of his sibling, as he grows on his own and is able to empathize with the whole situation. Informants observe that better empathy for others and greater acquaintance with other people with Down syndrome are among the enrichments of their lives thanks to their siblings. This enrichment could also have a partial impact on their relationships, which according to informants are very good and close. At the same time, they compare them to a normal, ordinary sibling relationship, which may mean that the intact sibling takes the individual with Down syndrome as an equal. The choice of study and, subsequently, employment for most of the informants was never influenced by their sibling Down syndrome. Only one case was the sister's Down syndrome a certain inspiration and model for the informant's choice of study. In relation to the environment, the informants never encountered a negative reaction directly to their sibling's Down syndrome and always sought a circle of friends and loved ones who positively accepted and were able to understand individuals with Down syndrome. As for the partners themselves, it was always important to the informants that they liked their siblings and, in a certain sense, could imagine a future with an individual with Down syndrome. The current regularity of contact is influenced by the fact that most of the informants no longer live together with their parents and siblings, but they still try to maintain a kind of regularity of contact every weekend. The near future with a sibling with Down syndrome is a topic that informants are already thinking about. They all agreed that they would be happy to take care of their sibling in any way they could when their parents could no longer. Some informants would choose homes for people with disabilities, where almost the majority of their siblings with Down syndrome are already or want to have them in their daily care. This fact indicates that the informants have a great feeling for the family. Cuskelly & Gunn (2006) pointed out the real benefits of having a sibling with Down syndrome. Siblings with Down syndrome showed more empathy and kindness towards their intact siblings, less conflict, and a warmer relationship. Siblings of a child with Down syndrome reported equal levels of self-sufficiency and self-care compared to intact siblings, leading the authors to conclude that siblings of a child with Down syndrome are not penalized for opportunities to participate in a normal childhood. As siblings age, many take on more caregiving roles compared to intact siblings. Siblings who take on additional responsibilities usually view this involvement as a positive engagement, rather than a burden. Furthermore, it was found that brothers assume the same responsibility as sisters who have a sibling with Down syndrome. Van Riper (2000) observed similarities rather than differences between siblings who have a sibling with Down syndrome and those who have an intact sibling. Parents of children with Down syndrome reported that their siblings had no more behavioural problems than intact siblings and no significant differences in social competence of siblings.

The third partial aim was to find out which factors could influence the relationship between siblings. This led to a research question: What factors could influence the relationship between siblings? It emerged from the statements of the informants that positive factors prevail over negative ones that could affect the relationship between siblings. Thanks to a Down syndrome sibling, intact siblings have developed new positive traits that help foster a positive relationship. These are independence and responsibility, which are some of the most common characteristics that appear in intact siblings. In addition to these qualities, the informants often also mentioned the emergence of new life values, where they first mentioned respect for health, valuing ordinary things, and a change in outlook on life. Then came the ability to care for another person. This positive factor is very important as it contributes to the overall interaction and affection of siblings. Given the relationship between the siblings, the attitude with which the informants approach their sibling certainly helped. They point out that they try to approach their siblings in a positive and friendly manner as equals, to be close to them and not spoil them. At the same time, all of these factors were supported by the time and activities that the siblings spent together and spent alone, which made their relationship closer. One of the negations that could affect the relationship between siblings is the excessive emotional fixation on the part of the child with Down syndrome. Several informants experienced feelings of loss of privacy and attachment due to excessive clinging to their siblings. They then added that they felt lonely in childhood. This claim may be based on the time when people with Down syndrome began attending a home for the disabled and the fact that they did not have another intact sibling. However, these two negative factors were not confirmed by all informants, but there is a probability that the informants could feel a certain restraint or modesty. Skotko, Levine & Goldstein (2011) focused on the feelings and perceptions of siblings of individuals with Down syndrome. The study results showed that intact individuals had affection for their siblings with Down syndrome, and older intact individuals also felt a sense of pride. Older siblings felt better people because of their Down syndrome siblings and planned to stay involved in their siblings' lives when they become adults. Most intact individuals described their relationship with their Down syndrome sibling as rewarding and positive.

RECOMMENDATIONS FOR SPECIAL EDUCATIONAL PRACTICE

The relationship between siblings of an individual with Down syndrome is a very sensitive topic. For some intact siblings, it can be difficult to talk about their sibling, so it is necessary to create conditions between them that suit both parties and give them as much a feeling of cohesion, equality, and closeness as possible. All of this depends mainly on the parents, as they are the closest people to their children. Therefore, parents should mainly communicate with their children about any problems, support each other, dedicate enough time to each other, but also turn to experts specialized in this field if necessary. Furthermore, parents should give intact children the feeling that they are not pushed away and not make too high demands on them, which would imply a kind of compensation for their own dreams and goals, but also compensation for their siblings with Down syndrome. Intact siblings should be involved as much as possible in joint life and activities with their sibling, as they are usually the only relatives and closest people who will care for their sibling in any way in the future. The experts themselves, specialized in this issue (social workers, psychologists, special educator) should be able to provide the family with such a degree of adequate support that the family learns to prevent problematic situations that could worsen the psychological state of their children. It is therefore recommended to create more awareness about this type of sibling relationship, where this information appropriate to the individual's age will be included, and at the same time to develop more such events where intact siblings themselves can meet, offer advice and share their experiences. Not only for intact siblings themselves, but also for entire families, it would be appropriate to create such programs where they have space to share their experiences.

CONCLUSION

Based on the analysis of the data obtained from the conducted research investigation, it was found that intact siblings occupy a proper and equal position in the family as their siblings with Down syndrome. The stated conclusion came from factors such as, for example, parents' efforts not to make any differences between children, to provide each of them with love, enough of their time, and to try to bond them as much as possible through joint holidays or various activities. During life, the relationship between siblings developed, when, from the initial lack of awareness of certain differences, they began to accept more that the sibling would lag behind the intact sibling in terms of their condition. The approach and attitude of an intact individual towards his sibling is like an equal when he strives for the greatest possible balance in their relationship. At the same time, they add their friendly, sometimes protective attitude to their surroundings. On the other hand, the surroundings of intact siblings accept Down syndrome siblings and the partners of siblings are positively inclined towards a relationship with individuals with Down syndrome. Intact siblings accept responsibility for their siblings and plan to ensure their care in the future, either in a social service facility or in the home environment.

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1.2 FAMILY AND TERMINALLY ILL CHILD FROM THE VIEW OF A SPECIAL PEDAGOGUE

Kristína Tkáčová and Terézia Harčaríková

Any family struggling with a serious-life-threatening illness of their child is essentially a “normal” family that is faced with an extremely stressful reality and is forced to cope with unique circumstances (Eiser, 2004). Experiencing cancer is a very unique family and individual experience that results in changes in a variety of areas. As Meitar (2004 in Kreitler, Arush, 2004) states, the family as a unit is shaken, each member is faced with a new reality and has to re-evaluate his or her own experience and relationships with other family members – parents with their sick child, with their other children, their relationship with each other as partners, and their relationship with their own parents. Siblings re-evaluate their relationship to their sick brother or sister and to other siblings, to their parents and grandparents; a child with cancer re-evaluates his or her relationship to parents, siblings and grandparents. Grandparents, on the other hand, have to face a new mission with regard to their own children, to a sick grandchild as well as to the healthy siblings.

No family is ready to fully prepared to accept that their child is sick. In a family with illness, all its members are affected by pain and suffering, which is reflected not only in closer but also in broader social interactions, and of course, also affects the quality of each family’s relationships. The family as a unit is shaken, each of its members faces a new reality, and must reconsider their own experiences and relationships. The authors consider it very important in relation to the presented issues to offer a special pedagogical view of the family and a sick child not only in the level of theoretical analysis, but also in the empirical level, where they present the results of research they carried out during their special pedagogical practice.

THE MULTIDIMENSIONAL DIMENSION OF THE FAMILY OF A TERMINALLY ILL CHILD

We tend to perceive the disease mainly from a medical point of view. However, it also has social, pedagogical, psychological and special pedagogical dimensions.

In *medical terms*, a disease can be characterized as any disruption of structure or function in the integrity of an organ (Crowley, 2014).

The disease mainly concerns the perception and attitude towards one's own disease. Due to the influence of the disease, social changes occur not only in the life of the individual, but also in the life and value orientation of the entire family.

The *psychological dimension* is also important, especially in terms of reactions to the illness and the acceptance of the reality of terminal illness by the terminally ill individual himself as well as by his family.

The pedagogical dimension is closely related to the education and educational rehabilitation of the terminally ill patient, not only in the school but often also in the family environment.

The special pedagogic dimension relates mainly to peculiarities in the education process and the necessity to modify and reduce the curriculum. It is also about the essential role and function of the special educator in working with the individual as well as working with the whole family of that individual.

Professional literature, primarily medical, deals with oncological and fatal diseases in children in abundance. It investigates the possibilities of diagnosis, treatment and medical support of such sick children. It presents the results of research in this area carried out in Slovakia and abroad. Considering the seriousness and nature of the issue, it is understandable, even necessary.

However, caring for a child with cancer – for an individual with cancer – is multidimensional. In addition to medicine, psychology, pedagogy other helping professions also play an important role. A child with cancer, like any other child, has the right to be educated to the end – in a hospital bed, in a children's hospice or in a family environment. Therefore, a special educator also plays an important role in comprehensive care. At the Department of Special Education of the Faculty of Education of Comenius University in Bratislava, we have also carried out research focused on the family of a terminally ill individual from the point of view of special pedagogy, mainly through diploma theses: An individual with an oncological disease in the context of pedagogy of the sick (Tkáčová, Harčaríková, 2014), Needs of a family with a lethally ill child (in special-pedagogical contexts), (Sojková, Harčaríková, 2015), The impact of muscular dystrophy, as a lethal disease, on the educational process of a pupil with this disease (Petriľáková, Tkáčová, 2016), Siblings of individuals with cancer (Baxová, Tkáčová, 2018), Education of individuals with cardiological diseases and its specifics (Demova, Mullerová, Harčaríková, 2018), Home education of individuals with the disease (Zakopčanová, Tkáčová,2020) Home education of pupils with life-threatening disease (Lokšová, Tkáčová, 2021).

ONCOLOGICAL DISEASE AND ITS IMPACT ON THE FAMILY

An incurable disease is a disease that leads to the death of an individual. These are all diseases that progress despite the use of available treatment procedures, they cannot be cured, or stop their progression (Jasenková, Mikesková, 2005). Based on the above information, it is clear that the term "individual with an incurable disease" means an individual with a fatal disease, while the term "lethal" is understood as deadly, life-threatening (Nagyová, 2015).

The family creates a social background for situations in which a person recognizes his illness, defines it, decides how to deal with it and how to communicate (Kapr, 1986 in Vágnerová, 1999). However, the family is also a social unit that is directly affected, limited and sometimes destroyed by the illness of its member. "Under the influence of illness changes, the roles and relationships of individual members change, sometimes also the overall lifestyle of the affected family, its values and norms" (Vágnerová, 1999, p. 58).

It very much depends on the behaviour of those closest to you as to how they will accept this change and what attitude they will adopt. The ill person attributes great importance to family members in making decisions and finding a way forward. Vágnerová (1999) believes that for the severely ill person, the family is the only social group that allows for acceptable social integration (which is accessible and manageable) and provides acceptable emotional support.

PARENTS OF AN INDIVIDUAL WITH AN ONCOLOGICAL DISEASE

Every parent has a natural need to bring a healthy child into the world. Parents view the child as an "extension" of their life. As Vágnerová (1999) claims, a sick child represents an unfair threat to a significant value, which for parents is the child's health. A child's illness is experienced emotionally from an adult's point of view because a small defenceless creature, who is just beginning its life, is suffering.

The birth of a seriously ill, disabled child or a child with a severe birth defect can greatly affect parents' self-esteem. If a child falls ill during life, parents may suffer from feelings of guilt and failure in their parental role. Mutual self-respect and the relationship of spouses can be seriously undermined by the birth of a child with a genetically determined defect. On the other hand, it can be the first impulse to think about the meaning of life and the values they gave priority to.

Parents may react to their child's illness with fear and anxiety, which are associated with a threat to the child's life. Parents certainly cannot come to terms with their own child's illness, at least in the beginning. This encourages them to develop active defensive reactions (Vágnerová, 1999). Parents want to fight for the child's recovery or at least try to improve their condition. They are convinced that the disease has to be fought, which is why, among other things, they are looking for social support – expert doctors and people who can support them emotionally and morally. They strive to have their actions positively acknowledged so that they can gain the necessary confidence and belief in a positive outcome. Parents' reactions to their child's terminal illness are individual, but most go through emotional reactions according to the stages as described, for example, by Kubler-Ross (1993).

Any illness interferes with the established patterns of the family, which has to deal with a new, unfamiliar situation. For the parents as well as the whole family, the announcement of the diagnosis comes as a severe shock, even if the parents "already knew something was wrong". The knowledge of a serious diagnosis causes anxiety and sadness in the parents, and they tend to defend themselves against these facts. The adaptation of a family with a child with cancer is never complete. As Říčan and Krejčířova (1997) claim, every deterioration in the course of the disease means a shock for the family, which is often many times greater than when the child's diagnosis is first announced. One of the most difficult things in a parent's life is accepting the fact that their child's life is in serious or critical danger.

And since the treatment of oncological disease is usually a long-term affair lasting several months or years, the psychological experience of the parents alternates between feelings and states of anxiety, depression and not infrequently the marital crisis itself. When the diagnosis is made, the first thing that occurs is shock, denial, and to varying degrees feelings of guilt, despair, and anger. Many times, parents experience a kind of numbness and disbelief at the imminent possibility of the death of their child, who until now has been full of life, energy, joy, and now they have before their eyes a weak, defenceless and suffering being. While for some, receiving a diagnosis is a disheartening confirmation of internal fears, for others, this knowledge can bring relief and a form of liberation (Lapwood, Goldman, 2012 in Goldman et al., 2012).

In these moments, it is not easy for them to divert their attention and thoughts to the ordinary things they have dealt with so far. Suddenly, they perceive only their own illness-related worries, and relatives or friends gradually fall by the wayside. Most of the time, those around the family try to understand the situation and help the family as much as possible, but if the cancer has been going on for a long time, it happens that contacts are cut off and only a few people are really left with the family. This state has a very depressing effect on the spouses, they begin to feel lonely, isolated and misunderstood by the people who have been close to them so far, which is very difficult to bear emotionally and psychologically. As a consequence, the intimate bond they have built up over the years can be seriously damaged (Aldridge, 2007).

The crisis also tends to appear in the area of faith and religion. If parents and other family members feel that not only God can, but that God will surely heal the child, the individual's faith is potentially compromised if the desired divine intervention does not occur. The parent therefore risks losing not only the child, but also the faith that could sustain him after the eventual death of the child (Macauley, Rushton, 2012).

Current research by Agbayani, Tucker, Nelson et al (2022) entitled Immunological and Psychosocial Functioning in Parents of Children with Cancer indicates that parents of children with cancer who were approached also reported poorer psychosocial outcomes: higher perceived stress, higher symptoms of anxiety and depression, more difficulties stemming from emotional problems, poorer general and mental health, and poorer social functioning.

Another recently presented research by Mohammadsalehi, Asgarian, Ghasemi et al. (2022), which focused on cancer resilience in parents of children with the disease, highlights that cancer resilience in families of children with the disease is significantly associated with higher social support, greater self-efficacy, and better general health. Intervention programs aimed at increasing family resilience and reducing stress by increasing social support and self-efficacy in patients' families are useful and necessary.

GRANDPARENTS AND THEIR ROLE IN A FAMILY WITH AN ONCOLOGICALLY ILL INDIVIDUAL

Grandparents are the ones who feel double the pain. The first is dealing with the pain of their own child, and the second is about their child's child – a grandchild (Aldridge, 2017). However, if the sick child has a sibling, the suffering increases even more, because the grandparents are worried and hurt when they see their other grandchildren also suffering from the consequences of the sibling's illness. Sometimes, they also feel a kind of detachment and a feeling of being unnecessary, especially when they are waiting for information about the course of the illness from their child, but their child, who is now also a parent, does not have the strength or the energy to explain all the details of the illness. Another reason may be the desire to protect grandparents from suffering and pain and so it happens that grandparents feel they are the last to know about their grandchild's condition. This is compounded by the fact that people try to protect themselves because they realise that in the stressful physical and mental situation they are in, they do not have the resources to manage their own emotions, let alone be supportive of their parents (Aldridge, 2017). However, according to the findings of a Brazilian study (Castillo, Bousso, 2016), it is very necessary to inform grandparents about the progress of their grandchild's illness and treatment. Being uninformed leads to more suffering and increases feelings of isolation and loneliness. Some grandparents are afraid that talking about the suffering with their child will make their pain even worse, so they choose to protect them from it by remaining silent. Others, however, based on the belief that close family members should share each other's burdens, look for possible means to help their children and grandchildren and thus find mutual support.

Many grandparents are overwhelmed with immense feelings of guilt and despair when their grandchild is diagnosed with cancer because they are alive, while their grandchild, who still has their whole life ahead of them, is in danger of dying. This situation leads to states of exhaustion, anxiety and helplessness (Lapwood, Goldman, 2012 in Goldman et al., 2012).

Scheinemann (2016) states that grandparents try to help their children by taking over the care of healthy siblings and giving them the time, love and attention that parents are unable to provide in a given situation. They may also spend time at the hospital with a sick grandchild or at outpatient appointments while one parent goes to work to secure funding for treatment and the other parent takes care of the other children and the household. It is not uncommon for grandparents to provide the family with financial assistance, which is much needed. Be it emotional or physical support, both of these make a big difference in a family's coping and quality of life.

It should also not be forgotten that grandparents, thanks to the wisdom gained through life experiences, can bring a different view and perspective onto the whole situation. Their perception of death has changed over the years, they no longer feel so much fear, they are reconciled to the mortality of man, and so they no longer treat death as their enemy. Many of them can bring to their children a different and deeper experience of the mysticism of life. For parents who are overwhelmed by daily worries and problems related to illness, grandparents can provide relief and peace of mind for their inner survival (Aldridge, 2007).

Research focusing on the role of grandparents of children with cancer in the hospital (Dias, Mendes-Castillo, 2021), identifies six categories of grandparent roles in the family with a terminally ill individual: To be a support to the family, to love their child and their grandchild, to be there for their child and their grandchild, to provide spiritual support to their child and their grandchild, to make efforts to manage their own feelings, and to balance the demands of hospitalization with the resources available to them. The research findings also highlight the importance of the role of grandparents in this experience and highlight the value of being seen by healthcare professionals as part of the family and care.

Kelada, Wakefield, Doolan et al. (2019) conducted research focused on grandparents of children with oncological disease – a controlled comparison of perceived family functioning. It is evident from the research findings that grandparents with a grandchild with cancer reported worse family functioning than grandparents with healthy grandchildren. Among grandparents with a grandchild with cancer, impaired family functioning was associated with fewer years since diagnosis, providing care to a sick grandchild and/or a healthy sibling, and living far from the sick grandchild. The inclusion of grandparents in interventions – starting with diagnosis – to reduce stress and increase family cohesion of a child with cancer is warranted, especially in the case of grandparents providing care to their sick grandchild or healthy sibling.

SIBLINGS OF INDIVIDUALS WITH ONCOLOGICAL DISEASE

Sibling relationships are often emotionally very complex, they include love, devotion, togetherness, but also rivalry and aggression in varying degrees of intensity. All these circumstances affect attitudes, experiences and adaptability to a sibling with an oncological disease. The occurrence of a serious or life-threatening illness in one child has enormous consequences for every other child in the family. This implies that when one child is ill, there are fewer opportunities for learning through sibling play, interaction and communication (Eiser, 2004). Other factors that influence this process are gender, the age of children, emotional and cognitive development, diagnosis and level of disability of a sibling, family relationships, mutual communication and social support (Murray, 1999). Siblings of individuals with serious or life-threatening illnesses are the most forgotten and emotionally overlooked group in the family. One child's illness can turn his or her siblings into "problematic children". Even after the possible death of a sick child, many parents do not manage to cope with the situation for a long time or resume their responsibilities.

Despite the fact that the oncological disease and its related treatment do not directly affect the healthy sibling, the dramatic physical changes they witness, such as hair loss, amputations or extreme weight loss, affect their psyche and everyday life. The family is stigmatized by a kind of otherness, and therefore siblings often find themselves in embarrassing situations full of frustration and fatigue over constantly answering incessant questions from those around them about the sibling's health status (Meitar 2004 in Kreitler and Arush et al., 2004).

Lapwood and Goldman (2012 in Goldman et al., 2012) further state that closed-mindedness and few questions asked about the ill sibling are not signs of disinterest or lack of concern. Parents are often so overwhelmed with caring for a sick child that they are unable to adequately meet the needs of their other children. Sometimes, in the desire to regain parental attention and favor, they start drawing attention to themselves with various false symptoms of oncological disease. A very frequent dramatic change in the family occurs when the mother goes to the hospital with the child, while the healthy siblings are taken care of by the father or another family member. The difficulty of this situation often causes healthy siblings to experience emotional and psychological isolation. This can then have an impact on their problematic behaviour, whether it is aggression or anti-social behaviour. In other cases, siblings try to be very responsible and behave according to the demands of their overburdened parents. It is not uncommon for older children to take on the parental role and responsibility for other siblings or even take care of a sick sibling themselves. Most of the housework is left to them. The anxieties and internal experiences of children growing up in a family where cancer is present are often manifested by psychosomatic problems such as interrupted sleep, bedwetting, abdominal pain and headaches, separation anxiety, constipation, back pain, weight loss or weight gain (Lapwood, Goldman, 2012 in Goldman et al., 2012).

Children and adolescents tend to fear the worst, not only regarding a sick brother or sister, but also their own health. Taiwanese researchers (Yang et al., 2013) found that if a child is hospitalized, siblings feel threatened by other patients in the hospital. They witness other suffering children, observe their changed appearance or even hear about the death of a patient whom they may have known from visits. Sometimes they believe that the medical staff is trying to kill their sibling. When well-meaning parents and members of the health care team try to shield siblings from knowledge and information regarding illness and treatment, such hiding of the truth often leads to even worse perceptions, feelings of isolation, guilt, and resentment in children. These concerns of theirs will never be resolved unless the closest family members or doctors discuss with the healthy siblings why individual procedures fail in the treatment. This is all the more important when siblings are to be tested for potential bone marrow donation. The reasons for the transplant should be explained, including the possibility of rejecting the graft regardless of its quality (Meitar 2004 in Kreitler and Arush et al., 2004).

Changes in routines and separation from individual family members experienced by siblings can lead to reduced social contact and impaired communication between parents and children.

One of the results of the study (Marques, Araújo, Sá, 2017) showed that the greater the impact of cancer on healthy siblings, the greater the impact of the disease on the entire family structure. Since the disease has negative effects on all aspects of life in the family, especially on healthy siblings, every change in the experience of this difficult situation affects all other members.

Research focused on the psychosocial functioning and risk factors in siblings of children with cancer (Long, Lehmann, Gerhardt, Carpenter et al. 2018) shows that mean levels of anxiety, depression and general adjustment are similar in siblings and comparison subjects, but cancer-related post-traumatic stress symptoms predominate. School-aged siblings show poorer school functioning and more absenteeism, but similar peer to peers relationships. Findings on quality of life are mixed. Risk factors for poor sibling adjustment include lower social support, poorer family functioning, lower income, and shorter time since diagnosis, but findings are inconsistent. Qualitative themes include siblings' maturity, compassion, and independence, but also strong negative emotions, insecurity, family disruption, limited parental support, problems at school, changed friendships, and unmet needs.

The research carried out by Baxová and Tkáčová (2018) focused on healthy siblings of individuals with an oncological disease points to the fact that in the desire for renewed parental favor and expressions of love, the sibling often reaches for different methods of attracting attention. Sometimes they fake symptoms of an oncological disease in the desire for parental interest, other times they are very helpful and caring, just to get praise and recognition from their parents. They have frequent psychosomatic illnesses, anxiety and depression, nightmares and increased sensitivity. The sibling usually gets the feeling of acceptance and the necessary daily routine at school, where the lessons and breaks spent with peers at least for a while divert his attention and the sibling can feel like they are a "normal" child again. However, many problems and complications are associated with school and preparation for teaching. Siblings show reduced concentration and attention in class, forgetting homework, missing classes, and poor performance. Another finding was the importance of communication and its very frequent failure in families with an individual with an oncological disease. The absence of communication leads to misconceptions and anxieties about the disease among siblings. Communication is especially important when a sibling is undergoing a bone marrow donation process, in which case poor information can cause minor or major psychological problems.

Research also shows that mutual separation when a brother or sister is in the hospital causes grief and sadness in siblings for the time spent together. On the other hand, it can be said that an even greater pain is the loss of parental attention and expressions of love, which is the most common source of anxiety and psychological difficulties in siblings. Parents are usually so busy taking care of an individual with oncological disease and providing financial security for the family, as usually one of the parents has to leave work, that they don't have enough strength and time to devote to their other children. However, this situation can be significantly improved by the efforts of parents to create special activities for other siblings or time spent together in which they would feel important and loved. We consider it very important to communicate openly, but age-appropriately, with healthy siblings. This avoids misinformation and misconceptions that siblings may get, for example, from the internet or from peers. The sensitive, understanding and attentive approach of teachers in schools is also very important, which can have a very positive influence on the siblings of individuals with oncological diseases.

One of the most up-to-date research studies Pariseau, Chevalier, Muriel, Long (2020) entitled Parental Awareness of Siblings' Adaptation: The perspectives of parents and siblings of children with oncological disease characterizes siblings' and parents' perceptions of parental awareness of siblings' psychosocial functioning and describes how family functioning influences parental awareness. Parents (N = 13) and siblings (N = 17, aged 8–17 years) from 13 families completed in-depth qualitative interviews regarding the siblings' psychosocial adjustment to cancer. Interviews were coded for dimensions of family functioning based on McMaster's model and analyzed using applied thematic analysis. Families were stratified based on a higher or lower level of parental awareness (ie, knowledge of the presence, severity, or content of siblings' cancer-related feelings). Parents' awareness was influenced by topics related to communication, affective involvement, roles, problem solving, and affective response. Parental awareness was hindered by siblings' reluctance to communicate their feelings to parents (eg, be positive/helpful), siblings' reluctance to rely on parents for emotional support, and parents not consistently asking about siblings' emotions. In addition, parental cancer-related stress and family disruption reduced parental attention to siblings and reduced parental tolerance for sibling negative emotions. Closer relationships before diagnosis, consistent communication and affective problem solving in response to changes related to oncological disease facilitated parents' higher awareness. The findings provide a more comprehensive understanding of the family processes underlying parental awareness and inform best practices for sibling assessment and support.

FAMILY AND ONCOLOGICALLY ILL CHILD THROUGH THE EYES OF A SPECIAL EDUCATOR

In addition to fulfilling individual developmental changes, educational care is an essential part of complex care for an individual with a disease, whether it is an individual with a favorable prognosis or an individual who is provided with palliative care. Educational care refers to the educational process at the time of hospitalization in the premises of the hospital and designated areas of the hospital or the educational process in the home environment (Nagyová, 2016).

Based on a review of the available literature and the aforementioned research that addresses the issue of educating students with terminal illness, we concluded that attention is mainly paid to the impact of illness and treatment on educational outcomes and intellectual abilities, while an essential part of education, which is the educational process, is neglected (Nagyová, 2016).

The main mission of the educator is to educate and enrich children with new knowledge, develop them and motivate them to perform better. Precisely because the life of terminally ill children is limited by a serious illness, it should be lived to the fullest and, if possible, in the same way as healthy children. The role of a special educator is irreplaceable in the education of sick children. The special educator should create favorable conditions for treatment, elimination of the consequences of the disease and other negative factors associated with hospitalization with special precisely-targeted pedagogic activities. Appropriately chosen special-educational interventions contribute to mitigating the negative consequences of hospitalization on children's personal development.

They often offer emotional and personal support to children as well as to their parents. They are the only ones to whom parents can turn to with their doubts and worries and to confide with about the fear and anxiety they are experiencing. They offer a listening ear to the parents and, it is not uncommon for the special educator to become a 'member' of their household. A dying child always deserves to be treated and raised as a child, and only secondarily as a dying child. Many incurable diseases cause the child to become isolated from the collective, including friends, and the question of education is also a controversial topic. As a result of an incurable disease, the child's physical and psychological condition deteriorates. According to Vágnerová (1999, p. 243), "educators should equally try to educate healthy as well as terminally ill children. Teach them everything they will need in life (no matter how short it is) and to pass on the knowledge they are interested in. Both healthy and sick children should be allowed access to education".

CONCLUSION

It is natural that quality and full-fledged cooperation of a special educator with a terminally ill child and his/her family requires time, to build a mutual relationship. We can argue that a child in the terminal stage of life no longer has an interest in the events around them, for example the desire to talk and play.

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1.3 THE IMPACT OF CHRONIC ILLNESS ON FAMILY QUALITY OF LIFE

Ľudmila Majerníková and Andrea Obročníková

PREFACE

In recent years, there has been an increase in chronic diseases, which are also affecting younger age groups of individuals at an increased rate. The family provides an important support system to the ill person and is undeniably important in helping with the problems of the ill member, which in the chronicity of the disease requires long-term support and hardship. The family as well as the quality of life of the relative is influenced by factors that we specify in more detail in the paper (type and nature of the disease, coping with the medical condition, self-management of treatment and care, occurrence of acute and chronic complications etc).

The word chronic means protracted, persistent (Vokurka, Hugo et al. 2006) and in the context of, or in conjunction with, illness we speak of chronic disease, which is the opposite of acute, sudden illness. Chronic disease is less abrupt than acute disease, its symptoms are present more or less permanently and can sometimes be barely noticeable (remission), but sometimes they worsen rapidly (exacerbation). Their persistent action can damage the organism and its organs, e.g. chronic kidney inflammation, chronic hepatitis etc. Some diseases are chronic from the outset, e.g. rheumatoid arthritis and some become chronic after repeated or untreated acute illnesses, e.g. smoker's bronchitis. The concept of chronic disease is not uniformly defined and conceptually anchored in contemporary medicine or nursing. Terms such as: chronic disease, long-term illness, relapsing illness, lifelong illness, are emerging. Křivohlavý (2002) lists terms that define long-term illness:

1. "Disease" – a term used for a nosological entity that has a proven etiopathogenesis as well as a therapeutic process; it is a classification of a disease from a medical point of view.

2. "Illness" – the term is related to the subjectivity of the disease carrier's condition. This includes the individual experience of the role of the sick person, survival, the sick person's view of what the illness is, the adoption of a value system and illness behaviour from the nuclear family; it is a classification of the illness from a psychological perspective.

3. "Sickness" – is a label for a condition in which an individual is in the officially defined social role of a sick person or patient; it is a classification from a sociological point of view.

Chrastina, Ivanová, Ježorská et al. (2012) provide two definitions of chronic disease:

1. an illness that requires at least six months of continuous medical care, causing permanent changes in lifestyle, behaviour and a constant process of adaptation to its possible unpredictable course.

2. an illness that is permanent or lasts for a long time and may slowly worsen over time. It may lead to death or may disappear completely. However, it may cause permanent physical changes and will certainly affect the quality of life of the ill individual.

Quality of life during the course of the disease depends on several factors, such as pain intensity, variability, duration and dynamics of changes in clinical symptoms of the disease. Many chronic diseases do not represent immediate life-threatening risk; they may be manifested by minimal symptoms but cause a gradual decline in quality of life (Nováková 2011). Chronic disease is a separate disease, it affects a person negatively, lasts for months to years, is diffused and has a cyclical course. The person can become depressed, and this negatively affects their quality of life. Kulichová, Jakubíková (2005) characterize a patient with chronic pain as **3D**, which means that they are **D**isabled, **D**epressed and abuse **D**rugs.

A chronic disease can worsen or reduce the quality of life physically, mentally and spiritually, as well as socially. In relation to the physical aspect, performance and independence can be reduced, and there can be an increase in fatigue, insomnia, appetite loss, nausea and obstipation. The mental life of the chronically ill patient can be accompanied by fear, anxiety, depression, suffering, loss of enjoyment of life and its meaning. In the social sphere, the person with chronic disease may feel that he or she is a burden to those around him or her, interpersonal relationships and sexual relations can be disturbed, and the person may become unable to fulfil normal social roles. Problems are compounded when the ill person has certain expectations and does not receive full emotional support or day-to-day technical support. The person may lose trust in those around them, become too self-reliant and socially isolated. A person with a chronic disease has specific dysfunctional needs that affect their lifestyle and limit them in different areas of daily life. The specific lifestyle with a chronic disease can become a dominant factor that influences the acceptance of the disease itself. Acceptance and coping with the limits of lifestyle with a chronic disease using coping strategies also influences the possible impact of the illness on a wide range of activities of daily living (Chrastina, Ivanová, Ježorská et al. 2012). The resulting, i.e., realized, lifestyle of individuals with chronic disease is based on a volatile confrontation with reality and life events that emerged with the illness and that persist and, depending on the condition, change or emerge as new ones in the case of chronic disease. Chronic disease, with its impacts, limitations and newly emerging needs, is seen as a major life change and alters not only the psychological, physical and social state of the ill person, but also affects the economy in both a broad (societal) and narrow (family) sense; in the case of children and young people, it also has an educational impact.

Chronic disease brings a long-term or permanent change in the individual's life situation, which complexly, secondarily, can affect the patient's status, social position, role and status. It is better for the ill person to try to find possible ways out, adapt to the situation, choose strategies that would help him/her not only to cope with the current situation, but also to try to influence it positively, using all their abilities, knowledge and possibilities so that their quality of life does not deteriorate further. Ondrivá et al. (2004) states that research has confirmed that quality of life is reduced by chronic disease, but many times it is reduced only in some of its components and stable or increased in others. Each step in a positive direction is a step toward greater patient well-being and possible physical healing success. We must also not forget the patient's relatives and loved ones who try to make sure that the patient's standard of living is at a reasonable level. It is desirable that they are the ones who are informed about how they can best help. It is to be expected that the subject of chronic pain will be encountered much more frequently by health professionals, and not only by them. The number of different types of cancer is currently on the increase, but even in the group of non-cancer diseases, chronic pain will be an accompanying symptom, such as spinal pain, where there is an upward trend. Chronic diseases such as diabetes melitus, multiple sclerosis and depression are also on an upward trend. It is important to note that chronic disease is more than a threat to physical integrity; it is a threat to one's self-concept and self-identity. The notion of who I am and what I wish to be changes and limits what I can still do. Chronic disease and the pain it entails has a negative impact on quality of life and is perceived as bad by the vast majority of sufferers. The patient's most important need is to be pain free. However, research shows that chronic pain does not affect social relationships (Gurkova, 2011).

OBJECTIVES AND METHODOLOGY OF THE PILOT STUDY

The aim of the pilot study was to compare the quality of life of the parents of children with type 1 diabetes mellitus (type 1 DM) to the standard population prevalence. In addition to this predominant aim, we set the following partial aims, which we will break down into 4 subgroups relating to the most common problems faced by the parents of children with type 1 DM in relation to diabetes self-care and the impact of type 1 DM on different domains within the family:

Partial Aim 1: To identify the most common problems of parents of children with type 1 DM in relation to diabetic self-care in the following areas: insulin application, dietary regimen, exercise regimen, self-monitoring (SMG) of glycaemic levels.

Partial Aim 2: To investigate the survival, and coping of parents of children with type 1 DM with their child's lifelong illness in the following areas: impact of the illness on the family home, impact of the illness on the parents' work area, impact of the illness on the family's budget, impact of the illness on the family's social welfare.

The pilot study focuses on the quality of life and diabetes self-care management of parents of children with type 1 DM For the study, we used in 1. Part 1 of the questionnaire- the standardized questionnaire of the World Health Organization WHOQOL-BREF (abridged version), which contains 26 Likert-type items covering 2 separate items assessing quality of life and 4 domains of quality of life.

Domain 1 Physical health, Domain 2 Experiencing, Domain 3 Social relationships, Domain 4 Environment (Dragomirecká, Bartonová, 2006).

For the research in the 2nd part of the questionnaire we used questions aimed at assessing the quality of life of parents of children with type 1 DM, in relation to coping with specific tasks related to the child's diabetic self-care. A total of 36 parents who have a child with type 1 DM participated in the entire research. The questionnaire designed for parents of children with type 1 DM was supplemented in part 1 with items related to demographic data of the respondents- age, relationship to the child, education, cohabitation of the parents in the household and their employment. In part 2 of the questionnaire the basic data of the child with type 1 DM- gender, age, duration of the disease and the level of the institution attended by the child with type 1 DM. It is important to note that the questionnaire was anonymous.

The representative sample of respondents in the research consisted of 36 parents aged 26 to 55 years, with an average age of 38.6 years. The sample included 32 mothers (89 %) and 4 fathers (11 %) of children with type 1 DM. Of these, 15 had children with type 1 DM and attended the Children's Endocrinology Outpatient Clinic, MEDIKARD, s.r.o. in Prešov.

RESULTS AND DISCUSSION

The pilot study was carried out using a questionnaire method in the children's endocrinological outpatient clinic MEDIKARD s.r.o. in Prešov, which was attended by a total of 36 parents whose average age was 38.6 years. Of these, 32 mothers and 4 fathers, who, based on their demographic data, most have completed secondary education with a graduation examination (maturita) and are not divorced, live in a shared household and are employed. They reported the gender of their children with type 1 DM in equal numbers for boys and girls. On average, the age category of children with type 1 DM fell mostly in the 6–10 year age range and as far as the disease duration is concerned it was most frequently in the 0–5 year range. The above stated findings show that most of the observed children with type 1 DM attend grade one of primary school.

The main aim of the study: *to compare the quality of life of parents of children with type 1 DM to the standard population prevalence.*

Based on our survey of the quality of life of parents of children with type 1 DM according to WHOQOL-BREF (short version), we assess the quality of life and its domains in comparison to the population norm as follows. The quality of life of SS is higher in SS compared to PN, suggesting that the parents of children with type 1 DM report a better quality of life than the general population, indicating that despite their child's diagnosis of a lifelong chronic disease, parents of children with type 1 DM have their quality of life well preserved. Domain 1 Physical Health, comparing SS and PN, we note a difference of not coping so well in SS, indicating that, albeit only to a small extent, the parents of children with type 1 DM in the physical domain areas experience some hardship in coping with daily or work responsibilities related to their child's lifelong disease. Domain 2 Survival, in the comparison of SS and PN, we assess the difference of better ability to cope in SS, which shows that in the individual items of survival, the parents of children with DM type 1, despite the lifelong disease of their child, know how to enjoy life, have a sense of what life is, know how to concentrate and are prepared for all the pitfalls that life will bring them, even in the context of the lifelong chronic disease of their child – DM type 1. Domain 3 Social Relationships, comparing SS and PN, we report a positive difference in personal relationships, feelings of security or support from friends for SS. This means that the parents of children with type 1 DM, despite their child's diagnosed disease, are not deprived in their social life, but on the contrary, they feel support and understanding from their loved ones. Domain 4 Environment, comparing SS and PN, we report the difference of better scores in the different domains of the domain for SS the parents of children with type 1 DM. This shows that the parents of children with type 1 DM have satisfactory access to health care, information, financial security or good conditions to engage in leisure activities, hobbies, despite the chronic disease of their child with type 1 DM.

Table 1: Evaluation of the raw scores of the quality of life domains

Raw score	Average (M)	Standard deviation (SD)
Domain 1 Physical health	14.35	1.98
Domain 2 Experiencing	15.29	2.75
Domain 3 Social relationships	15.30	2.98
Domain 4 Environment	13.92	2.37

The quality of life when comparing the study group (SS) and the population norm (PN), was higher in SS (3.97). Domain 1 Physical health when comparing SS and PN, was higher in PN (15.55). Domain 2 Survival, was worse in PN (14.78). Domain 3 Social relationships, was higher in SS (15.3). Domain 4 Environment, was higher in SS (13.92).

Table 2: Quality of life and its domains

Quality of life	3.97	0.70	3.82	0.72
Satisfaction with health	3.86	0.68	3.68	0.85
Domain 1 Physical health	14.35	1.98	15.55	2.55
Pain and unpleasant feelings	4.72	0.91	4.03	1.05
Dependency on medical care	1.64	0.83	4.16	0.95
Energy and tiredness	3.78	0.80	3.62	0.93
Mobility	3.58	0.76	4.27	0.84
Sleep	3.19	0.92	3.61	0.99
Everyday routines	3.67	0.86	3.76	0.78
Work performance	3.81	0.89	3.76	0.80

Domain 2 Experiencing	**15.29**	**2.75**	**14.78**	**2.43**
Joy in life	4.00	0.53	3.83	0.90
Meaning of life	4.31	0.62	3.86	0.85
Concentration	3.89	0.62	3.55	0.88
Physical looks acceptance	3.90	0.64	3.90	0.82
Satisfaction with oneself	3.83	0.65	3.57	0.76
Negative feelings	2.00	0.86	3.47	0.95
Domain 3 Social relations	**15.30**	**2.98**	**14.98**	**2.89**
Personal safety	3.68	0.71	3.24	0.79
Personal relationships	3.97	0.61	3.75	0.91
Sexual life	3.89	0.98	3.64	1.07
Support of friends	3.94	0.79	3.85	0.80
Domain 4 Environment	**13.92**	**2.37**	**13.30**	**2.08**
Environment	3.76	0.43	2.85	0.92
Financial situation	3.28	1.02	2.87	1.08
Access to information	3.83	0.69	3.87	0.77
Hobbies	3.34	0.98	3.33	1.00
Environment surrounding your home	3.81	0.80	3.54	0.86
Health care availability	3.50	0.97	3.70	0.79
Transport	3.75	0.87	3.19	1.07

n – number, M – average, SD – standard deviation,
populational norm* according to Dragomirecká, Bartoňová, 2006

Partial Aim 1: To identify the most common problems faced by parents of children with type 1 DM in relation to diabetes self-care in the following areas:

1. Insulin administration
2. Dietary regimen
3. Movement regimen
4. SMG glycaemia levels

When asked about the degree of coping with insulin application, adherence to dietary and exercise regimens, including SMG of glycaemic level, parents of children with type 1 DM overwhelmingly indicated the most frequent degree of coping in the responses of good and very good, indicating that in terms of the degree of coping with the given areas of diabetic self-care, parents of children with type 1 DM do not have a problem with it in most cases and manage this without much difficulty. Parents were asked to give their feedback and concerns regarding children with type 1 DM in relation to diabetes self-care as commented here: For insulin administration, the most common problem perceived by the parents was: *having to maintain* *timeliness and responsibility for administering this drug.* For adherence to the dietary regimen, the limiting factor which was perceived as a major challenge by parents of children with type 1 DM was: *the need to provide food in regular and precise doses.* In terms of adhering to the exercise regimen, the parents commented that: the fear that acute complications of children with type 1 DM during performance of physical activity by their child with type 1 DM. For the SMG of glycaemic levels, we investigated how many times a day parents of children with type 1 DM measure their children's glycaemic levels. Parents of children with type 1 DM most often measure their child's glycaemic level 6 times a day and visit a paediatric diabetes clinic at least once a month. They considered the financial cost of SMG devices and the frequency of SMG, or the child's reaction to the painfulness of the procedure, as limitations.

Partial Aim 2: How do parents of children with type 1 DM cope with their child's lifelong illness-type 1 DM in the following areas: 1. The impact of the illness on the family home. 2. The impact of the illness on the family's social sphere. 3. The impact of the illness on the parents' work area. 4. The impact of the illness on the financials of the family. We found that they felt the most support from their family and close friends. The financial burden was rated by parents as increased in terms of caring for their sick child, in terms of increased costs regarding a special diet, supplies for SMG implementation and insulin application as well as travel costs to see the doctor. The social domain was rated positively, with half of the respondents attending a support group for children with DM and their parents. The biggest positive aspect of using these services was the community support and advice they received during meetings. Parents' working lives were negatively affected by the fact that one parent in our study sample had to apply for reduced working hours to provide the necessary care for their child.

We compared the results of our study with the results of other available work focusing on the quality of life of parents of children with type 1 DM. Faulkner, Clark (1998, pp. 721–727) examined the quality of life of parents with children and adolescents with type 1 DM. In the study, parents of ill children had the greatest concern about the future, in terms of complications resulting from type 1 DM. In this study, the authors also found that parents of younger school-aged children reported significantly greater life satisfaction than parents of adolescent children. The Faulkner, Clark (1998, pp. 721–727) study also confirmed that parents with a good social background (with a focus on parents working and cohabiting) reported better life satisfaction and higher quality of life than those who were divorced.

The Slovak study conducted by Ovšonková et al. presents results measuring quality of life for both parents and children with type 1 DM, concluding that the overall quality of life measured in a subgroup of children was determined to be good. Girls and boys were shown to have the same level of quality of life. Children reported that they were most restricted in their diet and their greatest concerns were related to complications of DM, with girls having greater concerns than boys. Higher quality of life was demonstrated in children who injected insulin using an insulin pump compared to children who injected insulin by pen. Parents, like children, reported worrying about their child's long-term health problems as the greatest burden; caring for their child was the least burdensome. The majority of parents rated their children's health as good, as well as their quality of life.

CONCLUSION

The aim of comprehensive management of diabetes mellitus is to achieve optimal compensation of the disease and thus to create the preconditions for a better quality of life for children and their parents. By using quality of life assessment tools, the impact of the disease on the daily life of both children and parents can be identified and changes in quality of life can be observed after the implementation of appropriate interventions.

Quality of life assessment questionnaires can be part of a routine examination and can help to improve communication between the patient, family and health care team.

The scores obtained capture changes and individual responses to changes in treatment and should be discussed with the child/adolescent and parent and with the diabetes specialist, nurse, and possibly a psychologist. Specific quality of life measurement tools allow assessment of factors that are closely related to the disease and significantly affect the quality of life of the whole family.

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1.4 POSSIBILITIES FOR SUPPORTING A CHILD WITH VISUAL IMPAIRMENT AND LEARNING DISABILITIES AND THEIR FAMILY

Hana Ryšlavá and Zuzana Palounková

INTRODUCTION

A child with special educational needs is always challenging for the family. One of the causes of special educational needs can be visual impairment. In practice, visually impaired children are often diagnosed with learning disabilities more or less after the start of their compulsory schooling. Such a diagnosis further increases the burden on the family, both factually and psychologically, namely by devoting intensive time to re-education after school. The paper reflects on the possible links between visual impairment and the manifestations of learning disabilities. It provides suggestions on how to support the child and the family.

The paper discusses children with visual impairment (in the low vision range) and symptoms of learning disabilities (LDs). It is based on practical experience that shows that children with this specific combination of difficulties are increasingly brought to the attention of their schools, teachers, and parents. The children's parents are usually clients of school counselling centres themselves (these are usually special education centres for visually impaired children; however, they can also be pedagogical-psychological counselling centres). The parents contact these centres with a request for diagnosing and consequently confirming the presence of a learning disability. When a child with a visual impairment shows signs corresponding to learning disabilities, it can be challenging to distinguish the real cause of their difficulties. It might be unclear whether the symptoms result from a visual impairment or a learning disability. The experience has shown that this specific combination of difficulties is more likely to occur where the child has not received adequate educational support for their visual impairment.

In the first part of the paper, we define what we mean by visual impairment and learning disability and give the range we will be moving within. We recognise that the full breadth and all aspects of this issue cannot be covered in the scope of this paper, as the manifestations of each individual will be highly individualised depending on the type and degree of visual impairment and the type and degree of learning disabilities. In the next section, a comparison of the manifestations of visual impairment and learning disabilities, which are broken down by individual shortcomings of each sub-function, is made. This is followed by an overview of recommended approaches and options for supporting the child and their family. The issues addressed are illustrated by a short case study at the end.

DEFINITION OF VISUAL IMPAIRMENT AND LEARNING DISABILITIES

According to Hammill (1990, p. 81 in Pokorná, 2001, p. 72), learning disabilities can be defined as “a general term that refers to a diverse group of disorders manifested by significant difficulties in acquiring and using listening, speaking, reading, writing, and reasoning skills or difficulties in acquiring mathematical skills. These difficulties are based on the internal dispositions of each individual. They are thought to be caused by central nervous system dysfunction and can last throughout life. Problems in social adaptation, social perception and interaction may occur with learning disabilities but do not constitute a learning disability. Although learning disabilities may occur as a concomitant of other adverse conditions (e.g. sensory impairment, mental retardation, severe emotional disturbance) or external influences (such as cultural differences and inadequate or inappropriate teaching), they cannot be inferred from these conditions and influences”.

In this paper, we will focus on dyslexia and dysgraphia as two types of learning disabilities that are fundamentally affected by the level of visual perception. As stated by Jucovičová and Žáčková (2008, p. 13), “dyslexia is manifested by difficulties in reading, where reading is violated as an act in itself”. Individuals with dyslexia perform several typical, so-called dyslexic errors, which include the inability to follow the order of letters in words, mixing up similar letters, having trouble following a text (moving to a new line, keeping the eyes on the line), adding or omitting letters, syllables, or words, making up words or their endings, having difficulty controlling breathing, which has an impact on the intonation and melody of a sentence, and other manifestations. Reduced reading speed often influences the reading process as such, which results in low content comprehension. The child neglects the text’s content because of focusing on reading mechanics. Their general ability and reading level differ from one another. The child struggles with reading-dependent activities (Jucovičová, Žáčková, 2008, pp. 13–15).

The motor and sensorimotor weaknesses typically cause dysgraphic issues. These limitations impact the quality of written expressions as the writing appears unclear and illegible, letter joining is uneven, and size, shape and slant are not maintained. The child struggles to hold the writing on the line and keep to the edges of the page. A common phenomenon in children with dysgraphia is the incorrect holding of writing utensils or an unrelaxed arm when writing. Difficulties may also occur in visual memory, where the individual struggles to remember and arrange letter shapes. Dysgraphia is also accompanied by increased errors in writing, such as confusion of similar letter shapes, omission of letters or words, failure to follow the order of letters in a word, etc. Writing is often slow and not easy to read (Jucovičová, Žáčková, 2008, pp. 15–19).

Any child with an organ impairment of the eyes that causes difficulties, even if the defect is optimally corrected, is considered a pupil with low vision (Finková, 2011). The characteristic features are decreased visual acuity and even a visual field defect. Low vision can develop at any time during life. This paper focuses on pupils with low vision that arose prenatally or early postnatally. Low vision (mild, moderate, and severe) causes difficulties in everyday life in acquiring information through the visual route. It may be accompanied by other problems such as light blindness or colour blindness (Regec, Stejskalová et al., 2012).

Typical consequences of visual impairment in the low vision zone include sensory and, subsequently also, information deficit, disturbances in the development of cognitive processes, imagination, the need to adjust educational conditions, the impact on spatial orientation and independent movement (even if only slightly), inaccurate perception of objects and their details, poor differentiation of colours, letters, numbers and other symbolic representations, reduced concentration, weaker attention, slower work pace, faster fatigue, and sensitivity to visual hygiene (Regec, Stejskalová et al., 2012).

The visual function includes a variety of visual skills, not just the ability to see clearly. We will mention two of these skills – oculomotor (the ability of the eyes to move smoothly in all planes of the visual field) and binocularity (the ability of our eyes to work as a team allowing us to see one clear image and to change focus from far to near, etc.). The vestibular system and muscle tension directly support these skills.

Visual tasks such as writing or reading can be difficult for a pupil with difficulties in these functions. The child may get lost in text because their eyes jump or anticipate instead of moving smoothly across the line. They may have difficulty copying from the board, see double or distorted images, and may have eye pain or become tired more quickly. Reading can be challenging, exhausting and stressful for such a child. More practice without addressing vestibular difficulties and muscle tension can cause additional stress for the child and those trying to help them (Valenta et al., 2020, p. 164).

From the above, it is clear that certain sub-functions are necessary for mastering reading and writing, the sufficient development of which affects learning to read and write. In addition to the perceptual functions, we refer to the cognitive and motor functions (Jucovičová, Žáčková, 2008, p. 10). For this article, we will further focus on the functions of visual perception, motor skills, spatial orientation, and attention. The manifestations mentioned above are processed and sorted in a table.

COMPARISON OF SELECTED EXPRESSIONS BROKEN DOWN BY SELECTED SUB-FUNCTIONS

In this subsection, a comparison of selected manifestations broken down by selected sub-functions is made; see Table 1. For logical reasons, those functions directly connected with visual perception were selected. These are the ones where overlap or confusion of cause can easily occur.

Table 1: Overview of selected deficits in sub-functions in individuals with LDs (focusing on dyslexia and dysgraphia) and individuals with visual impairment in the low vision zone.

SELECTED SUB-FUNCTIONS		
Sub-functions	Intact function	Manifestations of LDs
Visual differentiation of figure and background	The pupil can recognise words and shapes (form) and eliminate words or shapes that are not essential (background).	The pupil is confused, considers everything on the page to be similarly important, or, on the contrary, cannot ignore unimportant information. They react from one stimulus to another or get stuck on unimportant details.
Visual analysis	The pupil can divide the whole text into parts and arrange the field of vision, i.e. distinguish words on a line or lines in a text.	Information blends and overlaps; it is impossible to register the exact details. The performance deteriorates when working with cluttered material that is overly detailed (typically, e.g. foreign language textbooks, workbooks).
Visual synthesis	The child can logically combine the components into a unit. For example, they can draw the missing parts of a picture, put together a word from letters, and put together a picture from several parts.	The idea of the whole unit is missing. The child cannot arrange the parts into a meaningful unit, finding it challenging to compose pictures. Difficulties manifest in reading (the child reads only letters or syllables for a long time), transcribing or describing the text.
Visual differentiation	The child can accurately distinguish between similar-looking stimuli, e.g. similar letters.	Similar-looking letters and other characters (shapes, pictures, objects...) are changed around by the child.
Distinguishing reverse shapes	The child distinguishes axially inverted shapes as distinct.	The child does not distinguish axially inverted shapes as distinct.
Visual memory	The child remembers the information acquired by sight and can recall it and use it.	The child finds it difficult to remember or recall information acquired by sight – letter and character shapes, figures and their parts, graphs, diagrams, maps
Orientation in space	The child understands that reading is from left to right and from top to bottom of the page.	The child skips lines, moves around the page unsystematically, sometimes reads words backwards, and fails to find where they are in the text quickly.
Attention	The child can focus on important stimuli and deliberately concentrate on them for a period of time.	The child cannot focus on important stimuli and deliberately concentrate on them for some time. They wander from one stimulus to another, focusing only for short periods, or fixate on a particular stimulus and are unable to shift attention elsewhere. Exercises requiring precision and care in execution are demanding.

Eye movement motor skills	The child fluently names and orders objects, symbols, and letters from the left. They fix them with their eyes.	The child gets lost in the text, skips words and lines, and returns to the part of the word already read.
Fine motor skills	The child can manipulate small objects, hold and functionally use writing utensils, and smoothly guide and coordinate hand movements.	The child cannot manipulate small objects, hold and functionally use writing utensils, and smoothly guide and coordinate hand movements. Graphomotor manifestation, including handwriting, is illegible and unorganised and may extend outside a defined space.
Gross motor skills	The child can coordinate the whole body and can plan and lead the desired movement.	The child has difficulty coordinating movements, appears clumsy, and often bumps into or drops objects and trips over obstacles.

As Table 1 shows, in many areas – sub-functions – the manifestations of visual impairment and learning disabilities are similar. Differences in the manifestations of individuals will depend mainly on the composition of deficits in each sub-function and the degree of these deficits, the type and degree of visual impairment, the degree of (in)support provided, and the individual's personality and general aptitudes. Functions developed above average in the individual concerned have the potential to compensate for the deficits to some extent, and thus they should also be taken into account. It should be clear from the above that establishing the causes of a particular child's difficulties can be quite challenging.

Given that we have so far concentrated on the similarities between the two groups of individuals (the visually impaired and LDs), it is also important to search for contrasts. The visual perception of individuals with specific learning difficulties may not be limited, it may be at an average level, but at the same time, other deficiencies not listed in Table 1 may occur. We are referring, in particular, to the whole area of auditory perception. The degree of development of the sub-functions that underlie the manifestations of LDs at school age can be well monitored as early as pre-school age. Given the child's age, targeted intervention can be used to develop sub-functions that show certain deficiencies. At the same time, all children should be provided with a range of varied activities that provide opportunities to develop all sub-functions. If we carry out developmental activities for a selected sub-function with a child, we may notice a gradual, albeit sometimes very gradual, improvement in that function. The same effect should be visible with expertly guided re-education of specific learning disabilities at school age.

The visual perception of individuals with visual impairment resulting from an organ-based visual defect is always negatively affected to a greater or lesser extent. Except for CVI (Cortical Visual Impairment), the problem is localised directly to the visual analyser. Suppose the visual impairment is irreversible (in many cases, progressive); no significant improvement can be expected when activities are implemented to develop sub-functions and re-educate specific learning disabilities. On the other hand, with optimally provided typhlopedic support, it can be expected that the child will experience no or minimal symptoms similar to (or identical to) those of LDs. Except, of course, for children with learning disabilities.

OPTIONS FOR SUPPORTING A CHILD WITH VISUAL IMPAIRMENT AND LEARNING DISABILITIES AND THEIR FAMILY

Regarding the support options, they are similar for individuals with learning disabilities and individuals with visual impairment. For individuals with LDs, we focus on manifestations and types of LDs (dyslexia and dysgraphia) that are linked to visual perception, motor skills, attention or memory (see Table 1). Individuals with visual impairments need enlarged and contrasting materials with good differentiation of figure and background. The material must be well structured and clear (without redundant details, notes, pictures, icons, etc.); appropriate font and background colour combinations can also help. Similarly, a pupil with LDs will prefer clear text, well contrasted and possibly with enlarged fonts, depending on the level of deficiencies in the area. For both kinds of pupils, a sans-serif font can be used. The text should be broken down into shorter and simpler sentences or paragraphs. The text can be supplemented with a picture, diagram or graph for better comprehension of the reading text. A bookmark is recommended for easier navigation in the text.

The pupil with dysgraphia should use wider-ruled notebooks, with the option of writing in larger print, auxiliary or slanted lines. They will benefit from writing and drawing utensils that leave an easy trace to relieve too much pressure on the writing utensil and keep the hand relaxed. This is precisely what will also help a pupil with a visual impairment. For them, it is additionally recommended to use distinctive writing utensils that do not easily bleed through (so as not to ruin the following pages).

Further, reducing the number of tasks, numerical examples, the amount of text, etc., is recommended due to the pupils’ faster fatigue and slower pace of work. Long copies or transcripts of text, classical dictations, and time-limited or competitive tasks involving visual perception are inappropriate for such pupils. It is important to remember that they should be given the opportunity to succeed in activities and tasks rather than being demotivated by frequent failure, which can be avoided by carefully selecting, thinking about and adapting activities, tasks or games that respect the pupil’s current level, build on their current aptitudes, exploit their strengths and work on their weaknesses. In addition, a pupil with visual impairment can use various special aids such as a folding board or magnifier and other optical aids.

Now, we come to family support. The information presented above makes it evident that a family who has a child with a visual impairment is exposed to many challenges. When it is suspected that a child with a visual impairment may also have a specific learning disability, the family come under even more pressure. Family support is essential in such a case. Firstly, professionals should help the family comprehend the nature and mechanisms of the difficulties the parents observe in their child. Further guidance should lead to the realisation that there are procedures available to improve the difficulties arising from LDs if the child is worked with systematically and over a long period. Considering the child's strengths while developing an action plan to strengthen the weak sub-functions is important. Similarly, it is necessary to select appropriate re-education procedures, techniques, strategies and aids to minimise the manifestation of learning difficulties and optimally promote learning to read and write. Additionally, this re-education procedure must respect the needs and specificities resulting from the visual impairment (see above for work principles). To promote quicker and longer-lasting improvement, the strategy should be the same at home and school, employing the same tools and procedures. Therefore, family involvement in this situation is both desirable and required.

Logically, the child's teacher should be the parents' first line of contact and support. However, their expertise in this field is often insufficient, and they are not entirely sure of the causes and nature of the child's difficulties and how to work with them. Therefore, in most cases, the teacher does not serve as a source for the parents; rather, they require it. The so-called school counselling centre members come into the picture at this point. In every school, this workplace is obligatorily staffed by an educational adviser and a prevention methodologist. However, even these workers might not be sufficiently skilled to work with children with these difficulties. Ideally, the school counselling centre should also employ a special needs teacher and a school psychologist (but these are not yet compulsory positions). And the special needs teacher is a professional who is (or should be) knowledgeable in working with pupils with learning disabilities. They have a great potential to support the teacher who is in daily contact with the child (to explain the causes and consequences, to suggest methods of teaching suitable for the child, to show the teacher how to apply the methods, to suggest modifications to the environment); the child itself (who can implement targeted re-education) and the child's family (to explain, to make connections, to recommend methods that can be used in homework with the child).

The school counselling centres and their staff play a significant role in assisting the child and the family. Special education centres for visually impaired pupils are most frequently involved if the focus is on a child with a visual impairment. They provide their services in compliance with Decree No 72/2005 Coll. on the Provision of Counselling Services in Schools and School Counselling Centres (as amended). The same legislative document also governs pedagogical-psychological counselling centres, where these pupils or their legal representatives can apply for counselling services. If we drastically simplify the whole counselling process, the result of such a service is an Examination Report and an Educational Recommendation. The Educational Referral, which outlines the child's unique educational needs and how to address them, is what binds the school to those needs. We believe the counsellor who worked with the child and produced the suggestion should provide a vocal statement alongside the educational recommendation. Ideally, this comment should be offered in person during the counsellor's consultation in the school. Only there will they have the chance to observe the child's learning environment, the educational tools used, the child's team, and the teacher. In addition, the counsellor can learn more about the applied teaching methods. Of course, each of these elements is equally important.

Utilising the services of private special education counselling facilities is the final choice, in addition to parental self-help. However, in this case, the availability of these services and the fact that they are fee-based may be a major obstacle. Families that must go to a larger town where these therapy institutes are typically located because they live in a smaller town or village, and those that are financially not well-off and unable to pay for such a service will be at a disadvantage.

CASE REPORT

A boy with congenital bilateral glaucoma was born in August 2012. The vision was reduced bilaterally in the zone of moderate amblyopia. He first visited the special education centre for the visually impaired (hereafter SPC) in October 2016. On the recommendation of the treating neurologist, the mother requested an examination and the issuance of an Educational Referral. Appropriate preschool provision was also addressed. There was a preschool in the place of his residence which was willing to accept a child with visual impairment. The preschool already had experience in this area. There were more children with visual impairment. The kindergarten was in regular contact with the SPC and used methodological guidance. The primary recommendations for the kindergarten were to enlarge materials, boost contrast, use distinctive contours of pictures, and distinctive writing utensils. The boy's educational requirements were fully met. Additionally, he attended consultations at the SPC (these have a re-educational focus) more or less regularly.

In January 2017, the kindergarten informed the centre that the family had moved to another town, but the mother herself had not reported this to the SPC. Since the family's whereabouts were unknown, the SPC's assistance was halted until April 2018, when they returned to their original residence and contacted the SPC again. When the assistance was interrupted, the boy did not attend any kindergarten. Upon his return, he had the opportunity to start attending the original kindergarten. It was clear that during the interruption, the child's needs were not fully addressed (he did not have visual material that corresponded to the specifics of his visual perception, significant writing needs, and no training in functional strategies for visual work,...); the mother confirmed this. The boy's vision had also deteriorated, and he had no adequate spectacle correction. In 2018, the boy turned six, and a school maturity diagnosis was carried out, which led to the recommendation to postpone schooling for one year. The boy's academic performance was within the norm. The mother was in favour of the schooling deferral, and the boy remained in kindergarten for the next school year. There, his needs were once more fully satisfied, his preschool skills were targetedly developed, work on the development of partial functions was done, and functional strategies for visual work were acquired, which was necessary for school education.

In 2019, the mother and the boy visited the centre several times. The mother was discussing which school to choose for the child. The boy was well prepared for the start of school. He began attending a mainstream primary school near his home in September 2019. Supportive measures such as a teaching assistant and suitable aids (a folding board, notebooks with wider bold lines, a magnifying glass, bold writing and drawing materials) were provided. The SPC was in contact with the school; consultations took place at the school and SPC. The boy was coping with the demands of the school; his letters were fixed correctly, and his reading performance on appropriately modified texts complied with the first half of first-grade requirements. The work pace was naturally slow; the boy got tired quickly. Homework was significantly limited due to the family's resources.

In January 2020, the family relocated again to a different region of the Czech Republic. The mother again did not inform the SPC about this fact. The SPC contacted her and offered help with the boy's new school (which was immediately provided). The SPC emphasised the importance of the mother contacting the school counselling centre in her new residence and asking for assistance in setting up support for her son in his new school. Unfortunately, this school was ultimately out of the commuting range of the original SPC, and therefore the boy's support was terminated for the second time.

In June 2020, the mother notified the SPC that they had moved to another (different) city, but it was already accessible by car from the former SPC. Thus, the cooperation was restarted after the six-month hiatus. According to the information available, the boy had been absent from school frequently during the previous six months, and little to no support had been provided for his visual impairment. The skills acquired at the school where he started school largely had disappeared over time, and no new skills had been acquired. As a result, the boy did not know all the alphabet letters at the end of first grade, and for those he knew, he miswrote them and read below the grade level.

The boy underwent counselling at the school and the SPC during the autumn while attending this school for the entire second half of second grade. In January 2021, the mother contacted the SPC stating that the family had relocated again to the very original place of residence. With the support of the SPC, it was possible to find a place for the boy in a mainstream primary school in his place of residence. He started there again with the best support possible (teaching assistant, complete equipment with aids for a pupil with low vision, special education course, the teacher's and teaching assistant's methodological guidance). The following school year included regular consultations in the school and re-education consultations in the SPC. The handwriting was still challenging to read, but effort fully implemented, an agreement was made to use only capital letters. Nevertheless, letters were written slowly and with errors without adhering to linearity. Reading was only possible on enlarged text (ideally 36 pt. size), non-fluent, line retention was difficult, and comprehension was minimal. He confused similar letters, shapes, and symbols, worked chaotically with unorganised material, and needed help finding what was required. He struggled to meet the teacher's requirements. His attention span was short; he became rapidly exhausted.

In June 2021, the teacher contacted the SPC to say that the boy unquestionably had a learning disability and that an immediate diagnosis was required to confirm these disorders. At the teacher's request, the mother asked for the boy to be examined at the SPC…

CONCLUSION

The paper highlights a relatively common problem when a child with visual impairment in the low vision zone starts to show symptoms of learning disabilities. It draws attention to the need for consistent provision of educational support based on the premise that the symptoms of learning disabilities may overlap with the effects of visual impairment, mainly where the child is not supported in relation to their impairment. It offers an overview which shows that reasonably targeted support can help a child with a learning disability and a child with a visual impairment in virtually the same way. The issues addressed are illustrated by a short case study at the end.

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2

ASPECTS OF EDUCATION IN THE DEVELOPMENT OF A CHILD IN A SOCIALLY DISADVANTAGED ENVIRONMENT

2.1 ANALYSIS OF A CASE STUDY OF A PUPIL FROM A SOCIALLY DISADVANTAGED ENVIRONMENT

Eva Zezulková and Helena Říhová

INTRODUCTION

According to many studies, compulsory pre-school and school education and upbringing have a higher added value if the child's family is also worked with, which at the same time strengthens the family's orientation towards the child's education and development. At the same time, research from the Czech environment shows that part of the school failure of children from disadvantaged backgrounds is related to inadequately addressed psychosocial risks or factors, such as unstable or non-residential housing for children.

The paper presents a case study of a pupil with a mild mental disability from a socially disadvantaged environment. Attention is paid to the cooperation of the school with the family and other professionals in order to reduce risky behaviors and support the motivation to learn. It describes the unsatisfactory family environment and the educational approaches of the parents, which act as a strong demotivating factor in the development of the pupil and further points to the low effectiveness of the support provided by the school and other cooperating institutions.

The Czech Republic is among the countries with the greatest educational inequalities, caused, among other things, by the low ability of the education system to equalize the social status of the family and motivate pupils to achieve higher levels of education. A related long-term problem is involving the family in the educational process, supporting the responsibility of parents in care and upbringing and their role in education. The priority goal of the Education Policy Strategy of the Czech Republic 2030+ is therefore *to strive to reduce inequality in access to quality education and to enable the maximum development of the potential of children, pupils and students*[1]. It is necessary to strengthen the cooperation between the family and the school both by educating of pedagogues and by methodically supporting of school councils, improving information and increasing mutual trust. Schools and teachers must be professionally prepared for effective communication with parents with an emphasis on understanding the positions of all participants in the education system, their rights and obligations. A higher

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[1] https://www.msmt.cz/vzdelavani/skolstvi-v-cr/strategie-2030

level of understanding is a prerequisite for reducing the risk of conflicts and at the same time meeting the needs of specific families.

An important trend is the area of *integrated rehabilitation*. In the interdepartmental area, it is necessary to pay increased attention to early education of parents of children and pupils from disadvantaged backgrounds, so that they are aware of the importance of pre-school and quality basic education and, in cooperation with the school, support their children on the way to developing the competencies needed for life. In order to strengthen the prevention of problems and timely work with families, it is necessary to support the connection of services in the social field (social and legal child protection departments, social service providers, etc.), healthcare (child psychology, pediatrics, etc.), municipal services (provision of apartments, etc.) and non-profit organizations (dealing with solving social problems, over-indebtedness, home tutoring, support of parental competences, etc.).

According to the Social Services Act[2], which regulates the conditions for the provision of help and support to natural persons in an adverse social situation, every person is entitled to free provision of basic social counseling on the possibilities of solving or preventing an adverse social situation[3]. Assistance must be based on the individually determined needs of persons and motivate them to activities that do not lead to the long-term persistence or deepening of an unfavorable social situation, but strengthen their social inclusion or act as a prevention of social exclusion[4] (Bartoňová, Vítková, 2015).

A CASE STUDY OF A PUPIL WITH A MILD INTELLECTUAL DISABILITY AND HYPERKINETIC SYNDROME, GROWING UP IN A SOCIALLY DISADVANTAGED ENVIRONMENT

Considering the case study presented below, we will give a brief definition of the basic terms.

Mental retardation, or mental disability, is a permanent decrease in intelligence due to organic damage of the brain. Retardation cannot be treated, because it is not a disease, but a permanent physiological condition (limited development of mental abilities, different development of some psychological characteristics, disorders in the ability to adaptation). Individuals whose mental development has been limited for reasons of other than organic

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[2] Social Services Act No. 108/2006 Coll. in the current version available from: https://www.zakonyprolidi.cz/cs/2006-108

[3] § 37 paragraph 2 of the Social Services Act No. 108/2006 Coll. in the current version available from: https://www.zakonyprolidi.cz/cs/2006-108

[4] social exclusion refers to the exclusion of a person from the normal life of society and the impossibility to participate in it as a result of an unfavorable social situation

brain damage (for example, due to the influence of the social environment, the impossibility of education, etc.) and show an IQ of 70 or more are considered to be mildly mentally retarded, but not for clinical reasons (Švarcová, 2006; Valenta et al. 2018). Mental retardation is a general reduction of below-average intellectual abilities that occurred during development and is accompanied by one or more disorders in the areas of maturation, learning, and social adaptability (Lechta, 2010). According to M. Bartoňová (2007), the main features of mental retardation are mainly a low level of mental abilities, which is mainly manifested by insufficient development of thinking, limited learning ability and, as a result, difficulty adapting to normal living conditions. The disability is permanent, although some improvement is possible depending on the etiology. The upper limit of achievable improvement for an individual is determined by the severity and cause of the disability, but also by environmental influences, i.e. educational and therapeutic influences.

Attention Deficit Hyperactivity Disorder (ADHD) is a disorder with a biological cause. ADHD is a common neuropsychological impairment that is mainly reported in children of preschool and younger school age. Children cannot concentrate on both playing and learning for a long time. They want to be the center of attention at any cost, they are impulsive, they don't think about their behavior, they don't enjoy anything for long. They don't have many friends because they are mostly unable to handle the rules of age appropriate social behavior (Škvorová, Škvor, 2003; Valenta, Krejčová, Hlebová et al., 2020).

Social disadvantage is a category denoting a wide range of causes of school failure of pupils due to non-health reasons, which have a cause outside school in the child's natural social background or stem from other life circumstances in children's lives outside the school grounds. These facts cannot be influenced by the child and become a burden for them in another social reality, in our case in the school environment. Social disadvantage is a very broad category, which is defined both in theory and in practice always a little differently, according to the interests, experiences and goals of the person who defines the term (Fischer, Škoda, 2008; Michalík, Baslerová, Felcmanová, 2015).

The presented case study is revised and supplemented based on the case study of Mgr. Helena Říhová, who was the pupil's class teacher for four years. Throughout this time, she cooperated with the family, a child psychiatrist[5] and other helping institutions. The case report describes the development of a student with a mild mental disability and hyperkinetic syndrome who grows up in a socially disadvantaged environment. It maps the influence of the family environment, the school environment and the action of helping institutions in the course of the student's life so far. The starting sources for compiling the case report were the pupil's school documentation, the analysis of the pupil's long-term observation and the conclusions of the communication with the interested experts of the helping institutions, the pupil and his family.

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[5] child psychiatrist

Basic information about the student

The 15-year-old boy is in the eighth grade, completing the 9th year of compulsory schooling. Physically healthy, fluent communicator, oriented. Diagnosed with mild mental retardation, hyperkinetic syndrome, speech defect. Throughout his actions in the classroom, the student strives to be perceived by the teacher as a person with an exceptional position in the group of classmates.

Family history

The family has been living in one city the whole time, but within the city it has moved repeatedly, always due to a deteriorated social situation, its material and social level has gradually declined. Currently, the family lives in a 2+0 apartment unit in a dormitory in unsatisfactory hygienic conditions. The mother has a basic education and is currently on parental leave with her youngest child, who is 2 years old. She has never been employed for a long time, she takes care of her family. She is prompt in communication, has good verbal expression with a tendency to dominant expressions, acts arrogantly in a conflict. She expresses herself in writing with minor grammatical errors, legibly, with a good ability to express an idea or request. As the only legal representative, she is the main person in negotiations concerning the pupil. The mother says in public about her son that *"he is an adult, he must be responsible for himself, I have other children"*. The stepfather is a trained bricklayer, lives with the family for a long time and participates in the education of the pupil. Although he has health problems, he tries to work, he is employed occasionally on construction sites to contribute to the family budget. The father involves the pupil in men's household chores. The student respects him within the limits of the norm, considers him a role model. His own father appeared only briefly in the boy's life, the pupil remembers him vaguely. The family uses available state support benefits. All family income is spent by the parents on housing and food for the children. Four adult offsprings of the father and four already adult offsprings of the mother live outside the family. One of the mother's other offsprings is placed in institutional care for health reasons. There are 7 siblings living in the family, the described pupil is the oldest of them.

The family has been in the care of the Department of Social and Legal Protection of Children (hereinafter DSLPCh) for 15 years, and for the same period the family has been assigned a field social worker of a non-profit organization who cooperates with the family. It helps parents with the processing of documents for authorities and doctors. He accompanies them to meetings with schools and authorities, tries to ensure health care for children and parents, reminds them of meetings and important dates. Other non-profit organizations and organizations dealing with the low-threshold use of children's and youth's free time also work closely with the family. The pupil also attends this with his siblings. He himself is often invited to weekend and residential trips. Cooperation with the family also takes place within the framework of community support and one-off material or food aid.

Personal anamnesis

The student was born healthy, as his mother's fifth child. He has also been raised by his stepfather since childhood. He did not suffer from any serious illnesses. The student is thin and tall, overall he is clumsy. Movements are less coordinated, fine motor skills are good, he likes to draw. He has a speech impediment and an overbite that causes impaired expression in places. The student has the status of the oldest sibling in the current family and a high degree of independence is required of him in dealing with all real-life situations. Until recently, a great deal of responsibility for the younger siblings was transferred to the pupil. By taking care of his siblings, he attracted some of his mother's attention. He was always nice to all his siblings. Strongly fixated on his mother from early childhood, he always demanded her attention fiercely, but with each additional sibling, her attention to her son has weakened. The student learned to attarct his mother's attention to himself in two ways; on the one hand, an intensely positive relationship with the youngest sibling, whom the mother cares for the most; on the other hand, a defiant, domineering and aggressive behavior towards the mother. He demands that she serve him, and disrespects her. The student is under the care of a pediatrician, a special pedagogic center and a child psychiatrist.

Anamnesis of the school environment

The student did not attend kindergarten. At the age of six, he was enrolled in elementary school, but it was decided to delay it further and the student was enrolled in a preparatory class. He always joined the class easily, he was welcoming and friendly to his classmates, but he didn't seek them out himself. If he fixated on a peer, it had to be a strong personality, at least outwardly successful and admirable, often from a significantly better economic background. From a very early school age, he was very accommodating to the point of being servile, helpful and fiercely diligent towards teachers and all adults. He tried to accommodate, to be liked, praised and accepted. He was always willing to cooperate and participate in everything for acceptance. Due to his almost exaggerated efforts to have good relations with adults, he was not well accepted by his classmates.

Description of the pupil's educational problems

Although the student graduated from the preparatory class, he was not successful in the first year and had to repeat it. He was repeatedly praised for his behavior (work for the class, involvement in joint activities, effort). At this time, fits of rage also appeared for the first time, significant psychomotor restlessness manifested by involuntary movements, impaired verbal expression, inability to concentrate. In case of failure, then by aggressiveness, which manifested itself in relational behavior (he still felt that he was being mocked). At home, he then caused trouble for his mother, refused to go to school, cried, got angry. The mother always solved the difficult situation by changing schools. During his attendance at the 1st grade, he gradually changed three elementary schools. He was repeatedly hospitalized in a psychiatric hospital without any concrete result. He failed again in the fourth year. He was diagnosed with mild mental retardation in the educational and psychological counseling center. Subsequently, he was transferred to the care of a special educational center for the mentally disabled and from the fifth grade he is educated at a primary school with a modified educational program established according to § 16, paragraph 9 of the Education Act[6].

After transferring to a school with a modified educational program, the student joined the group of the fifth grade class relatively smoothly. At first, the student was relieved and calmed down, because the school's demands on him were significantly reduced. At the same time, however, there was a dip in the family's financial situation, which led to an increase in tension. The student became an almost full-time guardian of his two younger siblings who attend the same school. He accompanied them to school every day, and from school they all left together to the low-threshold center, where they stayed for various activities until late in the afternoon. After dinner together, they went home around 6 p.m. The student's daily activities were therefore organized by adults to whom he clung, he tried to have good relations with them in order to be accepted, but who did not accept his specific developmental peculiarities. After the adaptation period, which lasted about one month, the pupil's behavior deteriorated significantly. There were manifestations of oppositional defiance not only towards classmates, but especially towards adult authorities (teachers, janitor), vulgar and disrespectful behavior towards these persons. For no apparent reason, he acted aggressively against female teachers and students. He attacked the pupils verbally and physically, again he felt that he was not accepted. He could not handle any stressful situation. The mother was called to the school, who confirmed that the situation was bad at home as well, but she could not describe the cause. She refused to actively address the situation, pointing out that she had other children who needed her. She appealed to the necessity of her son's self-control. However, he was not able to do this. When asked, the mother confirmed that the boy has medication, but does not want to take it. She herself said that her son likes best when he can go shopping alone with her or when he gets up early enough in the morning to have his mother all to himself.

The school's approach to solving the situation

The school became actively interested in the situation in the family, initiated the establishment of close cooperation with DSLPCh, whose staff, however, showed the family as socially very weak, but the parents as extremely cooperative, because they do not use addictive substances and take care of their children to the best of their abilities. After several more affective attacks by the pupil, an attempt to run away from school, repeated short-term absences out of defiance, at the request of the school, DSLPCh arranged contact with a field social worker of a non-profit organization that had been working with the

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[6] https://www.msmt.cz/dokumenty-3/skolsky-zakon

school for 12 years. This person was accepted by the student's mother and was a mediator for communication. She also had the most information about the family situation. Contact with the social worker revealed that the boy is strongly fixated not only on his mother, but also on his belongings, which he tries to protect. He likes nice clothes and his place. Due to the significantly worsened financial situation, they had to move to a hostel, where a family of nine got a 2+0 apartment to use. The student lost almost everything. He did not have a key position in his mother's family, he had to take care of his younger siblings all day long, except for school snacks, a cold dinner together in a low-threshold center and a second cold dinner at home, he had no food. He also lost the opportunity to have his own place in the apartment.

Based on this information, the school took steps to provide subsidized lunches for all siblings. This turned out to be important, the pupil looked forward to the meal, knowing that he could lose his subsidized lunches if he did not behave in an acceptable manner. Failing to ensure that the mother takes the younger sibling to school alone so that the pupil had time before school starts for his own peers and his schedule. However, behavioral problems persisted. They weren't that frequent anymore, but they always appeared for seemingly no reason. The student no longer chose classmates to attack, but only verbally attacked adults. He insulted them very vulgarly, deliberately verbally attacked the family members of the teachers ("*let your stinky children suck*", "*let her be licked by the old man if she can handle it*", "*is your fucking mother still alive*?", etc.). Sometimes he came to apologize the next day, sometimes he cried, changes in behavior happened like "turning a knob". The mother repeatedly refused to medicate the student at home because she had difficulties with it, she did not care about medication at school.

All these incidents were recorded and DSLPCh was again informed. The school was repeatedly informed that the family is being worked on and that the pupil needs a friendly approach. In the end, the field social worker managed to convince the mother of the necessity of medication at school. The school contacted the child psychiatrist and sent him a comprehensive report. The child psychiatrist was extremely helpful, providing information about the medication. When it turned out to be too strong because the student slept through almost the entire lesson, he allowed it to be adjusted for a trial period. The student then used this adjusted dosage for more than two years.

Seizures kept happening, mostly in September and October of the school year, and then randomly. Based on observations, it was discovered that autumn seizures are caused by the use of medication at school. The student did not take medication during the entire vacation, and after starting school there was an "invasion" of the active substance, which in the first weeks was always associated with unpleasant feelings of fatigue and lethargy. Once the active substance level became stable, these conditions were resolved. The second trigger always turned out to be a problem in the family, often financial. Long-term low incomes turned out to be less of a problem, a worse situation occurred with irregular incomes. For a while the family "enjoyed" and then vegetated. The student did not tolerate these changes extremely well, and this is still the case today.

For almost two years, it was possible to correct the situation and estimate the development. In the second half of the seventh year, however, there was a significant deterioration. There were most likely three triggers. The first was the birth of the youngest sister. After a very short time, the pupil found that he could no longer get his mother's attention. The second was the family's unaltered hope of obtaining rental housing in the family home. The student was very fixated on this idea, but the father ultimately did not agree to the change, because the place of his new residence did not have adequate transport services and there were no civic amenities nearby. The third for the student was the significant event of reaching the age of fifteen, which he was fixated on. He promised himself independence, imagined this constantly, but nothing actually happened. The student was so disappointed by all the described events that he stopped going to school, and used to have tantrums at home. His mother punished him by rejecting him, she didn't want to make amends, she didn't write the school any apology notes. As a result of unexcused absence, the student lost subsidized lunches.

The student is successful in school. He belongs to the better class average. School results matter to him, and he is willing to work hard for them. He is driven by the vision of immediate positive evaluation. He gets along with the teachers, fulfills his duties. He is regularly examined in a special educational center for the mentally disabled, always with good results. The support measures are well set and the pupil experiences success at school. He also participates in various competitions. He is actively involved in social gatherings and the cultural life of the school. He is excellent at verbalizing his needs, he can accurately describe and theoretically solve situations so that they are not conflictual. He knows how to behave, what the set rules require, how communication and relationships between people should look. However, he must be completely calm, this is how he describes the situation and sets up a solution in order to win praise and be successful at school. However, he cannot apply model situations practically. The school is in written contact with the child psychiatrist, informing him about the development. Medicines are prescribed by the mother of the pupil. However, they do not always show up for the scheduled check-up.

Unfortunately, cooperation with the Department of Social and Legal Protection of Children does not bring the expected result. The school repeatedly provides reports on the pupil and the progress of cooperation with the family. In them, it repeatedly mentions the mother's insufficient and indifferent approach to her son's schooling. The mother accuses the school of insufficient responsiveness to the family situation. According to the mother, the loss of the possibility of subsidized lunches is the fault of the school, which was not willing to tolerate the pupil's absence. The mother demands that the school contact the family and repeatedly ask if there is any need to apologize. She also demands that the school not discipline the student for inappropriate behavior and not tell the mother. The school should take advice and not inform her about the problems of the „adult“ son. The student has more or less basic school supplies, he brings a snack. They participate in school events on credit, but usually pay back small amounts. The school does not receive any feedback from DSLPCh. The family is further listed in the DSLPCh system as socially very weak, but striving and caring.

After the change of the long-term field worker, there was also a change in the approach to the family. Greater demands were placed on parents for independence in solving problems. However, the efforts of the new social worker to transfer duties and responsibilities to the mother and father led to a deterioration of the atmosphere in the family and cooperation with DSLPCh. The mother didn't understand and still doesn't understand why she has to start handling certain duties herself, and why higher demands are suddenly placed on her when everything has been working for so long.

CONCLUSIONS

The student is currently in the ninth year of compulsory schooling and attends the eighth grade. Educational difficulties at school are minimal, but the pupil is no longer motivated to complete basic education by extending compulsory schooling. His frustration tolerance in more difficult situations is very low. He handles rejection and failure very poorly, he still seeks the presence of other adults in a servile manner. In the case of strict demands to fulfill the task, he goes into defiance and opposition. He would like to be a car mechanic. He has a role model in his adult siblings from his father's side, who no longer lives with the family, but according to the student, has a permanent job, decent housing and a regular income. The student sees himself at the school also because of the promised pocket money for practical work. He cannot imagine the duties, commuting to another city, and the resulting responsibility, and he does not accept them.

The student's long-term dream is a large functioning family. He imagines that he will have a job, a house with a garden and a pool, a big car, enough money, a wife and many children. He can describe this dream colorfully. When asked how he's going to achieve all this, he simply answers that he will learn, someone will give him a good job and earn money. He never forgets to mention that he will take good care of his wife and cuddle and buy her different things with the children. He cannot answer more specific questions. Then he turns the situation into a joke and says that he can rob a bank too. He laughs at that and doesn't want to talk about the future anymore. The student currently feels good in the safe environment of the school and low-threshold facility, where he is with familiar people. In reality, the pupil is severely immature for life in society. He can, like his mother, often behave purposefully in order to gain attention or some favours. Under stress, failure to fulfill ideas, more difficult conditions for obtaining money, benefits, success, his aggressiveness increases, he gives up, looks for a victim and attacks him.

The family environment, enhanced by the educational approaches of the parents, acts as a strong demotivating factor in the development of the pupil. Parents take social counseling and support for granted without the ability to accept responsibility for the quality of their lives and the lives of their children. Despite the support provided by the school and other cooperating institutions, it is not possible to assume that the pupil will have successful socialization in the future.

DISCUSSION

According to Vašek (1996), mental disability can be understood as a lack of ability to transform information into knowledge, as a result of which also transform things and events into symbolic forms, store them, handle the transformed information in a meaningful way and participate in events. The learning of pupils with mental disabilities is characterized by a lower ability to implement general instructions for the given task, a prolonged first phase of learning (the so-called orientation), choosing the wrong strategy and sticking to the chosen procedure, an increased tendency to create stereotypical wrong reactions (Bartoňová, Bazalová, Pipeková, 2007; Krištofíková, 2001; Lechta, 2010; Valenta, Michalík, Lečbych, 2018). Although the pupil graduated from the preparatory class, the school failure in the first year was of such a nature that he had to repeat it. At first, the behavior was non-conflicting, gradually there were fits of rage, significant psychomotor restlessness manifested by involuntary movements, impaired verbal expression, inability to concentrate. In case of failure, then by aggressiveness, which manifested itself in relational behavior (he still felt that he was being mocked). The consequence was a dismissive attitude towards the school, exacerbated by the need to adapt several times to the new school classmates. The situation resulted in repeated hospitalization in a psychiatric hospital and associated medication. Unreasonable demands were placed on the pupil for a long period of four years from the beginning of school attendance.

The performance of a student with an intellectual disability is affected by the level of intelligence, but not directly proportionally. Those with a relatively good level of attention, short-term mechanical memory, spatial orientation and sensorimotor coordination perform better. Impulsivity, hyperactivity and inability to concentrate can seriously compromise a child's ability to learn anything new. They often begin to lag behind other peers in the class. In addition to behavioral problems, a child with ADHD may have learning difficulties (Hosák, Hrdlička, Libiger, 2015; Lechta, 2010; Michalík, Baslerová, Felcmanová, 2015; Svoboda, Krejčířová, Vágnerová, 2001; Škvorová, Škvor, 2003). If a person with an intellectual disability has not learned to manage different situations, they may develop neurotic or psychopathic symptoms as well as disorders of emotional development. On the other hand, they are often able to love their loved ones, are very sensitive to their pain, worries and are willing to help anyone who needs their help (Svoboda, Krejčířová, Vágnerová, 2001; Valenta, Michalík, Lečbych, 2018). A diagnosis of ADHD is another barrier to personal development for a student with a mild mental disability. Despite the change in the school's educational program, which was appropriate according to the student's abilities, the increased demands on the part of the mother to care for the younger siblings persisted. The student's special needs were not always accepted by the parents, which resulted in negative behavior towards peers and adults. Frustration tolerance decreased with increasing stress situations that the student could not handle.

Restless, distracted, disruptive at school, impulsive children cause many problems for parents. Their parents must always think about what will follow, they must always be alert, predict what may happen, what their child will “bring out”. A child often hears from his parents that it is terrible, that he is only embarrassing them. Therefore, in cooperation with doctors and trained pedagogues, it is necessary to clarify the real situation and the reasons for its occurrence to the closest family members and to behave according to this information and professional advice, to help children as much as possible and to support them in activities in which they have at least some positive results (Riefová, 1999). The pupil’s mother took a dismissive attitude towards actively dealing with risky manifestations of her son’s behavior and transferred the responsibility for inappropriate behavior exclusively to the school and her son. She did not accept her son’s special needs resulting from his disability and did not administer the recommended medication in any way. However, she was aware that her son was very emotionally dependent on her.

People with intellectual disabilities have a strong need for emotional security and safety. The development of higher emotions is difficult and delayed. In the manifestations of the will of individuals with mental disabilities, in addition to laxity and lack of initiative in behavior, one can also notice unrestrainedness, intemperance, and the inability to overcome certain obstacles. The consequence of the insufficient development of the personality as such is also the delayed socialization of these children, their long-lasting attachment to the mother and insufficiently developed social competences, which are necessary for independence (Lechta, 2010; Požár, 2007; Pöthe, 2020). The case study confirms the pupil’s strong fixation on his mother, who, however, cannot give him the expected level of attention due to taking care of other siblings. Therefore, the student draws attention to himself, on the one hand, by his intensely positive relationship with the youngest sibling, whom his mother takes care of the most, and on the other hand, by his defiant, domineering and aggressive behavior, during which he commands his mother, demands that she serve him, and disrespects her. However, the mother does not consider the above manifestations of her son’s behavior as signals to which she should pay increased attention.

Deficiencies in the cognitive sphere affect the formation of character and free qualities of persons with mental disabilities. With the low level of development of consciousness and self-awareness of these children, the education of moral principles, principles and moral convictions are very difficult. Free expressions of people with mental disabilities are characterized by increased suggestibility, emotional lability, impulsiveness, aggressiveness, and also anxiety and passivity (Hartl, Hartlová, 2004; Valenta, Michalík, Lečbych, 2018). As a result of improper upbringing, a child will bring a number of negative qualities and tendencies to school. On the contrary, with the right educational intervention, children with mental disabilities can achieve a much higher level of moral development than is generally assumed. The pupil dealt with the long-term unfavorable situation by stopping going to school, having tantrums at home, his mother punishing him by rejecting him and not writing him excuses. As a result of unexcused absence, the student lost subsidized lunches. If there are facts that may adversely affect the child’s development, the school has a reporting obligation to tell DSLPCh. The school took an active interest in the situation in the family and approached DSLPCh.

However, if it is a pupil who skips school, but at the same time maintains excellent grades, in this case the conclusion is offered that the child's development is not adversely affected by truancy, therefore it is not a pupil who needs to be provided with social-legal protection. DSLPCh are not obliged to inform schools about the measures taken in specific cases[7].

As the pupil's behavior continued to deteriorate, there was eventually a change in the field worker, who placed higher demands on the parents. This effort of the new social worker, on the contrary, led to a worsening of the atmosphere in the family. Cooperation with DSLPCh is therefore perceived negatively by the school. The school does not receive feedback from DSLPCh, the family is further listed in the DSLPCh system as socially very weak, but striving and caring.

In the case of pupils with mild mental disabilities, it is necessary to take into account the specifics of their expressions and personality assumptions in order to fulfill the demands associated with educational and socialization reality. The absence of interdisciplinary cooperation in ensuring timely support and the choice of an effective strategy has a fundamental impact on the areas of physical and psychological development, behavior and socialization of the pupil (Švarcová, 2006; Zezulková, 2013; Bartoňová, Vítková, 2016).

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7 Information on the procedure of the social and legal protection of children in cases of truancy, file no . 2014/11306-231

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2.2 PUPILS AT RISK OF SCHOOL FAILURE DUE TO RISKY FAMILY ENVIRONMENT

Markéta Heinzová and Kateřina Janků

INTRODUCTION

Thanks to awareness-raising, various organizations and professionals, the possibilities for supporting children at risk in a family environment are currently at a good level. However, from the point of view of primary school teachers, they often need to communicate and cooperate with parents. Often parents refuse to accept that their child might have a problem and do not trust and reach out to professionals or organizations. Unfortunately, we also still encounter cases where parents after divorce are unable to take a unified approach to their child's problems and their approach to solving any problem is always the opposite (this situation is even more challenging if the school has no contact with the other biological parents). However, often a parent in a difficult situation approaches the case positively and welcomes the offer and support of the school counselling center as well as contacts with organizations and professionals.

This paper highlights the importance and significance of a cooperative family for the successful and effective education of each student. A pupil whose family is not sufficiently supportive, has social or economic difficulties, and simply his/her family, i.e. most often parents, are not adequate and cooperative partners with teachers, is a pupil at risk of school failure and also often becomes a pupil who exhibits problems or even risky behaviour. In the form of this paper, we highlight the contexts that relate to family-school collaboration. We have selected three short case studies that illustrate the facts about the variety of problems that the school counselling team addresses in the school, and without positive collaboration with the pupil's family, these situations are intractable.

Parental involvement is considered one of the important educational goals and its value is remarkable for the whole educational and local communities it serves. Effective connections between the two "communities" – parents and school – promote children's social, emotional, and academic skills and competencies and growth (Hiatt-Michael, 2001). The family environment and family background play an important role in students' academic achievement, and therefore, if we blame schools or the school system for poor student performance, we soon find that parental involvement in the educational process is as important as school involvement (Mamta & Giraldo-García, 2018). The basic thesis is simple: The greater the level of parental involvement, the better the educational outcomes for children (Epstein, 1991 in Šváříček et al., 2020). Lack of parental involvement with the school is, in the view of many teachers, a major negative factor in pupils' education. Teachers interpret problems in cooperation or lack of cooperation with parents as more significant than any real problems that arise directly from teaching. High absenteeism is also associated with a lack of parental support. Parents do not put enough emphasis on school attendance, they excuse their children from school more often and leave their absences unexcused, they do not stay with them during periods of illness, and the result is missed material that no one catches up with the children at home (Němec et al., 2019).

As a result of the lack of parental involvement in their children's education, side effects of problem and risky behaviour arise, whereby the child reacts to the lack of positive symbiosis in the family and at school. Risk behaviour is behaviour that has been shown to increase health, social, educational and other risks to the individual or society (Miovský et al, 2015). Risk behaviour is behaviour that potentially exposes people to harm or significant risk of harm, prevents them from fulfilling their life potential and can cause significant morbidity or even mortality (Ministry of Education, 2018). Contemporary society in general places high demands on education and on the level of educational outcomes, which is certainly led by effective cooperation with pupils' parents. A summarizing phenomenon that we see in pupils with uncooperative families are difficulties in school achievement, which are not only led by the personality of the children themselves, their insecure motivation and will, but also by the upbringing in the family. These causal factors can be identified and addressed, especially if the children have a combination of specific learning and behavioural difficulties or other health issues or even disabilities. However, demotivating family backgrounds are often not influential at all. Relationships within the family, between children and their parents, siblings, birth or foster parents, are always a very complicated but also 'untouchable' phenomenon. As stated in the methodology for the preparation of the Minimum Prevention Program, it is necessary to support pupils in such a way that, thanks to supportive measures, the difficulties stop or decrease and such pupils return to a successful school group, especially on the basis of individual measures and the setting of cooperation with parents (Ministry of Education, 2018).

In this paper, we have decided to present three case studies of primary school pupils who, due to their family environment, show signs of problematic and even risky behaviour that could be corrected, and who are failing in the educational process, but despite recommendations and support from the school, there has not been a proper shift and the required positive change. The aim of the following case studies is to present cases that require increased cooperation between parents and the school in order to prevent the development of risky behaviour and total school failure.

CASE STUDIES

Case study 1: Boy 8 years, 9 months, 2nd grade

Child's medical history: The boy was born at term, with no complications at birth, psychomotor and speech development was normal, and the boy had no major injuries or illnesses.

Family situation: mother lives with her boyfriend, takes care of 2 children, takes various part-time jobs in addition to her main job. The father does not live with the family. The boy has one younger sister.

The boy attended kindergarten from the age of 3. He started school on time, without delay, at a primary school in north Bohemia. Subsequently, the family moved to Ostrava, so the first change of primary school took place, and the boy joined in Opava in the second grade. Adaptation in school was difficult, the boy did not respect the rules, was not able to sit at the desk and was unable to retain enough knowledge.

The child's problems: The boy has difficulties with attention and concentration, he finds it difficult to resolve conflicts, which occur more and more often. He resolves disagreements with classmates outside the rules (physical and psychological harm, the last conflict ended in an attempt at cyberbullying). Preparation for lessons is lax, often inadequate. School performance does not match the boy's expected intellectual abilities. The first attempts at truancy then appeared. Spends free time with classmates or alone outside.

Diagnostic data: Attention deficit disorder was confirmed at the orientation test. Most likely it was also a case of early schooling. The boy is communicative on contact. When dealing with disciplinary problems, he initially tries to deny, tries to lie. Subsequently, he admits everything, is willing to accept any punishment, the only concern is that his mother does not find out. When he is not at school he is at home or hanging around outside (when someone is home), once he joined a group of older children who were also not at school. He hasn't been to after school club yet, he is always polite with the teachers, he is helpful, he tries hard for a while but loses his zeal very quickly. He promises everything when we talk, but very quickly breaks the rules again.

From the interview with the mother: The boy's father was violent towards the mother, they lived in a small apartment and the boy was often present during the beatings. They left the father when the boy was 6 years old and moved to the other side of the country. The mother's new boyfriend abused alcohol, and after six months they broke up. The boy is emotionally unstable. He behaves sensitively, shows empathy, understanding, but very quickly can be aggressive, unwilling to listen to the other. He has no responsibilities at home, helps only occasionally. Rules are not set. When "misbehaving", punishment comes randomly and varied. He is always nice to his younger sister, takes her to school, picks her up from the day care. She gets on well with her mother's current partner. She refuses to talk about the time when they lived with her father. At the time of the settlement, the children's biological father had filed a petition with the court for access to the younger sister but shows no interest in the boys.

Proposed solution from the school's side: The mother has been given contacts where she can go for psychological help for herself and her child. She was recommended to Eurotopia or Elim. In joint sessions with the class teacher and the special educator, rules for functioning at home were set and clear punishments for non-compliance were established. The boy was enrolled in the school's after-school club, where he also chose several clubs (more control over his leisure time). Regular care from the school special education teacher was arranged (to alleviate attention difficulties). Regular contact between the mother and the school was recommended.

Conclusion from the perspective of the special educator: This boy has attention deficit disorder combined with social disadvantage. The situation has now calmed down. The boy spends time before and after school in the school day-care center and attends the ceramics and computer science clubs. There are rules set at home which he has to follow and fulfil his chosen duties, otherwise a pre-arranged punishment follows (at the beginning it was very difficult according to his mother, now the system works). At the same time the mother contacted a psychologist, they waited almost half a year, but now they are in care. At school, his grades have improved, conflicts with classmates are less frequent and most of the time the child is able to solve them on his own. The boy has a lesson once a week with a special educator (work on his attention ability), if necessary, he also attends a lesson with an assistant.

Case study 2: Girl 15 years, 7 months (treated from 13 years), 9th grade

Child's medical history: The girl was born at term, with no obstetric complications. She had only common childhood illnesses. Leg injury at age 7, school deferment for one year. The leg has been operated on several times. At 13, she had a bone lengthening operation.

Family situation: Parents are divorced. The girl has one sister of her own 5 years older. The girl is in the care of her father and has rarely seen her mother for a long time. She doesn't get on well with her father and sister.

At school, there was a history of school failure, educational difficulties and truancy. During the period of distance learning due to Covid 19, she underwent foot surgery, which caused prolonged absences. Subsequently, she was not managing the amount of learning and stopped joining online learning or joining without audio and video. She was unresponsive even when prompted by the teacher to attend lessons.

Diagnostic Data: The girl was examined in 5th grade at the Educational Psychological Counselling Centre with the diagnostic conclusion: lower aptitude, borderline learning disability, impaired memory. At the time of Covid 19 and surgery, there was a 2-year extension of the referral. A follow-up examination took place at the beginning of the 9th year and the recommendation was not extended. Unfortunately, the girl did not excel in any of her school subjects. She herself states that "apart from art and music, everything is a horror". The support measures were set up on the basis of a recommendation from the Pedagogical and Psychological Advisory Service, and after the recommendation ended, the mother stated that they could already manage everything on their own – they would have to attend special education classes in the morning or after school, which she found too burdensome.

She is currently in 9th grade and works at school, but homework is irregular. She has no friends at school and avoids social contact with her classmates. She spends her free time with a group of older children or on social media and mobile phone games.

Proposed solution by the school: The father cooperated with the school. Tutoring in individual subjects and regular care by the school's special educator were arranged. In the case of non-enrolment or enrolment in online lessons, the teachers called the father and thanks to the cooperation of the older sister, remediation always followed. Gradually, the situation with truancy during the time of online teaching improved. The father also asked for help in dealing with the situation at home. The girl refused to follow any rules and very often had conflicts with her father and older sister. She often blamed him for her mother's departure and her minimal interest in her and her sister. The father works as a driver and the girl would often leave the house and roam around with the gang. On one occasion the situation was taken up with the police. The father was concerned about the use of alcohol and cigarettes as well as experimenting with light drugs. On referral, they started attending family counselling and the girl also attended the educational care centre.

The girl is currently living with her mother. Her school performance has slightly deteriorated and this school year she no longer attends the school special educator, tutoring and educational intervention (recommended by the PPP) only sporadically. Absenteeism (apparently hidden truancy) is increasing again, but the mother excuses it retrospectively. Contact with her father and sister is gradually becoming more and more limited (last contact more than a month ago). No therapy is ongoing. In terms of school, however, there are no major problems at present. The mother has started to communicate more, informing herself about progress and behaviour. She wants custody of her daughter.

Conclusion from the perspective of the special educator:

We have diagnosed this girl as having a weak giftedness combined with a very weak will, a reluctance to learn even with a great effort of help and support from the school and family. She is currently in the care of her mother, her school performance has deteriorated even further, she will finish 9th grade with few satisfactory grades. She did not get into her chosen secondary school (hairdresser, caregiver), applied in the second round of admissions.

Case study 3: Girl 13 years, 5 months, 7th grade

Child's medical history: The girl was born at term, without complications. She was very dexterous from an early age, and was above average in all areas of development. She was happy to attend kindergarten and lower primary school; her development was completely uneventful. She had common childhood illnesses.

The girl's family is complete. Both parents work. The six years younger sister attends a school for children with speech impediments. She lives in an apartment on a housing estate near the school.

The child's problems: School progress began to deteriorate gradually during the upper primary school years to the current situation where the pupil is failing and at risk of repeating a year. Her school preparation at home is minimal and she is not completing her homework. Truancy occurs, with parents always excusing absences. She has been seen several times by schoolteachers in the presence of a group of high school students. Once even while smoking an electronic cigarette. She was also caught lying to the schoolteachers.

Diagnostic data: According to the interview with her parents, the girl claims that learning is challenging, but she regularly learns (to what extent and if indeed, they no longer check). She behaves normally at home; she is just more withdrawn. She gets along nicely with her sister (she is 6 years younger; they don't spend much time together), she brings her to and from school.

The school's solution: Parents were offered tutoring by individual teachers and the care of a special educator (only maths tutoring was used). They were advised that even hidden truancy that they subsequently excuse is a problem and must be addressed. Parents deny that their daughter smokes. They reject the daughter's lies and believe it (even when clearly explaining and documenting that the situation could not have happened this way). More monitoring of daughter's leisure time was recommended – they took contacts for low threshold facilities but did not use them for tutoring or leisure time. Contacts for psychologists were passed on.

The situation improved in the short term. For a period of time there was an improvement in grades and regular school attendance. Gradually, everything returned to normal. At the end of the 8th grade she took a remedial exam in mathematics. In the ninth grade, she failed overall.

Conclusion from the perspective of the special educator

It is very difficult to draw a conclusion for this girl, probably due to the parents' lack of time at work or time spent caring for her younger sister (she got everything she wanted, she could attend all the clubs she chose, but there was probably very little time spent together). She got into a clique, and the situation described above ensued. From hearsay and from classmates, we know that the girl is managing high school so far, but she has a lot of problems with grades and truancy. She is still with the same group of teenagers, she no longer hides her smoking, and we know of no other substance abuse.

SUMMARY

All pupils who go through the school counselling service receive appropriate specialist support. Whether it is the work of the school's special educator, guidance counsellor and prevention methodologist or school psychologist, it is clear that the school is interested in having happy children. In each of the three short cases mentioned here, the family's initial environment and the position and relationships that the family takes towards the school play an irreplaceable role. Cooperation between the family and the school is a key element in the education and development of children. When the family and the school support and cooperate with each other, children are provided with an environment in which they can learn, develop and achieve their potential better. In conclusion, we declare several aspects that positive cooperation between family and school exhibits:

- Open and regular communication: parents and teachers should maintain a regular and open dialogue. This means sharing information about the child's progress, needs, interests and also solving any problems together.
- Collaboration on the educational plan: Parents and teachers should work together to set educational goals and a plan for the child. Discuss how to support the child's learning and development both at school and at home.

- Participation in school activities: Parents should be encouraged to participate in school events such as parent-teacher conferences, public presentations, sporting events, etc. This strengthens the relationship between the family and the school and shows the child that all the adults in his/her life are interested in him/her.
- Supporting learning at home: Parents can support their children's learning at home by taking an interest in their homework, reading books, talking about what they have been learning at school and providing support when needed.
- Collaborative problem solving: When problems arise at school, the family and school should work together to solve them. This may include discussion, planning, and finding strategies together to help the child overcome obstacles.
- Mutual respect and understanding: The family and school should respect each other's roles and approaches to raising and educating children. It is important to be understanding of different perspectives and to work together for the benefit of the child.

Family and school cooperation require openness, communication and respect. When both parties work together and support each other, it has a positive effect on the child, his/her motivation, self-esteem and overall development.

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2.3 FAMILY IN THE NARRATIVES OF PENITENTIARY RECIDIVISTS

Beata Zajęcka

INTRODUCTION

In the Polish penitentiary system, the term person deprived of liberty is primarily understood to mean a person sentenced to imprisonment and punished with detention for misdemeanors, as well as a person under pretrial detention. It should be clearly emphasized that the environment of persons deprived of liberty is not a homogeneous environment. Prisoners differ from each other in many respects, ranging from gender and age, education and occupation, their history of criminal life, the category of crimes committed, prison experience, and the characteristics of the mechanisms of mental regulation of behavior and "susceptibility to influence, both negative and positive" (Szałański, 2006, p. 107). Among those in penitentiary institutions we can distinguish: juveniles, adults, first-time offenders, recidivists, convicted of common crimes and those convicted of crimes against life and health. The characteristics of prisoners take into account criminological aspects (who, why and what kind of crime they commit) and penitentiary aspects (who is serving a sentence) and socio-demographic aspects.

According to legal regulations (Criminal Code, 1997, Article 64§1) habitual recidivism means that: the offender was previously convicted of an intentional crime and was sentenced to imprisonment for that crime, therefore served at least 6 months of imprisonment from that sentence, and committed another intentional crime before the expiration of 5 years after serving that sentence and, moreover, similar to the crime for which he was previously convicted. Penitentiary recidivists are a category of persons who have previously served a prison sentence, even several times. They make up a significant percentage of the population serving sentences. As of 31. 11. 2022, out of 63,390 convicted and sentenced persons in prison isolation, recidivists accounted for 59,5 % of the prison population They are perpetrators of crimes against property (theft, burglary, seizure of property, appropriation, fencing, robbery). Other crimes committed by repeat offenders are basically concentrated in two groups of acts: against the family (non-alimony) and of a hooligan nature (sw.gov.pl).

Research conducted by Szczepanik (2015) on the shape of the criminal biography of recidivists and their readjustment to freedom allowed the emergence of categories of repeat offenders:

- those with an early onset of criminality: committing numerous, sometimes serious criminal acts, dating back to their juvenile years. Individuals were sentenced to imprisonment for the first time while they were still juveniles (before the age of 21);

- perpetrators of serious crimes: primarily robberies, burglaries, serious bodily injuries. Such persons come from among recidivists with early onset of criminal record;
- with a late onset of criminal record: committing criminal acts of very low intensity during juvenile years. Persons sentenced to imprisonment for the first time only at the age of 24–26;
- perpetrators of minor offences: occasional theft, violation of bodily integrity.

Prisoners-recidivists are a collection of different characters and personalities (Machel, 2006). The largest group among prisoners are those whose process of social derailment began in their early youth, coming from pathological or educationally inefficient families, with a consumerist attitude to life. In this group of those who repeatedly come into conflict with the law are many substance addicts. There are also people who would like to live a normal life after leaving prison, but they do not know what that means, what they should be like, what skills and competencies they should have. Reaching out to them and trying to arouse in them the desire to change is met with resistance. A long criminal career and multiple stays in prison isolation, lack of support from loved ones do not make it easier for them. According to a study of 358 convicts serving prison sentences who left prisons in 2000, within six years, 60 % of previously surveyed juveniles, 38.3 % of first-time adults and 63.7 % of recidivists were sentenced to prison again (Szymanowska, 2010). Where is the problem, which makes them destined to social oblivion? What role has the family environment played in shaping the patterns of criminal functioning in their lives?

FAMILY DETERMINANTS OF THE DEVELOPMENT OF CRIMINAL BEHAVIOR

In order to consider the role of the family environment in the genesis of criminal behavior, it is necessary to accept the thesis that the reference points for human activity are life experiences, the way of perceiving the social world and the processing of information acquired about it. According to research findings (Patterson, DeBaryshe, Ramsey 1989; Niewiadomska, 2007; Nowak, 2011; Opora, 2011; Kieszkowska, 2012; Fidelus, 2012), the development of an individual is determined by the organic satisfactions and the individual's own activities, but also depends on the external environment, primarily the social environment. All factors of development are interconnected and dependent on each other, however, special importance is given to the process of socialization and upbringing due to its role in shaping the human psyche. The experiences that are formed in the course of an individual's interaction with the environment later form the basis of their social activities. As a result, socially maladjusted and criminally derailed individuals exhibit poor adaptability, profound competence deficits and cognitive and emotional disorders.

An interesting theoretical construct derived from psychoanalytic-developmental psychology is Johnson's concept (1993, 2012), based on an approach that emphasizes family conditions in the development of criminal behavior. The researcher argues that a person's character and the sources of psychopathology are the result of a complex reaction of the individual to frustration caused by the environment, related to the lack of satisfaction of needs:

- attachment and bonding with a primary caregiver (Bowlby, 1969);
- individualization through independent exploration of the environment, self-activity and the building of psychological boundaries (Mahler, 1968);
- self-formed expression (Kohut, 1977; Lowen, 1983).

The family, which is a nurturing and socializing environment, is a source of influences that affect and stimulate or inhibit the development of the child, and is the terrain of the individual's primary life experiences. Its influence on life's destiny is decisive and cannot be replaced by any other influences. From the beginning of his life, the child confronts basic human problems, which he tries to solve, having at his disposal his own resources, environmental limitations and the still poor knowledge of the world. When this takes place in a traumatic environmental context, such early resolutions tend to become rigid and resistant to change. Therefore, the family environment is treated, "as a source of potential behavioral disorders that can lead to social maladjustment" (Wysocka, 2008, p. 199). This is particularly true for families affected by a variety of negative phenomena and pathogenic factors (poverty, unemployment, addictions, disintegration of the family system). The functioning of a child in a family presenting patterns of thinking and behavior correlated with behavior that exceeds social norms, may in adulthood result in a criminal style of thinking and the manifestation of deviant behavior (Walters, 2002). This view, historically, is among the earliest attempts at interpretation on theoretical grounds and is the most popular position on which attempts at practical solutions in the sphere of prevention, therapy and rehabilitation are based (Urban, 2000).

Analyzing the biographies of recidivists in penitentiaries (Pindel, 2009), it can be seen that in various areas of life, in which the choice between good and evil is made, the convicts have a lack or very low level of development of such a skill. As Kumala (2007) emphasizes, the reasons for this can be found in the lives of convicts (during childhood and adolescence), destructive circumstances, a string of humiliations, harms, degradations, a constant sense of danger, lack of time, warmth and love from parents, objectification, lack of role models, upbringing in a pathological family, a disturbed educational process, improper socialization, negative influences from the peer group, stays in correctional institutions.

RESEARCH

The subject of the analysis is the characteristics of the family environment of penitentiary recidivists, people who have previously served, even several times, imprisonment. They constitute a significant percentage of the sentenced prisoners' population. They have committed crimes against property (theft, burglary, seizure of property, misappropriation, fencing, robbery). The remaining offences committed by recidivists mainly focus on two groups of offences: against the family (non-alimony) and hooliganism.

The empirical research focusing on the perception of families of origin by the respondents was conducted with the use of qualitative dialogue research among 10 recidivists aged 34 to 73 years, with a different criminal history. The family, which is the educational and socializing environment, is the source of influences that influence and stimulate or inhibit the child's development, it is the area of the primary life experiences of the individual. Its influence on the life is decisive and cannot be replaced by any other factor. The narrative interviews show various experiences from the past that led to the formation of a criminal lifestyle. The life of penitentiary recidivists during childhood and adolescence is devastating. They have experienced numerous humiliations, injuries, a constant sense of danger, lack of time, warmth and love on the part of their parents, and treated them as objects. These experiences – accumulated in the family environment – became a source of potential behavioural disorders, which led the respondents to social maladjustment and later conflicts with the law.

In defining the research problem, it was aware that the issue of the role of the family environment in the genesis of criminal behavior is a largely penetrated area. However, there is a lack of detailed findings on prisoners' perceptions of their family of origin. It was decided to focus on the retrospective description of the family of origin sketched by prison recidivists, which is only a fragment of a broader study of the life stories of prison recidivists.

Qualitative research was implemented through interviews and allowed to focus on individual contexts – immeasurable and unobservable from the ceiling of questionnaires (Kvale, 2010). It was decided to choose this type of interview in order to give the conversation a direction of interest to the researcher while the subject was building a narrative (Rubacha, 2011). The interviews were recorded for transcription at a later stage of the research. The analysis and interpretation of the obtained research material took into account the principles/ stages adopted in qualitative research (data reduction, data representation, data verification – content-wise different from quantitative data analysis) (Babbie, 2009).

The research was conducted on a sample of 10 respondents. Participants in the study were people serving a prison sentence of at least 2 times, in prison, on furlough, and those already at liberty. The recidivists surveyed were men, ranging in age from 34 to 73, with various criminal histories:

- Tobiasz (34 years old) – in a correctional facility from age 17 to 18, has been in prison three times, first stay at age 19 released at age 21, second stay at age 23 released at age 29, third stay at age 29 released at age 34. After his last sentence he spent two months at large, he is currently in prison again.
- Marek (34 years old) – in a correctional institution from age 16 to 18, has been in prison twice, first stay at age 19 released at age 22, second stay at age 23, still in prison.
- Zygmunt (73 years old) – has been in prison twice, first stay at age 27 released at age 30, second stay at age 51 released at age 69. He has currently been at large for 4 years.
- Krzysztof (44 years old) – has been in prison three times, first stay at age 22 released at age 23, second stay at age 25 released at age 29, third stay at age 31 released at age 37. Currently he has been at large for 7 years.

- Adam (37 years old) – in correctional institution from age 13 until coming of age, three stays in prison, first stay at age 22 released at age 24, second stay at age 25 released at age 33, third stay at age 34, still in prison.
- Jakub (42 years old) – has been in prison twice, first stay at age 23 released at age 29, second stay at age 31 released at age 37. Currently he has been out for 5 years.
- Michał (48 years old) – in a correctional institution from age 15 to 17, has been in prison twice, first stay at age 24 released at age 29, second stay at age 29, still serving his sentence.
- Mateusz (59 years old) – has been in prison twice, the first time at age 27 released at age 47, the second time at age 51, is still serving his sentence.
- Robert (45 years old) – in a correctional facility from age 14 to 18, twice in prison, the first time at age 21 released at age 31, the second time at age 32, still serving his sentence.
- Tomasz (57 years old) – has been in prison twice, the first time at age 39 released at age 42, the second time at age 45 released at age 51. Currently he has been out for 6 years.

A RETROSPECTIVE PICTURE OF THE FAMILY OF ORIGIN OF THE RECIDIVISTS UNDER STUDY

During the interviews, each of the men interviewed recalled his childhood and what his family life was like.

Adam came from a multi-problem family, he speaks about it reluctantly and very negatively: *I had no childhood, my parents didn't even call me that. There was always alcohol in my house, and it was the most important thing. For the people I should call parents, alcohol came first, we didn't count. My father used to beat us, I remember all the time I had bruises, one bruise didn't go away before another appeared. There was nothing to eat, we walked around dirty, hungry. I don't know if you can call it childhood? Unconscious parents, and when they started to contact something they beat us. He doesn't even want to go back to those times.*

Adam grew up in a family with an alcohol problem, which consequently led to domestic violence, brawls, resulted in educational problems and the initiation of a juvenile's criminal "career." "An individual in a family with an alcohol problem experiences disruptions in his sense of security to a far greater extent than other children" (Gołembowska, 2009, p. 293). He experiences total confusion and chaos, accompanied by anxiety and lack of support. As a child, Adam often observed disturbed, "violent" relationships between his parents. Violence humiliates, causes suffering, breeds hatred and the desire for retaliation, and creates a vicious cycle in interpersonal relations. Children raised in an atmosphere of violence have basic socialization deficiencies, are distrustful of others, hostile, cannot cope with daily tasks, and have disorders related to their sense of identity (Pospiszyl, 2007).

Robert came from a pathological family, he recalls: *What I remember most from my childhood is that I was abused by my father. I resented my mother for this, that she didn't do anything about it, she never helped me, she even looked at it sometimes. She doesn't even want to talk about it. My childhood is a constant pain.*

The recidivist respondent grew up in a family with deficits in family resources and low levels of social competence, sexual violence. He also blames his mother, who was a passive-dependent person. Robert was often exposed in his family to involvement in traumatic and dangerous situations for his health. It was a toxic home, stripped from his childhood, where he experienced negative emotions, anxiety, and pain. As he recalled, in further conversation, this left a mark on him, his later problems with the law are linked to childhood sexual abuse.

According to Marek, he did not have a happy childhood*: My childhood? If you can call it a childhood. I don't know my parents and don't want to know, they gave me to the Children's Home when I was 2.5 years old, I became a problem for them. As far as I know, I ended up in the institution in a bad condition: I was full of bruises, malnourished and dehydrated. I lived in the belief that I was worthless and no one would ever love me and I would never have a family. So my childhood was a trauma for me, because every child needs love and support, and I was spurned all the time.* When asked if his childhood influenced his later life, Marek said: *You never know until the end, you can't say that unequivocally. However, I think that what happened to me in my youth left its mark. Maybe I wanted to unwind, I was looking for approval, understanding, love, all those things I didn't experience when I was young. So to some extent it certainly affected me.*

Marek, came from a pathological family. He was taken away from his biological parents and placed in foster care. His childhood did not go well. Marek's problems in social life undoubtedly originate from the insecurity, anxiety, fear and insecurity prevailing in the pathological family home. Parental attitudes and roles as well as unfavorable attachment patterns resulted in the formation of oppositional and rebellious disorders and the assumption of control and dominance in his later life.

Michał comes from a broken family, as he said*: I am an only child, my father left us when I was 4 years old, I was left alone with my mother. I wouldn't trade my mother for any other, she would give her life for me. She didn't let me feel the fact that my father wasn't with us, she was both father and mother to me. Mom gave me everything she had, at times things were not colorful, we did not overflow, it was hard.*

Michał functioned in a family with an incomplete structure. The recidivist respondent perceives his mother as a strong, resourceful person who supported him in various activities. From his narrative emerges a picture of a mother who is busy, tired and often helpless. Analyzing his childhood behavior, he admitted to his own mistakes and character traits that made life difficult for a single mother.

Krzysztof, came from a family of low socio-economic status, but in his opinion it was a properly functioning family: *In my family we never overflowed, we were not among the wealthy. But this was not a problem for us, my parents loved each other, we were the whole world for them. They didn't let us feel that we were inferior to others, we were well-dressed, fed, had everything we needed. I have three younger siblings, I took care of them when my parents were at work, picked them up from school, made dinner. Despite the fact that I had a lot of responsibilities, my childhood was successful.*

Jakub described his loved ones similarly: *My childhood was normal. I had parents who trusted me, two younger siblings. My parents worked hard so that we didn't lack anything, we were a loving family. You could say we were average.*

The recidivist surveyed, despite the fact that his family was not wealthy, recalled his childhood as successful. He pointed to his parents' loving and understanding upbringing. In a retrospective description of his childhood, he justified his parents' absence due to excess work and problems in securing the family's economic security. The memories of the subject outlined a picture of a complete family in which parents devoted little time to their child, although they loved and supported him on a daily basis.

On the other hand, Zygmunt was as an only child from a wealthy family: *I was an only child, my parents were wealthy, they had their own business, which prospered. I got what I wanted, well, except maybe one thing, I didn't feel any love from them, any support. They handled everything with money, when I imposed on them they gave me money to buy myself something. But in retrospect, this destroyed me in a way, all that mattered was money, nothing else mattered. My parents didn't pay attention to me, it didn't matter whether I studied, what I did. I grew up on my own, I learned everything on my own.*

The recidivist surveyed, despite being raised in a well-structured family, experienced, as he indicated in the interview, emotional coldness on the part of his parents, a lack of interest in his affairs and problems, and childhood loneliness. As Nowak (2022) found, children experiencing indifferent parental attitudes are lost, insecure, burdened with numerous deficits, including a lack of empathy and the ability to recognize and express emotions, and in adulthood are unable to form and consolidate family ties.

Tomasz on the other hand, came from a properly functioning family, and says of his childhood: *I remember my childhood well. I came from a wealthy family, my parents were high-ranking, they had good jobs. We always spent our free time as a family, going out, riding bikes. Our parents devoted a lot of time to us, they loved us and we loved them.*

Describing his family of origin, Mateusz emphasized: *I had a successful childhood, there were parents, younger siblings. It was normal as in any family.*

Tobiasz recalling his loved ones, emphasized that he came from a properly functioning family: *I always had everything I wanted, I was alone for a long time, then siblings appeared. My parents would give us everything, they loved unconditionally, they always stood behind us with a wall. We had an apartment, my dad had a good income, so we didn't lack anything.*

The overall picture of the functioning of the respondents' families of origin shows that they grew up in fully structured families. In their narratives, they recalled their childhood with fondness, created an image of properly functioning families and strong ties connecting them with their parents. The descriptions of family life made by the recidivists surveyed indicate that despite the problems their families faced, their parents did their best to bring them up, in accordance with their values, and provide them with a good future.

SUMMARY

Undertaking the research, it was thought that the family in the narratives of prison recidivists focuses on autobiographical memory, which is generally not a faithful copy of the record of events. However, when processed (interpreted), it serves to regulate behavior or determine the paths of one's own behavior. This memory enables a person to establish and maintain contacts with other people, use previous experiences, set goals and plan actions. Factual information and information about sequences of events are located in autobiographical memory. They are encoded in the form of pictorial, verbal and abstract records. In autobiographical memory, in addition to facts, interpretations of facts also appear. In defensive situations, a person often confuses them with each other, and then various distortions occur that are the source of narrative disorders. Abnormalities occurring in the area of autobiographical memory usually generate difficulties in social functioning (Robinson-Riegler, Robinson-Riegler 2004; Maruszewski, 2005).

The presented results of the study indicate that the recidivists studied came from families characterized by the presence of a pathological factor, which are mostly alcoholism of one or both parents, violence, sexual abuse. These were families with poor upbringing, low socioeconomic status, struggling with many problems that poorly educated and incapable parents do not know how to solve. They worked hard to support the family and lacked time to build good relationships with their children. All this resulted in reality disorders and inappropriate parenting attitudes. In their narratives, the recidivists interviewed also admitted that their parents loved them, surrounded them with care and understanding, but daily life forced hasty and cursory relationships, and this resulted in their educational influence not being significant. They often emphasized the strong emotional bond with their mother, who, without fail, devoted herself to their upbringing and supported them in various activities. This often ideal image of the family of origin presented in the narratives of the recidivists surveyed can have the character of idealizing the past, deforming the information provided or keeping silent about uncomfortable facts. This wishful thinking protects them from even more hurt and abandonment that they actually experienced.

The presented results of the study, which can be a prelude to further studies and analysis, clearly prove that each recidivist has his or her own history and experiences shaped in the family of origin. However, it should not be forgotten about the accumulation of unfavorable biopsychological and sociocultural factors that led to the formation of a criminal career.

Difficult experiences acquired in the family of origin result in rejection from the constructive environment, inability to function in assigned social roles such as husband, father, employee. Often, in the face of helplessness, there is a search for a path to an easy and pleasant life and being drawn to the margins of society, which, as a consequence, causes the beginning (continuation) of the criminal path and another stay in a penitentiary unit is already an easy adjustment. They return again and again to establishments, because crime is often a regular source of income for them.

As one of the recidivists interviewed said: *I ask myself whether or not I am thoroughly demoralized, whether there is hope for me to be a normal person someday. I try to compare myself to those I know, and I don't see much in common. If only you knew how hard it is to be a good person, it would be much easier for me. So, I ask one thing: when you deal with us, look at us and treat us like human beings.*

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2.4 MEASURING THE IMPACT OF PREVENTION PROGRAMMES AS A CHALLENGE – A PROPOSAL FOR MEASURING THE IMPACT OF A PRIMARY PREVENTION PROGRAMME AND ITS APPLICATION IN RESEARCH PRACTICE

Daniel Topinka and Jakub Janas

INTRODUCTION

One of the reasons why prevention and the application of a preventive way of thinking in the social sphere is not more widely promoted in the Czech Republic is its low legitimacy. Intuitively, it is assumed that prevention is beneficial, although there is a lack of clear evidence for this. Even though there is a large number of prevention programmes implemented in practice, there is no real knowledge of their actual benefits and effectiveness. Moreover, there is no argument as to how prevention programmes have been able to prevent, for example, inadequate social functioning or failure. The text approaches measuring the impact of prevention programmes as a challenge. It proposes a way of measuring the impacts. This is demonstrated through the example of a selected primary prevention programme. The aim is to take the reader through the process of impact measurement from the very beginning, when the evaluation measurement model was being developed, to its application in research practice, and finally to the results that the model has achieved. The text introduces impact measurement using a "difference-in-differences" approach and pairing. It illustrates the possibilities of applying the model and the conclusions that point to specific impacts of the observed prevention programme, particularly in the field of strengthening the resilience to social failure.

If we think about the support of families and children who are currently coping with difficult situations, we cannot avoid the topic of prevention. It has different meanings and in the text prevention is treated in the broadest possible sense, although the actual measurement of impacts is demonstrated 'only' using one selected example of a primary prevention programme. The word prevention comes from Latin, where *praeventus* means an intervention that has been carried out in advance. *Praeventia* stands for prevention – usually of harmful phenomena (Maříková, 1996, p. 842).

Prevention is usually found in the context of health interventions.[1] In the area of social work, prevention is associated with avoiding phenomena that are often described as negative and with ways of preventing their emergence, transmission and spread in society. In relation to social work, Matoušek (2016, p. 154) defines prevention as a set of measures "that are used to prevent social failure, especially those types of failure that threaten the basic values of society (crime, prostitution, toxic addiction, xenophobia, racism, social parasitism, violence, etc.)". In 1961, L. Rapoport recognized that prevention should consist of early identification, taking control, and ultimately eliminating the conditions that interfere with social functioning. Social work should be aimed at encouraging prevention by conceptualizing and stimulating a range of prevention activities and programmes. "Prevention can be any type of educational, instructional, health, social or other intervention directed at preventing the emergence of risk behaviour, preventing its further progression, mitigating already existing forms and manifestations of risk behaviour or helping to resolve its consequences" (Čech, 2012, p.107).

Prevention is often associated with the assumption of its usefulness. It is beneficial because it prevents negative consequences while its costs (not only economic) are much lower compared to the costs that society has to pay for solutions to deal with the consequences of any negative phenomena. Evidence on the benefits and the efficiency of prevention in the literature is abundant, even in topics close to those we are focusing on, such as youth risk behaviour or parental activation and competence (e.g. Ridenour, Murray, Hinde et al., 2022; Catalano, Kuklinski, Sterling, 2018; De Graaf, Speetjens, Smit et al., 2008; Kuklinski, Oesterle, Briney et al., 2021). The studies mentioned above show that it is necessary to apply holistic and social-ecological approaches when evaluating the impacts of prevention (Bronfenbrenner, 1979; Santrock, 2007). These approaches should target broader units and contextual influences (not only the client, but the whole family system, value system, norms, institutional aid, legal system, etc.). In addition, prevention prevents phenomena that are not static but dynamic – they evolve over time and are procedural in nature. During interventions, a number of factors and influences are in effect, based both on the level of the individual and on the social and cultural environment surrounding the intervention. The effectiveness of prevention is not achieved through restrictions, prohibitions or coercion, but through the thoughtful and targeted promotion of pro-social attitudes and behaviour.

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[1] The goal is to prevent human health disorders, the onset of disease or the consequences of disease. It is obvious that the topic of measuring the impact of prevention is at an advanced level in healthcare. This is related to the longer-term application of evidence-based approaches in healthcare or medicine (Evidence-Based Healthcare, Evidence-Based Medicine; in the Czech environment, e.g. Marečková, Kugarová et al., 2015).

SCEPTICISM AROUND IMPACT MEASUREMENT IN PREVENTION

Matoušek (2016, p. 154) acknowledges that prevention activities in the Czech Republic are disorganized, uncoordinated, uninventive and ineffective. What is the reason for this evaluation? The system of support for families with children in the Czech Republic does not sufficiently use the potential of preventive thinking and the ability of programmes to effectively prevent problems. Preventive programmes are supposed to help families and children to avoid failing to cope with the demands placed on them by the social environment, in order to prevent disproportionate social functioning. Unfortunately, the period that precedes the emergence of acute demand for services (e.g. social services) has not received much attention. There is no systemic and coordinated development and support of services or programmes that apply interdisciplinary collaboration, holistic and social-ecological approaches that would firstly design and then implement programmes aimed at improving people's lives and preventing people from becoming future clients of the services. Services tend to be more about intervention than prevention. This applies to social and preventive services as well as to various types of educational, social or other programmes. Services struggle with how to apply preventive thinking, while programmes are developed without any link to the causes of the phenomena and are designed more or less intuitively, reactively and are unable to demonstrate their effects.

One of the reasons why prevention is not more widely promoted in social issues in our country is its low legitimacy. Intuitively, it is assumed to be beneficial and effective, however there is no credible evidence for this statement. The actual benefits of prevention are unknown and there are no arguments about how prevention services or programmes have been able to avoid social failure. There is scepticism about efforts to evaluate the impact of prevention programmes in the Czech Republic. Their utilization is quite minimal and the available studies that were carried out, which focus mainly on primary prevention topics are an exception (e.g. Miovský, Miovská, Řehan, Trapková, B., 2007; Miovská, Miovský, Václavková, 2008; Miovský, Šťastná, Gabrhelík, Jurystová, 2011; Miovský, Novák, P., Šťastná, Gabrhelík, Jurystová, Vopravil, 2012; Nevoralová, Pavlovská, Šťastná, 2012; Miovský et al., 2015). The results of the evaluations show how difficult it is to measure the impacts, even despite the involvement of experimental and quasi-experimental research designs. The findings can be read from different angles and discussed as to why the effect of the programmes is not very significant or is only observable in certain groups of participants. Some of the available outcomes can be read with puzzlement. So what is the situation really like? Are some of the results not convincing because prevention programmes are either poorly designed, unsuccessfully implemented, or because their impact cannot be measured due to methodological difficulties? Or is the measurement influenced by other important background factors that are affecting the programmes and it is not possible to capture and identify them? There may be more than one cause, what is more, these causes may operate simultaneously. Some foreign authors also tend to be reserved and cautious in their evaluations and firm conclusions (especially in meta-analyses).

The following text is a report on an effort to create an evaluation model that would be able to measure the impacts of risk behaviour prevention programmes or services (whether in education, outside education, or in social prevention services). It describes how the draft impact measurement model was developed and then tested on one prevention programme example (in reality it was tested on just under a dozen of different programmes and services). It presents the entire process of impact measurement from the very beginning, when the evaluation measurement model was developed, to its application in research practice, and finally discusses the outcomes it produced.

PROPOSED MODEL FOR MEASURING THE IMPACTS OF PREVENTION

When measuring the impacts of the programme, we asked the following questions: *Has the implementation of the new prevention programme resulted in participants being more resilient to social failure? In what ways are the impacts manifested in different areas of social life?* In designing the measurement model that was to provide the answers, we proceeded from the following considerations. On the one hand, there is no easily measurable direct causal relationship between the prevention programme and the prevention of risk behaviour of children. We cannot assume that when a participant completes the prevention programme, we will immediately observe an impact in their behaviour. It is not that simple. Completion of the programme is not a guarantee that it will automatically lead to the expected behavioural change. In addition, we may observe that completing the programme does not lead to any behavioural change at all, or may even lead to a behavioural deterioration, and thus the opposite of what is expected. In contrast, the expected relationship may be influenced by a number of variables, some of which we can identify more easily than others. It is understandable that the outcome of the programme can be influenced by a number of factors: the mood of the participant, the preparedness of the lecturer, the relevance of the topic and a number of other circumstances that are both known or unknown to us.

The risk behaviour that the programmes try to prevent includes various forms of behaviour that affect the social or psychological functioning of the individual or threaten their social environment, such as aggressive behaviour, delinquent behaviour, risk behaviour towards social institutions, gambling, etc. These forms of risk behaviour occur at the pre-pathological level of the phenomenon under observation, i.e. they do not transfer to the pathological level, for example, addictive behaviour (Širůčková, 2012, p. 127).

The question is how to measure the prevention of risk behaviour. Let us try to take inspiration from the attitude theory, especially the theory of planned behaviour. Attitudes represent an individual's relatively settled tendency to behave in a certain way in a certain situation, beliefs and feelings in relation to a certain behaviour or situation, and thus can to some extent suggest how an individual will behave in a certain situation. The theory of reasoned action is based on five factors. One of these is attitudes, which play a role in predicting behaviour. Additionally, they include subjective norm, perceived control, intention and actual behaviour measured over a period of time (Beck, Ajzen, 1991). Attitudes (opinion about behaviour and its assessment), subjective norm (opinion and perception of society) and perceived control (feasibility of behaviour) are independent variables (predictors), in other words, determinants of behaviour. The combination of these three predictors contribute to the intention that influences the final behaviour. “This relationship can be interpreted in the sense that the more favourable the individual’s opinion (attitude) and the opinion of others in their surroundings (subjective norm) about the examined behaviour and the higher the individual’s control over this behaviour (perceived control), the greater the intention to behave this way” (Příhodová, Preiss, 2019, p. 43). This led us to the decision to measure the impacts through *changes in attitudes* among programme participants.

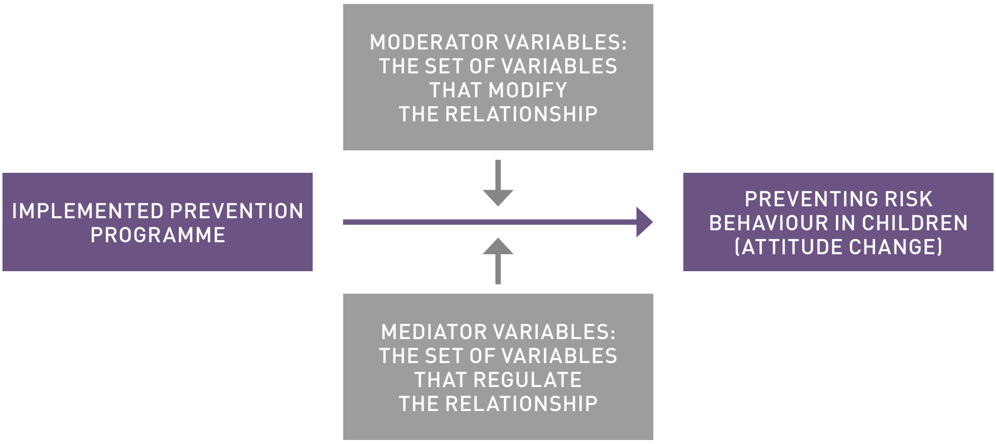
However, despite this, there was a need to further come to terms with the fact that a number of other circumstances and influences actually affect the impact of the programme. These can be divided into two separate categories of influencing variables:

a) *Moderator variables* – represent a set of variables that modify (reduce/increase) the relationship between the programme and the behaviour; they relate to the context and the characteristics of the surroundings, the ecology of the child’s environment, e.g. the child’s level of vulnerability, the family’s poverty, the level of resilience (in theory referred to as the “suppressed connection”).

b) *Mediator variables* – they consist of a set of variables that regulate the relationship between the programme and the behaviour, e.g. the credibility and the attractiveness of the source of information (credibility of the source, personality of the lecturer, expertise, attractiveness and relevance of the topic), the style, the structure and the content of the information conveyed (facts, space for reflection, emotions, complexity of the information), the characteristics of the recipients of the information (maturity of the children, age), the quality and the preparation of the programme, etc. In addition, the degree of programme readiness reduces or increases the influence on attitudes and is a prerequisite for successfully inducing a change or an attitude formation (in theory referred to as a “developmental sequence”).

These variables intervene and influence the causal relationship. Therefore, they need to be “under control”. Figure 1 illustrates the relationships and the influences between each category of variables that describe the *causal relational framework* that became the initial framework for the measurement.

Figure 1: Causal model of relationships between variables



The need to analyse causal relationships led to the use of quantitative research methods. The underlying assumption was that a well-designed and prepared prevention programme should lead to greater resilience of participants to risk behaviour and strengthening of their social functioning. The basic starting method was the *quasi-experimental Difference-in-Differences (DiD) method*, which was extended to include *mediation and moderation analyses*. Both approaches complemented each other, creating the preconditions for measuring causal relationships while controlling the influences (suppressed association, developmental sequence).

The Difference-in-Differences (DiD) method is one of the most commonly used methods in impact evaluation studies (Fredriksson, Oliveira, 2019). It is based on a procedure that is able to determine the impact of a prevention programme based on the observed outcomes using two difference measures, the first one determined by time and the second one by the identification of control and target groups (Potluka, Špaček, 2014; Greene, Liu, 2020). Therefore, within the method, one difference is determined by time (before and after the intervention) and the other by subjects (supported and unsupported). In our case, we chose to observe differences before the start of the prevention programme and then after at least one month after the end of the programme. Furthermore, we compared two groups – a target group (supported) that completed the prevention programme and a control group that did not participate in the programme (unsupported). We selected the group randomly so that it had the same or very similar background (e.g. neighboring class, class from a similar school in the city). Within these "four groups", data were generated through a single questionnaire.[2]

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[2] The calculation of Difference-in-Differences (DiD) followed the formula: DiD = (CT1 – CT0) – (KT1 – KT0), where CT1 = Target group after the programme, CT0 = Target group before the programme, KT1 = Control group after the programme and KT0 = Control group before the programme.

The degree of influence of other variables was determined by mediation and moderation analysis using a linear regression. Mediation analysis does not identify a simple relationship between two phenomena, but is a deeper analysis of the process that takes place between these variables. Mediation is most often used to analyse various intervention programmes and measure their impacts. Within its framework, it examines the relationship between two variables: the independent variable, in other words, the cause, and the dependent variable, in other words, the effect (Baron, Kenny, 1986, p. 1174). The main goal is to find out how the variable X affects the variable Y through one or more mediator variables. Thus, variation in the variable X causes variation in one or more mediators M, which in turn cause variation in the variable Y. Subsequently, empirical relationships are tested using a statistical methodological approach (Hayes, 2013; Iacobucci, 2008).

Mediation analysis describes the direct or indirect ways in which the independent variable X transmits its effect on the dependent variable Y through one or a set of mediator variables. Therefore, the mediator variable enters directly into the examined relationship and indicates the ways in which the studied phenomena are interrelated (MacKinnon, 2008). While the mediator is a variable which is directly inserted into the relationship between two variables and influences the entire relationship of the model, the moderator can be considered a variable that influences the strength of the relationship and possibly the direction between the independent and the dependent variable. Mediator variables are able to show how phenomena are related (Baron, Kenny 1986, p. 1174). The aim of *moderation analysis* is to determine whether the strength of the relationship between X and Y depends on the moderator variable. Mediators focus on the mechanisms through which the effect occurs, while the moderator provides information about when the effects are present (MacKinnon, 2007). Moderation analysis examines the extent to which the relationship between the independent and the dependent variable is influenced by one or more other variables. The moderator variable (or a set of variables) influences the strength of the examined relationship between the independent and the dependent variable, or alternatively, their direction (MacKinnon 2008).

MEASURED PRIMARY PREVENTION PROGRAMME

The final outcomes presented in the text relate to the measured primary prevention programme, which focused on the development of classroom climate and positive relationships not only between classmates but also between students and teachers. It was implemented by the staff of the Pedagogical-Psychological Counselling Centre Ostrava (PPP). This organisation provides a range of primary prevention programmes for risk behaviour for primary and secondary schools in Ostrava.

The impact was measured in a programme aimed at primary school students in 6th grade and students in the first year of secondary school. The programme is complex, long-term and seeks to positively develop students’ personality, social skills and competences. It focuses on promoting a positive classroom climate and relationships among students through getting to know each other, appreciating each other and developing cooperation within the classroom. It aims to prevent the manifestation of risk behaviour, it is not a selective and indicated prevention programme (intervention work with the class). The programme was created as a completely new idea and was prepared according to the principles of effective primary prevention and in relation to the causes of risk behaviour. It is interactive, adapted to the age of the target group and the needs of the specific class. It is organised by PPP prevention methodologists and is available free of charge. The programme takes place in the school in pre-arranged premises. It consists of three sessions that last for two periods. The individual sessions build on each other.[3]

The PPP prevention methodologist clarifies the conditions for the implementation of the prevention programme with the school prevention methodologist and the teacher prior to the start of the programme. The participation of the class teacher in the sessions is considered essential. At the end of each meeting, the teacher and the lecturer evaluate the progress of the intervention and agree on a plan for the next meeting. The school then receives a written record summarising the process, the outcomes of the meeting and any recommendations for dealing with the class.

APPLICATION OF THE PREVENTION IMPACT MEASUREMENT MODEL

Moreover, we present impact measurement and its outcomes using a causal model and measurements in target and control groups. Firstly, all variables – attitudinal, mediator and moderator – had to be identified.

Attitudinal variables were constructed based on theories – especially the theory of reasoned action, social cognitive theory, learning theory and protection motivation theory. Attitudinal variables were sorted into three categories based on what they contribute to the prevention of risk behaviours:

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[3] The main goal of the first session is to gain new information that supports the ability to establish and develop healthy relationships in the classroom. The programme focuses on activities, games, group discussion and reflection to encourage students to get to know each other in a different way than they are normally used to. The second meeting aims to convey the positive value of collaboration through team activities and subsequent reflection to students. Collaborative activities and games are part of this session. These activities are followed by a group discussion and reflection. The purpose of the third meeting is to promote classroom relationships through activities focused on mutual appreciation and positive perceptions of classmates. The agenda again includes activities and games aimed at finding good qualities and appreciating each other. Group discussion and evaluation of the activities are also part of each activity.

a) strengthening of social functioning – at the individual level[4]
b) strengthening of social functioning – at the environmental level[5]
c) resilience to risk behaviour[6]

Determining the mediator and moderator variables was much more complicated than expected. It was difficult to identify/find specific influence variables. We anticipated that there was a need to construct a set of variables that reflected the experience of the lecturers of the prevention programmes. Therefore, we held two focus group discussions with experts, who had direct experience of lecturing or evaluating prevention programmes. In the discussions, external and internal factors that, according to the experts' experience, influence the effectiveness of the programmes were identified. After categorization of these findings, moderator and mediator variables were created.

Moderator variables included: measurement span, prevention object, programme length, programme re-design rate, programme preparation, overall assessment of programme readiness, momentary emotions, friends at school, positive relationship with school, friends outside of school, family support, safe family, belonging to a socially excluded locality, frequency of moving, support from close friends and family and life satisfaction.

Mediator variables included: participant gender; participant age; motivation to participate; I liked the programme; I felt good during the programme; the programme was up-to-date; I had experience with the mentioned problems; the programme raised concerns; the programme was engaging; it did not repeat the already known information; the programme was entertaining; it was funny; the lecturer was understandable; the lecturer was credible; there was an opportunity to participate; nothing disturbed the programme; I was active; I received a reward; I have not attended a similar programme this year; it worked with illustrative examples; stories, the programme was too long; it offered alternative behaviour patterns; the lecturer used modern technology; I learned specific information; it covered what I did not know; I discussed the programme with friends; I would recommend the programme to friends; I discussed the programme with my family; I applied what I learned; overall evaluation of the programme.

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[4] Belief in the correct behaviour; Knowing where to seek help; Ability to offer help; Absence of one's own risk behaviour; Refraining from risk behaviour in the future; Ability to point out bad behaviour; Awareness of the consequences of one's own risk behaviour; Ability to accept praise; Successful social functioning.

[5] Expectation of appreciation of behaviour by the social environment; Mutual peer support; Respect for instructions of moral authority; Healthy pro-social way of life; Awareness of the norm of (correct) behaviour; Respect for behavioural norms.

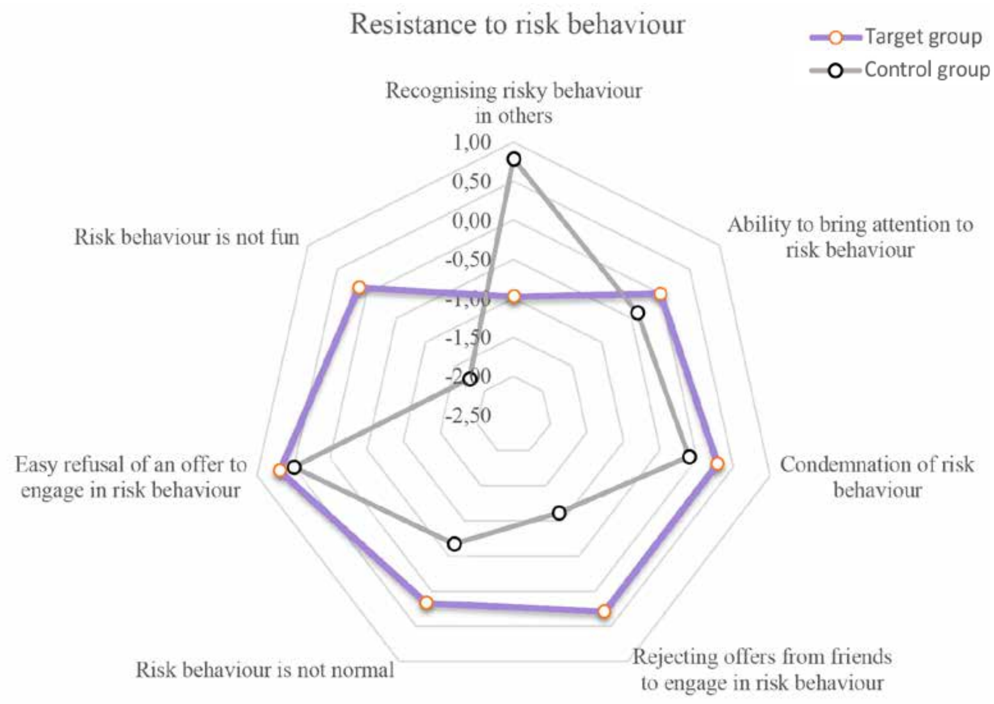
[6] Recognition of risk behaviour in others; Ability to point out risk behaviour; Condemnation of risk behaviour; Refusal of friends' offers to engage in risk behaviour; Risk behaviour is not normal; Easy refusal of offers to engage in risk behaviour; Risk behaviour is not fun; Refusal of risk behaviour under pressure.

This was followed by the creation of a questionnaire. Firstly, a universal questionnaire was created and all variables were incorporated into it. The traits were created and then the questions were formulated. The wording of the questions and the dramaturgy of the questionnaire were adapted directly to the evaluated prevention programme and its participants. Data collection took place in two time slots (before and after the programme), spaced at least one month apart. In addition, the questionnaire distributed after the prevention programme was expanded to include a set of questions measuring respondents' satisfaction with the programme. Data collection was similar for the control group, with the same time interval as for the target/supported group. Each questionnaire contained a respondent identifier, which subsequently allowed pairing the questionnaires.

The questionnaires were collected between March and June 2022 from the target group in six schools (four primary schools and two secondary schools). For the control group, the collection took place in two primary schools in the 6th grade. A total of 105 questionnaires were paired for the target group and 28 for the control group. A total of 133 questionnaires were then evaluated. Finally, an analysis followed. Their results are briefly summarized below.

For each of the three categories of attitudinal variables, the difference between the control and the target groups was calculated. For the category of resilience to risk behaviour, the results can be seen in the following graph.

Graph 1 Resistance to risk behaviour – difference in shifts between control and target group

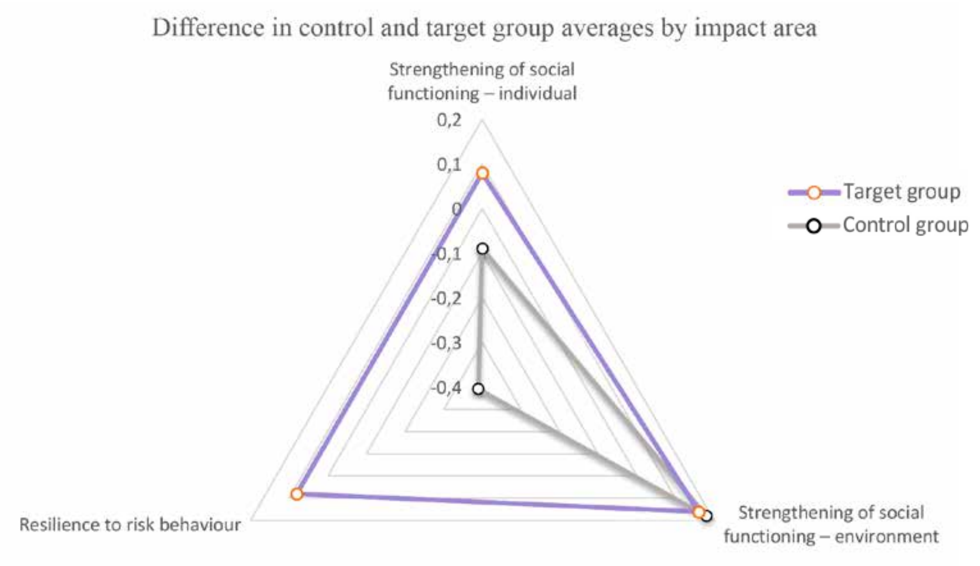


We observed an increase in resilience to risk behaviour over time in the target/supported group. This relates in particular to the ability to reject risk behaviour and resist peer pressure (the offer of friends to engage in risk behaviour) and the acceptance that risk behaviour is not an appropriate leisure activity. Values also increased for the statement that risk behaviour cannot be considered the norm (normal), for the condemnation of risk behaviour, for the ability to bring risk behaviour to the attention of others (peers, teachers, family members) and for the evaluation of the unpretentiousness of refusing risk behaviour (evaluation of how easy it is to refuse an incentive). However, there is one point where the evaluation differs. It concerns the recognition of risk behaviour in others. In contrast, there was an improvement in the control group. The explanation for this may be that the measured prevention programme focused primarily on the theme of developing classroom climate and positive relationships, rather than on strengthening of social functioning at the level of the "external" environment.

Nevertheless, it cannot be ruled out that the children realised that the behaviour could be hidden and thus difficult to detect. Children who completed the programme may think more about how difficult it is to identify risk behaviour, know which risk behaviour can occur among children and approach the subject more responsibly. However, it cannot be dismissed that in the control group there may have occurred a phenomenon that we did not detect, for example, the students may have encountered some kind of risk behaviour, solved an incident in the classroom, which may have "positively" influenced their recognition skills.

Looking at the final comparison of differences across the three attitude areas, the programme had the greatest impact in the area of resilience to risk behaviour. Moreover, it had a positive, though not as large, impact on strengthening of social functioning on the individual level. No impacts were found in strengthening of social functioning at the level of the environment. This is logical as the programme did not target this area.

Graph 2 Difference in control and target group averages by impact area



If we refrain from categorizing the observed impacts in the areas of strengthening of social functioning and look at the impacts through the values of each variable, then it is clear that the greatest impact of the programme were found in the condemnation of risk behaviour, rejection of friends' offers to engage in risk behaviour, the ability to bring attention to individuals' bad behaviour, rejection of risk behaviour as a leisure activity and respect for behavioural norms.

Mediation and moderation analyses showed that mediator variables had no effect on the impact of the programme. In other words, environmental and other suppressed connections do not manifest themselves. We believe that this is due to the fact that the children come from an ordinary social environment that is not burdened by unfavourable characteristics. In the moderation analysis, however, the influences of some variables were significant. Resilience to risk behaviour was the most affected area, with moderator variables affecting up to one-third of this. In particular, resilience is positively affected by the presence of friends at school, i.e. establishing strong social relationships (35.7 %), and on the other hand, it is reduced by the frequency of moving (36.6 %) – i.e. the instability of children in a place. Stronger influences are also seen for the strengthening of social functioning at the environmental level, e.g. almost two-fifths of this is positively influenced by living in a safe family (38.2 %) or by declared life satisfaction (38.4 %). The values of the moderator variables' influence on the strengthening of the individual's social functioning were much smaller, with approximately one-fifth of the influence coming from momentary emotions (19.3 %) and support from the close surroundings (19.5 %).

FINAL DISCUSSION

Most of the time it is intuitively assumed that prevention is helpful, but the actual impact is rarely specified. There is considerable scepticism about our ability to measure the impact of prevention programmes and services. We hope that the text dispels these doubts and approaches measuring the impact of prevention programmes as a challenge. It presents an example of measuring the impact by demonstrating a model for measuring a primary prevention programme that focuses on the development of classroom climate and positive relationships, not only among classmates.

The design of the model for measuring the impact of prevention was based on the idea that there is no easily measurable direct causal relationship between the prevention programme and the prevention of risk behaviour in children and focused on observing changes in children's attitudes. At the same time, it also examined the degree of influence of other circumstances that may strengthen or weaken this impact. The impact was evaluated in three areas: strengthening of social functioning – at the individual level; strengthening of social functioning – at the environmental level, and resilience to risk behaviour.

The answer to the question whether the implementation of the prevention programme has resulted in the participants being more resilient to social failure is yes. Resilience is the area that the prevention programme impacted the most. We can discuss the extent of this impact. When comparing the averages in the different areas, there were no dramatic changes. However, we have to take into account that the programme's focus was on developing a classroom climate and positive relationships, i.e. social relationships that are formed over time and are complex and less easily influenced by one-time interventions from the outside. This shows that expectations of change need to be set in relation to the opportunities and conditions in which the intervention takes place. Nevertheless, we can be satisfied that even after more than a month the programme is still showing results in the form of higher levels of children's resilience to risk behaviour. In particular, the children's ability to reject risk behaviour, their ability to resist peer pressure and their acceptance that risk behaviour is not an appropriate leisure activity increased. The impact is also visible in the fact that children do not consider risk behaviour to be a norm, the condemnation of risk behaviour increased, the ability to point out risk behaviour also increased and children are prepared to reject risk behaviour more easily.

What can we say to the question about the manifestation of impact in different areas of social functioning? The programme had a positive, albeit not so large, impact on strengthening of social functioning at the individual level. We did not find any impact in the area of strengthening of social functioning at the environmental level. This is logical because the programme did not target this specific area. The largest impact were observed in the areas of condemnation of risk behaviour, rejection of friends' offers to engage in risk behaviour, ability to draw an individual's attention to bad behaviour, rejection of risk behaviour as a leisure activity and respect for behavioural norms.

We find it interesting that no mediator variables showed an influence on the overall programme impact. This is probably determined by the social composition of the children, who come from ordinary social backgrounds. However, for the moderation analysis, the effects of some variables are significant. Resilience to risk behaviour was the most influenced area, with moderator variables affecting up to one-third of it. Stronger influences were also observed for strengthening of social functioning, where the characteristics of the child's background and the safety of the family environment are particularly prominent.

It is clear that, based on the results and findings, programme implementers can think of a number of improvements. Similarly, schools can safely offer the tested programme to their students and teachers.

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3 ASPECTS OF EDUCATION IN THE DEVELOPMENT OF A CHILD WITH SCHOOL FAILURE RISK

3.1 THE IMPACT OF DISTANCE LEARNING ON THE MENTAL HEALTH OF PUPILS, THEIR SOCIAL AND COMMUNICATION SKILLS – OBSERVATIONS FROM SCHOOL SPEECH THERAPY PRACTICE

Yveta Odstrčilíková, Kristína Papajová and Petra Volná

INTRODUCTION

We were inspired to address the issue of the impact of distance learning on the mental health of pupils, their social and communication skills by the thematic report of the Czech School Inspectorate (CSI), which focused on distance education in primary and secondary schools and described the approaches, shifts and experiences of schools one year since the onset of the Covid-19 disease pandemic. It focused, among other things, on pupils with special educational needs (SEN), for whom it recorded significantly lower participation in online synchronous learning than for pupils without SEN. The highest level of participation in online synchronous learning was recorded by the CSI for pupils with SEN at the second level of primary schools. For all pupils, the Czech School Inspectorate found a higher rate of delegation of educational responsibilities to legal representatives (Pavlas, Zatloukal, Andrys & Neumajer, 2021).

The paper is focused on mapping and the impact of distance learning on the mental health of pupils, their social and communication skills, and the possibility of preparation in a family environment. Significant observations of teachers/parents with online education, based on data from a questionnaire survey, were processed for further procedures of special education interventions in practice. Also, the paper reflects practical experiences from conducting online individual speech therapy interventions in a special education centre and the possibility of cooperation in families with children with impaired communication skills.

According to legal representatives, pupils learned less in distance learning than in full-time education. They believe that this situation will have a long-term negative impact on education. On the contrary, they welcome the fact that children have learned to work independently and have improved their use of educational applications (Nielsen Admosphere, 2021).

In connection with distance learning, we can also mention the increase in the number of pupils in individual education (Český statistický úřad, 2022), which we have also encountered in our Special Education Centre for Children with Speech Disorders (SPC). Overall, the increase of pupils in individual education for both grades was 27.6 % compared to the school years 2020/2021 and 2021/2022 (Český statistický úřad, 2022). This may to some extent be related to the fact that 20 % of parents found the distance form of education more suitable than the full-time form (Nielsen Admosphere, 2021).

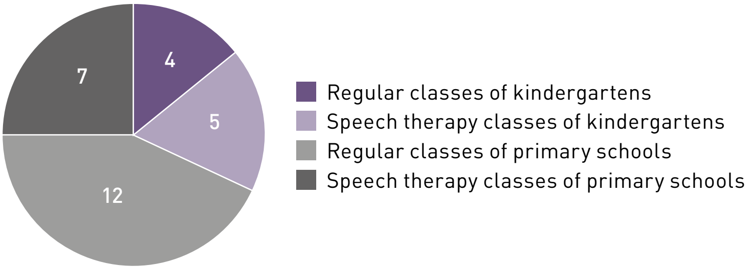
The service of the SPC was maintained during the epidemic of Covid-19 disease, but was adapted to the current situation according to the Emergency Measure of the Ministry of Health. Therefore, for a period of time, speech therapy intervention was provided to clients in an online form. In the conclusion of the post, insights and information that were obtained during the online interventions were presented.

In terms of students' social skills and mental health, 63% of parents perceived the lack of extracurricular activities as problematic during the distance learning period. About half of the parents also identified their child's dependence on digital devices as a problem, which was created or intensified as a result of the pandemic and distance learning. Increased family tension due to uncertainty and fear caused by the pandemic was reported by 16 % of parents (Nielsen Admosphere, 2021). Similarly, a press release from the Helpline and Parents' Helpline (Linka bezpečí, 2021) shows an increase of mental health problems (up 45 % year-on-year), internet problems (up 18 % year-on-year) in helpline enquiries. The Parent Helpline for 2021 published a significant increase of 66 % in the topic of mental health difficulties in children, with parents most frequently addressing the topic of self-harm, anxiety, depression and suicidal thoughts in children and adolescents.

INVESTIGATION

On the basis of the above-mentioned professional documents, a questionnaire survey was carried out in order to map the impact of distance learning on teachers' perception of children and pupils with impaired communication skills. The questionnaire contained a total of 10 closed questions to which teachers chose their answers from the options YES x NO x DON'T KNOW. The last part was devoted to the possibility of expressing their own opinions, observations from practice. The questionnaires were distributed online through a web link sent to specific e-mail addresses of teachers of kindergartens and primary schools in the Zlín Region, where children and pupils with impaired communication skills. are educated. A total of 131 school establishments were contacted and 28 completed questionnaires were returned. Of this number, 5 questionnaires were from speech therapy classes of kindergartens, 7 from speech therapy classes of primary schools, 4 from regular classes of kindergartens, 12 from regular classes of primary schools.

Chart 1: Percentage of different types of schools

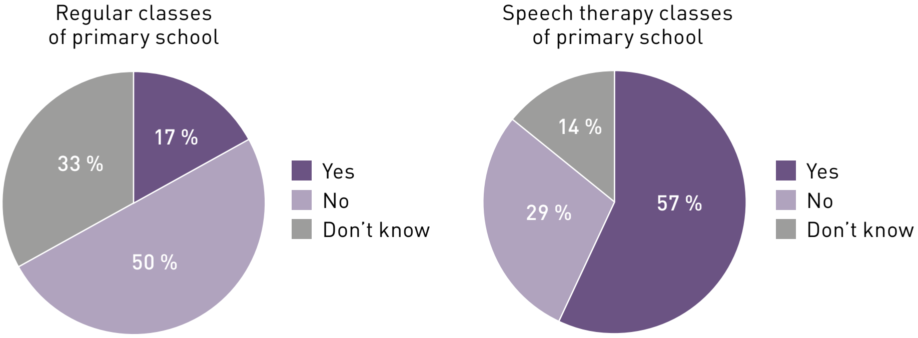


RESULTS OF THE INVESTIGATION

From the questionnaire survey, which focused on the impact of distance learning on students' mental health, social and communication skills, it was found that:

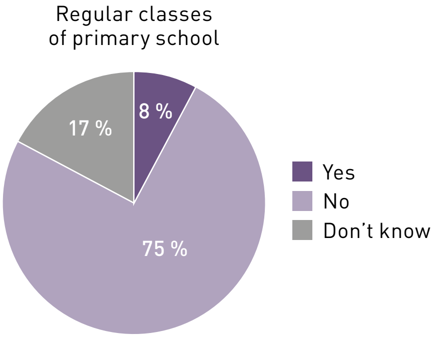
1. Chart 2 shows the percentage comparison of the system of regular and speech therapy classes in primary schools on the question of whether teachers observed an increase in the overuse of electronic devices, the Internet and social networks among pupils with impaired communication skills. The results show that teachers from speech therapy classes of primary schools registered a higher increase in the overuse of the above-mentioned electronic devices among their pupils compared to teachers from regular classes of primary schools.

Chart 2: Percentage comparison of the system of regular and speech therapy classes in primary schools



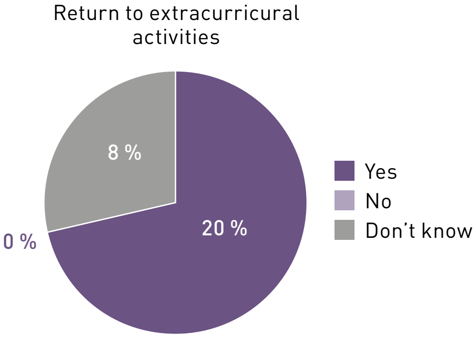
2. Regarding the question of the increase in psychological difficulties of pupils with impaired communication skills during or after distance learning, teachers of speech therapy classes in kindergartens and primary schools and regular kindergarten classes answered that they did not observe any change. Only teachers from regular primary school classes observed an increase in psychological difficulties, and only in a minimal number of cases (Chart 3).

Chart 3: Percentage of increase in psychological difficulties among pupils from mainstream classes of primary school



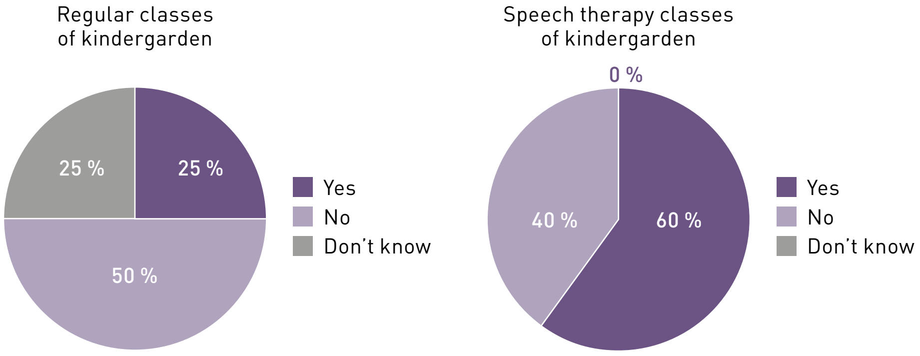
3. Teachers in the surveyed sample from all types of schools report that most children and pupils have returned to their extracurricular activities. The answer "Don't know" was mainly chosen by the teachers of kindergartens.

Chart 4: Percentage of children and pupils returning to extracurricular activities.



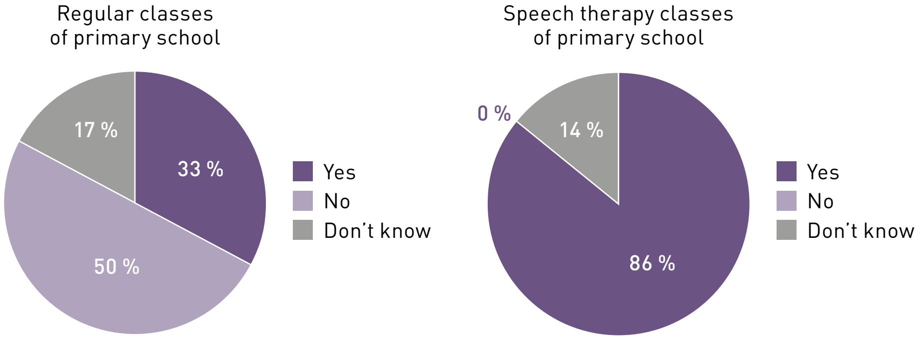
4. Chart 5 presents a percentage comparison of the system of regular and speech therapy classes in kindergartens on the question whether teachers observed a worsening of symptoms of impaired communication skills during the distance learning period. It can be observed that teachers from speech therapy classes in kindergartens registered a higher increase in the worsening of symptoms of impaired communication skills than teachers from regular kindergarten classes.

Chart 5: Percentage comparison of the system of regular and speech therapy classes in kindergartens



5. When asked whether teachers recorded greater comprehension difficulties for pupils with impaired communication skills during distance learning, positive responses were more frequently recorded among teachers from speech therapy classes in primary schools, as can be seen in Chart 6.

Chart 6: Percentage comparison of the system of regular and speech therapy classes in primary schools



CONCLUSION

The questionnaire survey and the online speech therapy interventions implemented in the SPC provided insights and information that could be used in the future, e.g. in the case of the reintroduction of distance learning:

1. There is a need for awareness-raising in the context of addictions to electronic devices and digital literacy.

2. In the case of clients with impaired communication skills, this survey sample did not show a need for an across-the-board increase in psychological care.
3. A very positive finding is that pupils are returning to extracurricular activities, but it is still necessary to continue to educate them about their importance.
4. It is advisable to inform the teachers in the kindergarten speech therapy classes regarding the possibility of providing speech therapy intervention during the distance learning period.
5. It is desirable to provide methodological support to teachers from speech therapy classes in primary schools in the area of supporting pupils' understanding during distance learning.
6. For online speech therapy intervention it is necessary to provide a suitable PC program, acceptable technical equipment, a quiet environment and the presence of a legal representative. It is essential to use more frequent motivation and include relaxation activities and manipulative activities.

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3.2 THE INFLUENCE OF THE FAMILY ENVIRONMENT ON THE SCHOOL PERFORMANCE OF STUDENTS

Alexandra Honová and Kateřina Janků

INTRODUCTION

School success means achieving good results and progress in education, it can be considered as a positive synonym for the results of pupils' work in the classroom, while pupils themselves most often associate school success with classification, grades and basically with the overall assessment of their abilities. For teachers and parents, school success should essentially mean the opposite of school failure, which is often defined as a situation where a pupil does not achieve the expected educational outcomes. This situation may be manifested, for example, by lowered grades, repeating a bad grade, failing tests or exams, but also by problem or risky behaviour or inadequate levels of communication with teachers and classmates. In this paper, we will show how the family environment can influence the school performance of pupils. We have chosen to convey the information in the form of two case studies, the first of which shows the negative consequences of an uncooperative family and the absence of any concern for the child who is failing not only in school but also in his/her everyday life. In the second case, we will show the positive value of maintaining a regular school routine and supporting the pupil in a holistic way, even in his/her free time, and how this is evident in the pupil's school performance.

There are many factors that can cause school failure, such as poor study habits, inappropriate educational methods, improper motivation to study, low self-esteem, health problems or difficulties in the family environment. School failure can also be caused by a lack of support and assistance from teachers and the school. It is important to recognise that school failure is not only a matter of individual performance but is also influenced by the education system and the wider social and cultural context. It is therefore important to look for solutions to school failure not only at the level of the individual but also at the level of the system and educational policy.

Conceptually, the strategies towards preventing pupils' school failure belong to the Minimum Prevention Programme, which is a binding document for the school. Preventing school failure is an activity in which the whole school counselling team should be involved, not just the prevention methodologist. The specific content of this strategy for preventing school failure, bullying and other forms of risk behaviour is not laid down in any binding legislation or methodological material. There is no uniform template for its inclusion in the school's documentation. In conclusion, the development of a strategy to prevent school failure, as well as to prevent bullying and other manifestations of problematic or risky behaviour is a continuous process and the follow-up documentation should be "tailored" to the pupils of the school. Promoting pupils' success at school is therefore primarily based on a school atmosphere in which each pupil's learning is supported, which is reflected in good interpersonal relationships between pupils, between pupils and teachers, and between the school, pupils and their legal guardians. We are talking about mutual and positive cooperation between the different actors of education (Pushkina and Musilova, 2018; Kohoutek, 2018).

Student success or failure in school can be measured in a variety of ways, including grades and grading, standardized tests, academic progress indicators, etc. Its negative consequences can be severe and can include lowered self-esteem and self-worth, social exclusion, failure to reach their full potential, and even a negative impact on children's future career and life success. This is why it is important to identify the causes of school failure in particular pupils early on and to actively try to address them. This may include providing support services such as individual attention, tutoring, individual therapy or counselling, changes in the environment or approach to education, or working to improve communication and relationships with family, teachers and classmates. As stated by Knoll and Troníčková (2017), it is appropriate to distinguish between progressive (absolute) school failure, where the pupil fails overall due to a lack of intellect, and temporary, transient or partial school failure, which is associated with extra-intellectual reasons that can usually be eliminated. Some of these possible causes may include lack of motivation to learn, poor study habits, inappropriate learning environments, poor relationships with teachers or classmates, disrupted family relationships, or other personal or health problems. Although school success may be influenced by school-related factors – the quality of education, including the way in which learning material is delivered and presented, the manner of assessment, the way in which teaching is conducted, and its preferred forms and methods – our text focuses primarily on family-related factors and the family's potential relationship to the school and the student's school responsibilities. Smetáčková and Štech (2021) summarize in their research study the fact that research on the family's influence on pupils' school achievement focuses mainly on four areas, namely, the structural characteristics of the family, such as, for example, the socioeconomic status of the family, the process variables in relation to school (parenting styles and family support for schooling), the aspirations and ambitions of parents in relation to their children's planned education, and the factors that threaten their fulfilment.

The family environment plays an important role in shaping pupils' school achievement. Parents, as well as other family members – siblings, grandparents, extended family etc – can clearly support their children and help them to do well at school or, conversely, can contribute to school failure. A supportive family environment can then motivate pupils to learn and encourage their interest in education. Parents should be active partners in helping their children develop a positive attitude towards learning and towards school as an institution. Examples of this may include help with homework, support for learning-related interests and activities, regular conversations about school performance and goals, and many other activities.

On the other hand, an adverse family environment can contribute to school failure. Parents who do not express an interest in their children's education or parents who criticize their efforts can create a negative relationship between students and school, demotivation and disinterest. They can also make their children feel alone, without the support and help they need from their families. Zezulková and Janků (2020) point to the unity of educational and educational action by the school and parents as a fundamental pedagogical principle that supports the quality development of children. The need to apply the principle of unity of educational action appears to be crucial, especially in the current conditions of inclusive education. Parents need to be actively involved in their children's educational process, to be informed about what is happening at school and to be able to share their views and concerns with teachers and other professionals. It is important to create a space for open communication between parents and teachers so that problems can be solved quickly and effectively (Zezulková and Janků, 2020; Průcha, 2013).

The occurrence of problem and risky behaviour of pupils, which is related to school failure of pupils, increases over time, fixes and shapes the personality of the pupil himself. Consequently, the effectiveness of any further intervention does not correspond to the efforts expended by educators, and everything is much harder and takes longer to resolve. Pupils with manifestations of risk behaviour have serious deficits in the emotional sphere, which limit them in relation to themselves and the subjectively important circumstances of their lives, as well as in their success in establishing and maintaining appropriate interpersonal relationships. They often face mistrust from classmates and teachers who do not know how to react to different behaviour. Disruptions in social skills can significantly impair adaptation to the school environment and the educational process. Long-term unresolved deficits in social skills of communication, cooperation with peers, establishing social relationships with adults, etc. can transform into problem behaviour (Zezulková et al, 2023).

The documented case studies, just a small part of which we present here, are evidence of the life of a boy from a dysfunctional family environment without adequate and long-term support from the state system, and in the second case, on the contrary, of a boy with functioning social support, despite living in a dysfunctional family environment. Both selected pupils were closely monitored by the educational counsellor in the primary school throughout their schooling. The case studies have been anonymised and structured based on the authors' stated aims, namely to show, through concrete examples, key moments in the lives and schooling of both boys that had an impact on the primary school environment and, consequently, on the future of both boys.

CASE STUDIES

1. Case study

A present case is that of an 18-year-old young man whose childhood was marked by a completely dysfunctional family. During his pre-school and junior school years, this boy lived in a family that was failing miserably in all areas of meeting basic human needs. As a result of the non-caring family, the boy found himself in a situation where, practically from the 3rd grade onwards, he had to stop attending school. Initially, it was a case of truancy covered by the family, when the mother and father did not send him to school, and later it was a case of targeted truancy as a result of the child's loss of regular activities and work habits. The development of all the life events involved in this boy's story is very negative and probably not over yet.

Family history: Parents: mother, born in 1984, unmarried with no education; father, foreign national, never living with the family, the boy was raised by his siblings' father (born in 1981). Siblings: sister born in 2004, brother born in 2008, brother born in 2010, brother born in 2012, sister born in 2014, brother born in 2016, sister born in 2018, sister born in 2019, brother born in 2021. Of the 9 half-siblings, the boy has 5 brothers and 4 sisters.

The family changed accommodation approximately every two years, the last permanent accommodation of the family was a hostel, room 1+0, kitchen and bathroom in the corridor, all shared by several families. The family had a history of repeated domestic violence against the mother, who was beaten and kicked by the father in a drunken state, which was witnessed by the children. In addition, the stepfather was a substance abuser.

Personal history: The boy was born spontaneously, by head, unbaptized, was breastfed until about 3 years of age, no recorded injuries, common childhood illnesses were recorded, which passed without complications. Speech development was significantly delayed, as was psychomotor development due to an unstimulating environment. According to the paediatrician, turning of the child was recorded at about 9–10 months, the boy did not crawl or climb, he started to walk at about 1.5 years of age.

Report from the school environment – selected facts: The boy did not attend kindergarten, preschool education was provided only in the preparatory class of primary school, where he entered at the age of 5. Following enrolment in Grade 1, the child's legal guardian was advised to consider deferring compulsory schooling, which was subsequently implemented, for the 2012/2013 school year. As part of the deferral of compulsory schooling, he again attended the preparatory year of the same school.

Already at this time, an initial pedagogical diagnosis revealed a significant speech deficit. For this reason, the boy was examined at the Special Education Centre for speech defects and the following conclusions were made: Delayed speech development, articulatory clumsiness and delays in the phonetic-phonological plane (auditory discrimination of the sounds of the mother tongue and their pronunciation), in the lexical-semantic plane (understanding of speech within the range of ordinary speech, at the same time also understanding of instructions, interpretation, concepts, messages, narration), in the morphological-syntactic level (use of individual word types, bending of words – timing, inflection, forming sentences and clauses), and in the pragmatic level of speech (use of speech in practice, in social context, e.g. The ability to request or announce information, express relationships, feelings, experiences, events, etc.).

The conclusions of the Special Education Centre showed that:

- Compound instructions need to be simplified and repeated for the boy due to impaired short-term auditory memory.
- The boy's speech is dyslexic, unintelligible and there are repetitions of vowels/syllables at the beginning, middle and end of words.
- The boy's speech articulation status: rhotacism bohemicus.
- The boy's auditory analysis and synthesis skills are well below the norm.
- Vocabulary is at a low level for his age, in particular his understanding of temporal and spatial relationships is poor.
- The boy cooperates reluctantly, without interest or motivation. He resigns in advance to a number of tasks and answers 'I don't know'. The examination revealed impaired communication skills in terms of sound, content and grammar.

As a result, the boy spoke only in simple sentences with agrammatism and had difficulty pronouncing multisyllabic words. He was inattentive at work studies, did not like to finish his them, and showed a general reluctance to this.

He was often very tired in the school environment, which was the result of an unsatisfactory home environment where he did not have his own bed, he slept with his siblings on the floor, and there were always younger children present in the household who often got up at night and cried.

Following an assessment at the Special Education Centre for speech impediments, the mother was referred to and provided with specialist speech and language therapy by a clinical speech and language therapist in collaboration with the school special education teacher. Unfortunately, the mother only attended twice, and despite intervention by the Department of Social Services and a non-profit organization, no further visits to the speech therapist occurred. Therefore, all speech therapy care was only implemented at school.

In 2017, at the age of 12, the boy was transferred to the care of the Special Education Centre for Pupils with Learning Disabilities, following a recommendation from the Special Education Centre for Speech Defects. At this time, the boy already has very significant difficulties in expressing himself independently, due to severe impairment of speech fluency, which significantly affects his school performance and behaviour towards his classmates. The global level of intellectual ability was currently in the middle of the mild intellectual disability range.

School attendance: The boy started Year 1 in the 2013/2014 school year and has already missed 175 excused lessons in the first half of the year. Attendance deteriorated significantly in the second half of the year, when he missed 96 hours with excused absence and 40 hours without excused absence. Considering the age of the child, it can clearly be said that this was truancy caused by the child's legal guardians. The primary school where the boy entered follows strictly the Methodological Guideline of the Ministry of Education in these cases of truancy, and any unexcused absence of more than 25 hours is duly reported to the Department of Social Affairs and the Misdemeanour Department. In Year 1, despite the individual approach, tutoring at school and the presence of a teaching assistant in the classroom, the boy's educational failure continues and he ends with failing grades in all core subjects.

In the 2014/2015 school year, he repeats Year 1, now successfully, but we are also experiencing very high excused and unexcused absences.

In the 2015/2016 and 2016/2017 school years, the boy is repeatedly failing school and is graded inadequate again in most core subjects.

The school has repeatedly requested the Department of Child Welfare to intervene with the family. This has occurred, with the family being contacted by a non-profit organization. However, cooperation with the non-profit organization is optional and on a voluntary level and therefore very often fails. Court supervision was established in the family because problems with high unexcused absences began to occur with all the other school-age children.

In the 2017/2018 school year, the pupil practically does not attend school at all – at that time he was a pupil of the 4th year and fulfilled the 5th year of compulsory school attendance.

The school, through the guidance counsellor and the school counselling centre, intervened monthly in writing in case of the pupil's absences, yet there was no timely intervention by the state and the boy's development was severely damaged.

Table 1: An overview of the pupil's absenteeism trends during his time at school

Nr. of hours	2013/2014 1. grade	2014/2015	2015/2016	2016/2017	2017/2018	2018/2019 5. grade
Excused	271	251	155	352	15	7
Not excused	40	60	90	86	597	619

The child had been arbitrarily leaving the family since the fourth grade, spending time away from home without explanation or parental knowledge. During this time, minor crimes of theft were committed. Over time, there was an escalation in the student's behavior, where he got away with de facto criminal activity. The boy repeatedly committed robberies against younger children in cooperation with other children, often stealing only small items, but there were quite brutal physical attacks and these victims were severely traumatized. This situation lasted for a very long period of time, two whole school years, when the boy was practically not attending school and there was no court decision on educational measures in the sense of ordering institutional or protective education. This did not happen until October 2019, when the boy was placed in a children's home with a school, at the age of 14. The other school-age siblings were also placed in a children's home. There were only 2 children left in the family, who at the time were of pre-school and toddler age. Despite the placement of the boy in a children's home with school, there was no improvement in attendance and school performance, as the boy was permanently on the run, where he continued to commit serious crimes. There have been repeated brutal physical attacks by him, the most recent being the robbery of a nearly 80-year-old woman. Following this incident, the boy was placed in a remand prison and was finally sentenced to imprisonment by a court decision.

Conclusion

De facto, we can conclude that there has been a total devastation of the child's personality without adequate upbringing, when his free and moral qualities have not formed in any way. Clearly, there has been a total absence of meaningfulness and effectiveness of family upbringing, which has led to a situation where the boy is currently completely illiterate, does not read, does not write. In our opinion, further socialisation, or resocialisation within the framework of an institutional stay, has very little chance of success. The boy completely ignores social norms and principles of behaviour in society. In fact, it can be said that he does not know the social norms of behaviour. Given his childhood, his family situation and the marked deprivation in all components of his personality, this is the result of a long-term crisis he has experienced since childhood. Intervention by aid organisations and the public authorities should have been more intensive and, above all, timely. Family environmental pathologies have clearly affected the development of this child's personality.

2. Case study

The second case study concerns a boy for whom compulsory schooling and the support of the state system brought about a major life transformation, and which helped him in a fundamental way to move towards a better future.

Family history: Parents: mother born in 1979, unmarried with no education and on long-term parental leave; father born in 1959, educated, working. Siblings: brother born in 2007 with mild intellectual disability and behavioural disorder, sister born in 2008 with moderate intellectual disability, sister born in 2010 with delayed speech development, brother born in 2011 with moderate intellectual disability, sister born in 2013, brother born in 2015. The boy has three sisters and three brothers.

The family has moved 7 times in 5 years within different hostels, the last known place of accommodation is a unimobile. The parents' partnership is peaceful, they are very nice to each other in public and the mother has a dominant personality.

Personal history: The boy was born at term, by spontaneous delivery, the child was not baptized, walking since the age of 2, speech development was fine, no serious illnesses and injuries recorded by the paediatrician.

In 2017, the boy was diagnosed by a paediatric neurologist with attention deficit hyperactivity disorder (ADHD) marked impulsivity plus affective lability, and nocturnal enuresis with medication. At home, they complained of and verbal aggression, severe impulsivity, destruction of things, and disrespect for authority, which manifested itself in aggression towards both parents.

Report from the school environment – selected facts: The boy also did not attend kindergarten, and preschool education was again provided only in the preparatory class of the primary school, which he entered at the age of 5. This was followed by enrolment in Grade 1, at which point the child's legal guardian was advised to consider deferring compulsory schooling, which was subsequently implemented, for the 2015/2016 school year. As part of the deferral of compulsory schooling, he again attended the preparatory year of the same school.

In the 2016/2017 school year, the boy started the first year of primary school. The description of his negative behaviour, as interpreted by his mother, is completely different in the school environment. At school, the boy showed himself to be a bright boy interested in learning new information, calm, focused on work and on learning. He was very motivated to perform through praise and recognition. The boy was grateful for the individual attention and afternoon tutoring, where he reported on his own, even though his mother did not want him to do so because she had to wait longer to pick up his other siblings from school at the same time. The boy had an exemplary attendance record. The mother communicated at school that although she would sometimes like to have left him at home (e.g. because of the younger children's illness and complicated transport to school), her son insisted on attending school. The pupil's academic performance was exemplary throughout his schooling, with straight A's. He demanded attendance at the library in the after-school club, where he went individually with the teacher in the afternoon and borrowed books but did not take them home by his own choice, lest his siblings destroyed the books.

Regardless of the complicated family situation – a high number of children in the family, living in inadequate living conditions, siblings with different limits and disabilities, an older brother with a serious psychiatric diagnosis – the boy is fully aware, hardworking, trouble-free and eager to learn as much as possible. As early as the fourth grade, he started attending an organization providing tutoring and leisure activities for students on his own. Through this non-profit organization, he met a high school teacher who is involved in the organisation. Together with this teacher, they worked intensively on the admission process for the eight-year high school. The boy then successfully passed the exams and is currently a student at the Ostrava grammar school.

Conclusion

It is quite evident that despite a complicated family background and an unsatisfactory family situation that did not support the boy's learning and self-development, he was able to reach his potential on his own and to the maximum extent possible. Thanks to the support of the teachers and the support services set up, which the boy decided to make use of, and with the support of a specific person who was dedicated to him beyond the usual leisure activities provided, the boy was able to learn well. A crucial aspect of this case is the exceptionally strong desire and drive to continuously acquire new information and to keep learning.

SUMMARY

The two case studies we have presented here highlight a social and pedagogical practice that is occurring, and increasingly so, in our Czech schools. Many primary schools are dealing with cases of problematic families who do not take a proper interest in their children's education and do not place emphasis on educational values. The mismatch between parents' and teachers' views on children's preparation for school, their learning habits and learning outcomes is proving to be central to the personality formation of these children. The school has always been an institution that promots cooperation with the family and the community. The question remains regarding the motivation of families to get an education, which is unfortunately often zero. There is no choice but to work more with the children themselves, as seen in the second case study, and to fight boldly for a better future for them.

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3.3 PARTICIPATION OF CHILDREN AND PARENTS AS A KEY ELEMENT IN A PARENTAL EDUCATION PROGRAM

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INTRODUCTION

International treaties give the family an important role in the upbringing of their children (Bouma, et al., 2020). The Human Rights Convention (European Court of Human Rights, 1950) in Article 8 provides for the right to respect for private and family life unless there is a situation of lack of protection. Also, the Convention on the Rights of the Child (CRC, 1989) in Article 9 provides that children have the right to be raised by their own parents. However, there are situations where children are separated from their parents. This is the beginning of an intensely emotional process for the whole family (children and parents). Research by Balsells, et al. (2019) and Urrea et al. (2020) reports that the lack of information (information about the reasons for separation, information about the measure taken or information about future changes in children's lives) influences children's adjustment to the measure and their attitude towards the changes that they and their parents will bring about. The attitude of families to protection measures is fundamental to progress in foster care and reunification processes. Therefore, the **participation of families** in the whole process is necessary. In this regard, also, the CRC (Articles 4 and 19) recognises the importance of supporting parents in fulfilling their parental responsibility and ensuring the best interests of the child.

In the child protection system, the training of parents in parenting is fundamental. The ecological approach developed by Bronfenbrenner (1987) has allowed us to understand how people develop within a framework of interconnected systems, ranging from the closest microsystems – family, peers and school – to the macrosystems where beliefs, values and ideologies are located. Consequently, situations of abuse, neglect and abandonment are also analysed from a more contextual perspective and less focused exclusively on the individual responsibilities of parents. The **ecological approach** makes it possible to understand that situations of neglect are the result of fragile balances between parental competencies, the needs of children and adolescents and the context in which the family develops.

The **positive parenting approach** has highlighted the change in the model of intervention with families. In this approach, the participation of families is an essential element that promotes the involvement of parents and increases their awareness of the situation they are experiencing in order to improve the exercise of parenthood. According to Recommendation Rec (2006)19 of the Committee of Ministers to member states on policy to support positive parenting (2006:3) positive parenting is defined as *"parental behaviour based on the best interests of the child that is nurturing, empowering, non-violent and provides recognition and guidance which involves setting of boundaries to enable the full development of the child"*.

Accordingly, new professional practices are being developed (Rodrigo et al., 2015; Chamberland & Lacharité, 2012; Serbati et al., 2016) with a scientific basis that includes an ecological, inclusive and participatory approach (Balsells, et al., 2019).

In this framework of positive parenting, the family is conceived as having the capacity to take care of their children and the analysis is focused on competencies and not only on analysing their weaknesses and risk factors. From this perspective, the active participation of families appears as an unavoidable element to generate teaching and learning processes, to improve the exercise of parenting and to restore the family bond (Balsells, et al., 2019).

In the same way, this approach has highlighted the influence of children in the exercise of parenthood. According to the CRC, children and adolescents have the right to participate and be protagonists in the processes of family socialisation (Articles 12 and 13). This implies considering that children, through their personal and social competences and resources, can interact and modify their reality (Bouma, 2018; Cossar et al., 2016; Lundy, 2007). From this perspective, the role of parents is to facilitate the child's exercise of his or her rights by providing direction and guidance appropriate to the child's evolving capacities (Article 5).

It is about challenging unidirectional theories of socialisation and promoting socialisation as a bidirectional process of adaptation, accommodation and negotiation between parents and children (Mateos, et al., 2021) by working together throughout the fostering and reunification process through an ecological perspective, and a combination of intervention and evaluation, so that those involved become protagonists in the process of evaluating their actions and learn to assess their own progress.

According to this perspective, **parental education programmes** allow for the improvement of parental competences to ensure the well-being of the child in his or her biological family. Specifically, third generation programmes aim to promote the quality of family functioning as a system (Martín-Quintana et al., 2009), taking into account the dynamic and participatory elements of the family, involving both parents and children as active agents in the possibility of family restoration.

In this sense, it seems necessary to explore which elements constitute the participation of families in parental education programmes.

RESEARCH DESIGN

Foster care measures are carried out with the objective of protecting children. These involve the beginning of an intensely emotional process for the whole family (children and parents). Perceptions of change were examined among children and parents who participated in the Walking Family program (Balsells, et al., 2015) which takes on a child-right based approach into its purpose of promoting specific parenting skills in a process of fostering and reunification. A qualitative research was carried out based on 27 focus group comprising 59 children and adolescents and 72 parents out of the total 135 and 147 programme participants respectively. Research showed a need for considering their perceptions, their views, and their voices and involving them in the reunification process. Also, maintaining the relationships between parents and their children in foster care help children feel loved by their parents, and help parents feel involved by their children to change.

The research was developed using a qualitative design to know the perceptions of change of children and parents who participated in The Walking Family Program (Balsells, et al., 2015). This program takes on a participatory and ecosystemic approach into its purpose of promoting specific parenting skills in a process of fostering and reunification. It is carried out with families with children between 8 and 16 years old who are in foster care with a diagnosis of reunification. It includes 5 modules related to five major issues: type of foster care, visits and contacts, preparing to return home, earlier days at home after reunification and consolidation of the reunification. The first two modules are specific to foster care, while the next three are developed in the moments before reunification. This allows for an independent structure, so it can be implemented in a flexible way. Each module comprises 3 sessions that include three types of activities: group activities with parents, group activities with children, and group activities with families (where both parents and their children are included). The whole program is based on participatory strategies and group methodology as it promotes the learning of effective strategies to face daily problems, the self-analysis about their own and others' attitudes, and finally, it helps parents, children and adolescents to understand the different perspectives which may appear in the same situation. The professionals of the child protection system are in charge of leading and coordinating the different agents involved in its implementation: specialised childcare teams, residential centres, teams working with foster families, educators working with biological families, etc.

This quality design enables capturing the participants' different points of view and discovering their experience in the process of foster care and family reunification, and their passage through the program. Moreover, it gives children and parents the opportunity to externalize and give value to their experiences and feelings. This, in turn, allows the researchers to describe and understand the participants' views about their foster care and family reunification process, in order to propose new methods of socio-educational intervention.

PARTICIPANTS AND INSTRUMENTS

The Walking Family Program was implemented in different regions of Spain and Portugal for families already under the Child Protection System. There were 114 families with 96 mothers, 46 fathers and 5 others (Table 1), and their 135 children (Table 2).

Table 1: Families participating in the program and in the study

Characteristics	Families Program (n=114)	%	Parents Study (n=73)	%
Type of family unit				
Marriage or domestic partnership	34	29.8%	21	28.8%
Single-parent family	58	50.9%	29	39.7%
Reconstructed family	22	19.3%	10	13.7%
Other / Non-Response / Don't Know			13	17.8%
Family Figures participating				
Maternal figure	63	55.3%	33	45.2%
Paternal figure	13	11.4%	5	6.8%
Maternal and paternal figure	33	28.9%	22	30.2%
Other / Non-Response / Don't Know	5	4.4%	13	17.8%
Mean age of parents	**42.71 years old**		**39.9 years old**	

Table 2: Children participating in the program and in the study

Characteristics	Children Program (n=135)	%	Children Study (n=59)	%
Sex				
Female	69	51.1%	26	44.1%
Male	66	48.9%	29	49.1%
Non-Response / Don't Know			4	6.8%
Age				
Less than 5 years old	2	1.5%	11	18.6%
5 to 8 years old	23	17.0%	20	34.0%
9 to 12 years old	46	34.1%	18	30.2%
13 to 16 years old	55	40.7%	3	5.2%
More than 17 years old	9	6.7%	7	12.0%
Protective measure *(only for M1, M2, M3)*	(n=115)			
Kinship foster care	13	11.4%	2	3.4%
Non-kinship foster care	3	2.6%	2	3.4%
Residential foster care	93	80.8%	31	52.5%
Other / Non-Response / Don't Know	6	5.2%	24	40.7%

The qualitatiwve research was carried out based on 27 focus groups (Table 3) comprising of 72 parents (Table 1) and 59 children (Table 2) out of a total of 147, plus 135 programme participants, respectively.

Table 3. Characteristics of the focus groups

Characteristics	Focus Groups (n=27)	Participants (n=132)
Parents *(FG_Parents)*	14	73
Children *(FG_Children)*	13	59

Three documents were prepared to collect data from the focus groups: (a) the participants' identification data, (b) researchers' observations regarding the relevant aspects that occurred during the meeting, and (c) the question script for the focus group. The Walking Family Program's objectives served as the basis for developing the question script. The same questions were written in different ways to adapt to the understanding of parents and children.

PROCEDURE AND DATA ANALYSIS

Data collection took place shortly after implementing the program to encourage participants to remember their experience in detail. The focus groups were recorded in audio and transcribed verbatim to ensure the accuracy of the information. Before starting the session, the procedures and rules were explained to the participants, and they were asked to sign a consent form. The participants' anonymity and confidentiality were guaranteed based on the project, which was presented to and approved by the Bioethics Commission of the university where this study was carried out (file number IRB00003099).

The information analysis was conducted through a content analysis, specifically using discourse analysis (Rapley, 2014). The system of analysis categories was developed by collecting information from the participants and relating it to the conceptual contributions of the literature. This process ensured the credibility of the research and reliability and validity of the study (Gibbs, 2012) from reviewing the system by different researchers who checked and verified its validity. The category system was used for coding all the focus groups using Atlas. ti qualitative data analysis tool.

Although the same family experiences were observed, obtaining information from both parties, and triangulating this information made it possible to interpret different perspectives on the same reality.

RESULTS

Current research, such as the evaluation of The Walking Family Program, has shown that the participation of families is a catalyst for the return home of their sons and daughters. It helps them to better understand the reasons for the separation and to get involved in their process for a successful family reunification.

It is important to **involve families and recognize their value** throughout the foster care and reunification process to allow for adjustment and adaptability of all family members. Children and parents are able to interpret, understand, express, reconcile and negotiate about the situation they are experiencing. This awareness gradually develops as parents and children reflect on their own fostering process and family trajectory. On the eve of their return home, participants verbalise that having gone through the programme has enabled them to recognise their capacity to develop parenting skills.

> *"I discovered that I had the skills. Then I discovered that the solution was in me. Then I brought out all the abilities that I had inside me, that I didn't even think I had before, and I discovered them." FG_Parents_2*

Parents emphasise that they are now more aware of their own potential to meet their children's needs, which motivates them to recover and adapt the elements of the context to welcome their children back into the family home.

> *"Before, as a mother, I was hopeless, I didn't take care of my son, I was sick... then I found strength in me... a possibility, a desire to go on living, a desire to recover, a desire to take care of my son." FG_Parents_13*

That is why they claim their leading role and that they are considered both during the intervention and in the new family life. There lies the importance that both children and their parents should do their part to improve their situation.

> *"They began to explain to me that she also felt things and had many things going on, and that she had a problem. This made me reflect, and yes, I realized that she supported me, not with everything, but with what she could." FG_Children_3*

Specifically, in the initial moments of the fostering measure, there are children and parents who do not understand the measure. Suddenly they find themselves separated from their home, from their family and the new situation generates confusion and anger towards the child protection system. The **understanding and acceptance of situations of abuse or neglect** are fundamental so that they can contribute to their self-assessment of family parenthood. For this, it is necessary to give them the information they require, accompany them and support them so that they can make a realistic analysis of their situation and achieve a greater understanding and acceptance of it.

> *“I had not realized that things were going wrong at home until I worked with this, and now I realize it.” FG_Parents_10*

> *“You realize that it has worked, both for her and for me. I have more patience, and she is not so irritable.” FG_Children_1*

In turn, this greater visibility of the situation makes the relationship between parents and children gain security and they develop a commitment and respect towards the different agents involved in foster care because they see that they are needed.

During the measure, it is important to consider children and parents in the **joint planning of the visits** and in carrying out shared leisure activities together. Also, it is important to promote the expression of feelings and the improvement of communication. Children, above all, want to share, they want to have someone to talk to, they want to be listened to and shown affection and, they want to show affection too.

> *“We talk more and have more fun. During our previous visits we used to stand idle and ask questions like ‘how are you’ ,and they were a bit boring.” FG_ Children_6*

> *“Instead of being angry and saying it in a bad way, I say it in a better way.” FG_ Parents_1*

> *“Sharing the notebook helped me understand how my mother felt, and it sure helped her understand how I felt.” FG_Children_6*

In the stage of returning home, the participation of children and parents is necessary to facilitate family life. Adjustments should be made in family dynamics and each family member should participate in agreeing on routines, rules and limits. They also highly value being able to participate in household chores and continue to share emotions and feelings with their parents.

> *“Now, the good things that I did in the center, I do them at home too.” FG_Children_11*

> *“I believe that by living with her, we share our emotions, and that helps.” FG_Parents_5*

DISCUSSION & CONCLUSIONS

In accordance with the above, it is important to go one step further in the concept and application of participation (Urrea, et al., 2022). It is important to listen to the protagonists to make decisions regarding their case plan, but also show that they are part of their change process and that they can participate in it (Mateos, et al., 2020).

The results reflect how, when asked about their reality and about how they are living and what they are feeling, parents and children reflect and become aware of their strengths and weaknesses in relation to parenting competences. The family engagement in the context of the child protection system (Toros, DiNitto, & Tiko, 2018), maximising the families' strengths and accompanying them in making choices to improve their situation rather than imposing solutions is the cornerstone for moving forward. This includes considering the family's point of view as the central element in both understanding the children's needs and moving forward with the case plan (Balsells et al., 2018).

Similarly, the results show that the participating parents have improved their appreciation of their children's active participation in decisions about family coexistence. They are more realistic about their children's needs, but also about their ability to propose, discuss and agree on rules that are beneficial for both parties and that favour coexistence. This active role of the child in the protection system is one of the aspects studied and demanded in recent years (Bouma, et al., 2018; Mateos, et al., 2020). Previously, it was considered counterproductive to incorporate children in their care processes and they were left out in accordance with the idea that they should be protected from any counterproductive situation, an idea contradictory to the basic principles of the CRC. Therefore, adopting the Convention on the Rights of the Child (CRC) and REC 19 on policy to support positive parenting as a frame of reference in all decisions made in the case plan would be an appropriate strategy.

In addition, the participation of children and adolescents in the family intervention provides a different vision of the situation and helps both parents as well as themselves to be aware of the problem; to improve parental skills that support communication and the relationship between family members, and to improve the perception of the changes that parents and children are making to restore family life. Adopting the Positive Adolescent Development approach (Benson et al., 2007), will help adults to see children and adolescents as catalysts for change, because parents feel challenged by their children to make changes that lead to an improvement in their situation. In the same way, the participation of the sons and daughters in the case plan and listening to them will make the adults, both fathers and mothers and professionals, discover how the children see and experience the situation (Templeton et al., 2020).

However, returning to the biological family is not always the best option for children (Bejenaru & Tucker, 2017). In this case, the participation of the children and adolescents in their process is also important so that they are aware of it, of the difficulties of their family and of what returning home would mean for them. In those who are not going to complete the reunification process, it is important to promote an intervention that provides stability and quality between parents and children to contribute to the well-being of the child (Dozier et al., 2014).

In turn to the application of participatory strategies, the results evidence how the tools used throughout the program, such as object permanence and exchange help establish links between family members, improve communication between them, and help perceive the motivation of different family members about reunification. Additionally, they allow establishing ways other than verbal language with the use of multiple languages (verbal, written, visual, enactive, dramatic, plastic, etc.). For this reason, it is important to break with the traditional intervention methods that establish a single mode of communication, and do not always adjust to the motivations (Dillon et al., 2016) or diverse languages of participants to the progression towards the application of participatory strategies, such as group learning or artistic languages (Balsells et al., 2022).

In addition, the application of participatory methods that consider multiple languages must be accompanied by a change in the role of professionals. The professionals need to become facilitators of the process, where they help participants know more about themselves (Bouma et al., 2018). In turn, they must establish a good relationship with parents and children for the process to be successful. This requires specific professional competencies (Mateos, et al., 2022), and an attitude on the part of the professional that demonstrates commitment, interest, and empathy for the participants, as well as consideration for their views and recognition of their strengths.

ACKNOWLEDGEMENTS

The authors want to thank people participating in the Walking Family Program and in the research project. This study was developed by the research group GRISIJ (Research Group on Socio-Educational Interventions in Childhood and Youth) and was supported by the Spanish Ministry of Science, Innovation and Universities (RTI2018-099305-B-C21).

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CONCLUSION

The resilience of the parents and foster parents of children shows their ability to adapt, adjust and cope with difficult situations and stressful events in their lives, especially when they are parents of children with special needs. Resilience is the ability to withstand pressures, changes and uncertainties and to look for opportunities and ways to use these difficulties for the benefit of the whole family. For parents of children with special needs, this ability is extremely important.

The key elements of resilience that we have also been able to identify from the texts of the individual authors of this monographic book include, in particular, a positive attitude, i.e. a positive approach to life's challenges, which may not be at all easy. Resilient parents tend to view these, often very difficult challenges, as opportunities for learning and growth rather than insuperable obstacles. They are open to change and able to adapt to new situations and circumstances. This flexibility is important when caring for and raising a child who constantly requires different adjustments to lifestyle, schedules and daily routines. Other factors in their resilience certainly include emotional regulation, the ability to manage stress and stressful situations very well, aided by the support of the whole family, professionals, friends and the whole environment in which the family lives. A resilient parent can believe in finding positive solutions, knowing that they must communicate and share their burdens openly and effectively in order to gain a future perspective for the child and themselves. It is impossible for these parents not to take care of themselves, their physical, and most importantly, their mental health, as well. They themselves know that they would subsequently be unable to take care of their child and continuously raise them to the highest possible age. So they learn to relax and rest, because mistakes and failures are part of everyone's life and it is necessary to throw caution to the wind from time to time.

The capacity for resilience is an ever-evolving aspect that can have a profound effect on the overall quality of family life. However, without adequate and relevant information about the child's diagnosis or special needs, such a parent cannot function and focus on the positive aspects of their child and build a good relationship with them. It is appropriate to invite diagnosticians – doctors, psychologists and special educators – into their lives. It is important to have someone to turn to. Resilient parents must fight for their partner relationship and also for the sibling relationship of all their children. And for this they need to have a high degree of patience.

After studying some parts of our text, which are sub-chapters on parenting children with disabilities and severe diseases, children with risky and problematic behaviour and children from socially disadvantaged backgrounds, it is important to realise again that each child is unique and requires an individual approach. We see some consensus in the need to increase the quality and quantity of cooperation with professionals who have specific competences, with family counsellors and with organisations focused on this type of special needs. Teachers deserve methodological support, and increased interest from psychologists would support the coexistence between parents and children and their successful integration into the school process. As far as the challenges are concerned, it is necessary to enhance children's social functioning and increase their resilience to risky behaviour, which is increasingly prevalent and is often caused by the bad use of leisure time by children.

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INDEX OF NAMES

CURRENT QUESTIONS OF SPECIAL EDUCATION

PARENTAL RESILIENCE AND SUPPORT IN RAISING CHILDREN WITH SPECIAL NEEDS

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Published by: Silesian university in Opava, Na Rybníčku 626/1, 746 01 Opava
First edition
Place and year of publication: Opava 2023
Number of printed versions: 100
Number of pages: 162
Graphics: Dorota Lubojacká
Photo on the cover: www.freepik.com
Print: Moravapress, s. r. o., Cihelní 3356/72, 702 00 Moravská Ostrava a Přívoz

ISBN 978-80-7510-567-7 (print)
ISBN 978-80-7510-568-4 (online)

Book is not for sale.

SILESIAN
UNIVERSITY
FACULTY OF PUBLIC
POLICIES IN OPAVA