

Key Factors Supporting or Inhibiting the Process of Identity Acceptance Related to Families with Disabled Children

Marta Kolarikova*

Silesian University in Opava, Faculty of Public Policies in Opava, Czech Republic

Abstract

Purpose: The paper describes key factors supporting or inhibiting the process of identity acceptance related to families with visually disabled children. The goal of the research was to understand the factors that influence the acceptance of this difficult situation

Methods: Authentic testimony was obtained from in-depth interviews with 19 families who had to cope with a child's severe disability. A comprehensive multiple case study was developed, part of which is presented in the paper, to gain better insight into the issue.

Results: The research identified a gradual process of family acceptance related to the child's disability and its consequences, the factors that may positively or negatively affect this process and the levels of satisfaction of families with existing advisory services. Authenticity of the facts identified in such a way is an important outcome and it may positively affect other families who are just beginning to deal with the disabilities of their own children.

Conclusions: 1. Health care professionals must be able to sensitively communicate with families in order that the family understands the diagnosis and the consequences of the family member's disability.

2. Partner and family relationships must be based on mutual respect, support, trust and understanding, respecting the needs of individual family members;

3. A functional social support network;

4. Counseling services should respect the needs of families. The system should be coherent and cooperative and its offer should be extended.

The article presents the results of research carried out in 19 families with children suffering from visual impairments in Czech Republic. The results reflect the current functioning, experiences, needs and recommendations of the families. The aim of the research is to understand the factors that influence the process of acceptance of this difficult situation and dealing with it, and to find out the needs of these families in terms of their own function and the use of the counseling services offered.

Based on the analysis, it was discovered that for this group no research has been conducted on such a scale in the Czech Republic.

There were four research questions:

1. Did the family understand the cause of the child's disability and its consequences?
2. Was there a change in the relationship between partners after the birth of a child with disabilities?
3. Have there been changes in social relationships and the support from the social support network?
4. What are the recommendations for families who find themselves in a similar life situation?

Keywords: Child's disability; Parenting stress; Psychological well-being; Quality of life; Social support; Authentic testimony

Background

The professional experience of the author identified the need to address the family as a whole because, for the development of a child, it is important not only to know the what, when and how of the child's upbringing when providing counseling services, but also whether the family is cohesive, if individual members support each other and whether they have accepted the identity of a family of a visually impaired child. It is very important that a child recognize the psychological well-being and safe environment within the family.

The attention of those who provide professional services to these families is mostly devoted to the development of disabled children, development of their cognitive abilities and particularly the issues of education and social integration. However, the practice shows that there is not sufficient attention paid to the family as a whole, which means the background that is so necessary and required for the healthy

development of children with visual disabilities is not given sufficient attention.

One of the major factors supporting the process understands the cause of the disability. This fact is confirmed by the results of research conducted in families with disabled children in the Czech Republic

***Corresponding author:** Marta Kolarikova, Vice dean, Silesian University in Opava, Faculty of Public Policies in Opava, Olbrichova 25, Opava, Czech Republic 74706, Czech Republic, Tel: 0420739612463; E-mail: marta.kolarikova@fvp.slu.cz

Received August 21, 2014; **Accepted** October 07, 2014; **Published** October 15, 2014

Citation: Kolarikova M (2014) Key Factors Supporting or Inhibiting the Process of Identity Acceptance Related to Families with Disabled Children. J Psychol Psychother 4: 160. doi: [10.4172/2161-0487.1000160](https://doi.org/10.4172/2161-0487.1000160)

Copyright: © 2014 Kolarikova M. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

and abroad [1-6]. It is equally important that attention is paid not only to the children with disabilities, but to the family as a whole, the relationships between its members and the needs of each member. This occurs sporadically in research in the Czech Republic (Vagnerova [1], for families of children with physical and mental disabilities or Vancura [2], families with children with mental disabilities). In foreign practice more attention is given to this concept when working with families, e.g., working with the father, siblings, grandparents [6-8]. The recommendation is to support the activities of self-help groups, organizing so-called family camps, whose great benefit is precisely the psychological strengthening of individual members, in the mutual support of individuals with similar concerns, uncertainties and joys [9].

Social support for the family is important especially at the beginning because many families may perceive the birth of a child with disabilities as a social stigma [10]. Vagnerova [1] and Matejcek [11] emphasize the risk of loneliness within families because of the inability to express emotions freely. The birth of a child with a disability changes formal and informal social networks. The family should strive to maintain the existing social network, should be able to ask for the offered support, or if need be, modify its direction. Social support for the family has an especially positive effect, but it may be useless, unhelpful or harmful, costing the family a lot of energy. The reverse side of support is dealt with in the Czech Republic by such as Krivohlavy [12] and Mares [13]. If parents can freely express their emotions, sadness, fear, joy, and it enables their friends to stay friends [14]. Changing the number of friends can be an important indicator of family stress [1].

In the first months/years of children's lives, most parents try to get the correct development for the children suffering from visual disabilities. For example, the parents focus on this topic when concluding their "contracts" with professional counseling agencies.

In the Czech Republic there are no studies that address the quality of life of families with visually impaired children. The absence of such research and over twenty years of experience of the author provided the impetus for the implemented study. This approach was confirmed by preliminary research in 2008 [15] in families who have visually impaired children. 54 % of respondents confirmed that they required professional assistance in the early years aimed to the education and development of children rather than the kind of assistance aimed to psychological management of this situation and support of the entire family.

In recent years studies on this topic have appeared in the Czech Republic as well. Vancura [2] devoted his attention to families with children having mental disabilities; Vagnerova [1] carried out extensive research on mothers of children having cerebral palsy or mental disabilities and also foster mothers having these children in their care. Research of this scale in families of children with visual impairment in the Czech Republic has not yet been conducted.

Design

Families with visually impaired children are not the subject of research surveys also probably because of the relatively small number of these children. Statistical data for the Czech Republic in 2013, for example, shows that in the age of 0-14 years, a total 6715 children with visual impairments lived in the Czech Republic, i.e., 7% of the total number of children with disabilities [16].

So families with children suffering from visual impairments represent a relatively small group of families to which counseling care is provided, when compared with groups of families with children

suffering from mental disabilities (17%) or physical disabilities (22%).

With respect to the chosen research group (its size and willingness to cooperate), I was not able to choose a representative sample and subsequently generalize the related results. I chose a multiple case study as the type of research due to the fact that the work was aimed to gaining better insight into the issue by using more cases.

I used a mixed method design, including both qualitative (semi-structured interview) and quantitative (questionnaires) methods. Questionnaires were used for a more comprehensive understanding of the data obtained from the qualitative data.

Research group

I chose the method of simple intentional selection in which the research participants were sought out through institutions according to predefined criteria.

The research group consisted of 19 families with children suffering from visual impairments, those of the age up to 10 years. Ten families contacted me through institutions called "Early Care Center" and 9 families participated through institutions called "Special Education Center".

Respondents were represented by members of families I was in contact with. The original intention to meet the whole family at once was not possible due to the workload of family members. The research group was consisted of representatives of 19 families - 17 women (average age 36.9 years) and two men (average age 41.5 years). I will use the first names of respondents in the following text. The names have been changed.

During visits in the families there were also related partners present in four interviews, there were also elder siblings present in three cases of interview and there was a grandparent present in two of those cases.

74% (n=14) of respondents in the research group were in a stable partner relationship (13 married couples, 1 couple of partners), 4 (21%) respondents were divorced without any permanent relationship; one respondent (5%) was widowed. Most respondents (n=12) had completed the secondary level of education (63%), 9 were employed (47%) and 18 lived separately (95%) without grandparents.

Another characteristic of the group refers to children suffering from visual impairments who consisted of 10 boys (average age 6.6 years) and 9 girls (average age 4.6 years).

In terms of the degree of disability, 11% (n=2) of children suffered from light visual impairment, 21% (n=4) of children suffered from serious visual impairment (with diagnosed progression), 47% (n=9) of those were virtually blind and 21% (n=4) of those were completely blind.

The last characteristic that was monitored was the siblings of the participants. Four disabled children of the entire group did not have any siblings. 11 children had one sibling and four children had two siblings. The average age level was 8.6 years (extreme values: the youngest sibling was two years old, the oldest one was 24 years old). Two children came from multiple pregnancies: one of triplets and one of twins.

Methods of data collection

With regard to the objective and research questions, I chose the method of semi-structured interview and questionnaires of FHI and SSQ6.

An in-depth semi-structured interview represented the best solution for the needs of my research. I used in-depth inquiries with possibility of subsequent inquiries to refine and complement answers of a respondent. It is also possible to check whether the answer is understood correctly. There is a certain "core" to which other pieces of information are attached, those presented by the respondent who considered them as important.

Family Hardiness Index (FHI; [17]): The questionnaire is a 20-item measure of resistance towards stress, focusing on the resources of resistance in a family; the questionnaire is used to determine the level of resilience in the family system in terms of activation of inner forces in the family. Sub-scales are: commitment, challenge and control. COMMITMENT includes the feeling of tranquility, cohesive strength, determination; CHALLENGE constitutes the acceptance of challenges and the related activity; and CONTROL is the feeling of control over events [17].

Item responses range from 0 (false) to 3 (true); higher scores indicate greater family hardiness. Internal consistency is satisfactory ($\alpha=0.65-0.82$) and temporal stability is strong ($r=0.86$). For this study the stability was 0.85.

In terms of psychometric characteristics, the overall internal reliability for the FHI is 0.82, the value of internal reliability for the sub-scales are: Commitment 0.81, Challenge 0.80, Control 0.65. The FHI method of detecting family hardiness is positively correlated with the flexibility of family, the style of dealing with family time and routine, family, marriage and 'community' satisfaction. Test-retest reliability is 0.86 for the FHI. With regard to the size of the sample which was collected, I did not check for the psychometric properties of small scale and present them. This could be the limitation of the study. The results were only partially evaluated.

The social support questionnaire: A supporting social network is very important for families with children suffering from disabilities. Krivohlavy [18] points out the fact that people in a difficult situation may partly rely on themselves and their personal qualities (ability to handle various problems, knowledge of coping strategies or vulnerability) and partly on the people around them. Coping with difficult situations also depends on provided social support and an existing social network. The value obtained in the questionnaire negatively correlates with neuroticism: a positive correlation is detected in the field of social perception.

The full version of the questionnaire with 27 questions mapped the perceived social support. Mr. Sarason reduced this questionnaire to the form of SSQ6. The questionnaire consists of two parts: the first part is aimed at seeking WHO is perceived by a tested person as a provider of social support (or whom the tested person may contact if necessary); the second part is aimed at determining the LEVEL of satisfaction with the social support provided by its recipient. Krivohlavy [18] says that the results indicate the social satisfaction of people. Shortened version of the questionnaire (SSQ6) contains six questions:

1. Whom can you really count on to be dependable when you need help?
2. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?
3. Who accepts you totally, including both your worst and your best points?
4. Whom can you really count on to care about you, regardless of

what is happening to you?

5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?
6. Whom can you count on to console you when you are very upset?

For each question, the person being interviewed will enter the name of the person who, according to the interviewee, can provide the social support in the given area, and at the same time, indicate the level of satisfaction with the perceived social support on a scale from 0 (not at all) to 6 (most).

The SSQ6 method determines the level of satisfaction with the social support provided, which, according to Krivohlavy [12], is much more important than the actual process. It is assumed that the social support which is chosen in such a way is stable over time, at least for the subsequent three years.

Criterion validity: a negative correlation between the SSQ and a depression scale (ranging from -0.22 to -0.43), and correlations of 0.57 and 0.34 were obtained between an optimism scale and the satisfaction score and the number score, respectively.

The number scores yielded an inter-item correlation ranging from 0.35 to 0.71 ($m=0.54$). The Cronbach's alpha for internal reliability was 0.97. The inter-item correlations for the satisfaction scores ranged from 0.21 to 0.74, and the coefficient alpha was 0.94. Test-retest correlations of 0.90 for overall number scores and satisfaction scores of 0.83 were obtained [17].

Ethical Problems of the Study

Individuals participated in my research on the basis of their own decision to respond to the request which was formulated in the basic assumptions and goal of the research. During the face-to-face meetings, I again informed the participants of the aims of the research, selected methods, I asked them for permission to record using a voice recorder and to sign the informed consent form.

The research was aimed at a very sensitive period in the life of the respondents regardless of the time that had passed since the discovery of the child's visual impairment. I had to keep this fact in mind and be increasingly sensitive when asking questions which I expected to be sensitive, painful for the respondent. It was important to know how to listen and notice the points in the interview which I could rely on, and the points which respondents preferred to avoid, preventing potential embarrassment and not stopping the course of the interview. I tried to create atmosphere of freedom of choice as to when and how and whether or not to answer the question, I tried to offer an opportunity for catharsis or on the contrary, space for explanation or expression of feelings, emotions. It was evident that the interviews were emotionally tense for all respondents, yet I believe that no one was left feeling that something was said which they did not want to say. Feedback of the respondents confirmed that the interview - in spite of very sensitive spots - brought relief to the people, perspective, and new ideas.

Methods of data collection

An in-depth semi-structured interview, containing a total of 16 groups of questions, represented the best solution for the needs of my research. When creating the scheme of the interview, I used the predefined objective of research and the research questions.

Data collection for the research conducted took almost three years (2009 -2011) in the domestic environment of all the participants, at the

time and date chosen by the participants as the most suitable.

An average interview took about two or three hours. While meeting with the families, I also had opportunities to interact with other family members, adult siblings of the disabled children, partners, grandparents. I could see family interactions and environments.

Data Analysis

I compiled data from the interview using open coding. I fixed the matrix (audio recording on the recorder), and carried out the transcription. In the transcription of the recordings I have carried out so-called reduction of the first order where the parts of sentences that did not carry any information and recorded sounds were omitted. The prepared data were tested by the open coding method. I assigned labels to topics which were located in the texts. Topics selected were related to the research questions, information from professional literature, and the terms used by respondents and emerging ideas. I first established thematic sub-categories on the level of individual cases and then I looked for linkages between the cases and created a superior category. To that end, I created a system of categories and subcategories based on the resulting connections which allowed me to interpret the results as a whole.

Given the nature of the research, the presented categories do not constitute a separate system of unrelated categories. On the contrary, there are often cases of thematic overlaps. Taking the results obtained, I created a categorical system which is supplemented by the authentic statements of respondents for the purpose of clearer illustration.

If I want to understand the feelings and coping related to such difficult life situations, which includes the birth of a child suffering from disabilities, I have to start from the very beginning of the gradual process of coming to terms with this situation. First, I will deal with categories that capture the beginning of this process, namely acceptance of the child's diagnosis, understanding the disability and seeking blame as well as the gradually arising process of accepting the identity of a family having a visually impaired child. In the category related to diagnosis acceptance there are subcategories devoted to birth expectation, families with children born prematurely and families with children with other causes of visual impairment. As for the category called Understanding the Causes, I identified subcategories of understanding and misunderstanding of the causes of the disability as well as the related consequences. The last category, called Seeking someone to blame, is put in this place due to the great influence on the process of coming to terms with a disability because it can significantly slow down or stop the process.

Expectation

A large proportion of families belonging to the observed group (89%) expected the birth of a healthy child. Only one woman had a difficult pregnancy. She and her husband were warned of possible difficulties. Another family had a genetic predisposition in the family history (congenital cataracts). So, they knew of the risk of visual impairment. None of the families admitted any complication in their statements.

Non-acceptance of any complication was present even in families which were informed about the risks, but even those families did not accept the possibility that their child could be disabled. All naturally hope that they will avoid the problems and their child will be fortunate enough to be born without any difficulties.

The category called Diagnosis Acceptance belongs to the process

of coping with the basic starting point. The statements show clear tendencies of most people who do not believe communicated facts in the beginning. Instead, they deny the facts and twist the words of doctors. The summary given by Vendula is very poignant: "Probably, everyone has heard the following words when a new baby is to be born: Whatever it is, we wish the baby to be healthy!" Until you really experience such kind of problems, it's just a phrase. A phrase that changes in the face of reality. Only then you realize just how much you want to believe."

Understanding the Causes

To accept the diagnosis and continue in the process of coping (or to start the process), it is important to accept and understand the cause. Part of the research group of families understood the cause of disability due to sufficient explanations given them by doctors or those found by them on the Internet or in professional books. Another part of the families has not yet understood the cause. However, they admit that they "quit their investigations and do not want to deal with the problem anymore."

If the explanation given by the doctors was not sufficient, then the families look for an explanation elsewhere. Most of the families admitted that they had sat down and compared the medical report with a Latin dictionary. Then they browsed through books of ophthalmology. Sometimes they found help or direction in the media (radio, television, internet discussions) or in discussions with other families having children suffering from visual disabilities.

Unfortunately, cases of individual families in many ways had one thing in common. The common denominator was dissatisfaction with the manner in which diagnoses were communicated to them, specifically, the communication on the side of medical staff, doctors and nurses. Families themselves realize the fact that they were very sensitive in that period of time. In another time and another set of circumstances, they would accept the words of the medical staff with less distress. But memories of these events are very bitter and painful, even now, after so many years. There remain feelings of betrayal and disappointment by the careless approach taken in the communication of bad news.

Seeking Someone to Blame

Partnership relations may be affected by the process of looking for someone to blame. This phenomenon formed a separate category in our research. Many parents openly admitted that they had had unpleasant and intrusive thoughts of their own guilt in their minds.

The process of seeking a guilty person had different forms in the research group. Mutual accusation of partners tended to occur in families in which a dysfunctional relationship previously existed. These relationships were impaired even before the child birth. The parents of the wife accused their son-in-law. Mothers-in-law accused their daughters-in-law or even parents were accusing their own daughter. Paradoxically, there was temporary improvement of a relationship in the case of the father of a female-respondent accusing the husband. However, it was really only for a very short time.

Although the events were already several years old, the statements were again very emotional. Both open and hidden accusations only contributed to further problems in these poorly functioning families, which led to subsequent disintegration of the family.

Functioning of the Immediate Family

Analysis of the obtained data (interviews, questionnaires) clearly

showed the greatest importance was the need for mutual support of partners which was mentioned by all families. Even the single respondents who did not currently have a partner were aware of the great importance of this psychological support.

The most important thing was to “be together”. The most important thing in the world for these people was to cry together, to talk together -mainly not to be alone. It was important to draw support from each other even though they realized that the situation would not change.

Blanka: “You simply have to be very patient; I think about it in general way. We survived because my husband and I went through it together. When you know that you have someone to cry with and when you know that nobody will ask you anything and you may just cry and cry, it can help you very much in the very first days. Simply said, people in these moments do not want anything else.”

In families that stood out as being able to handle the present situation, there is obvious mutual support among the partners and their parents, or perhaps even the support provided by elder children. If one of the family members do not feel well, others will support him. They will help him with the child, they will let him go for a vacation or they will just go for a walk together. The common denominator is to allow everyone in families to have their own space, to respect their personal needs and hobbies, and to assist each other in working with children suffering from disabilities.

The research sample consisted of 26% of single-parent families (four divorced women, one man – a widower). All the families were intact after the communication of the child’s disability. However, all female respondents agreed that their relationships had previously been problematic and that the problems of this difficult situation were only sharpened and focused, and the crisis was deepened more and more by the disagreement and mutual misunderstanding.

The cases vary considerably. However, sub-categories with common characteristics can be found. One of these is being blamed by a partner.

Female respondents spoke about their struggling with the situation, when their partners were not only unsupportive, but even accused them of improperly raising the child (Cecilia eventually accepted this guilt for a long time). In two cases, this reduction of maternal self-confidence eventually contributed to a deteriorated ability to care for the child. The female respondents realize that in response to the accusations they began to behave differently. They ceased to be demanding of the child and tried to make life easier for the child as much as possible, which contributed to the current lack of independence of these children.

Accusation from the side of the partner’s parents represents another sub-category which was common in some families. The parents of the partner accused the respondent of failing to take proper care of the spouse, which led to persistent attempts to manage the situation and maintain good relationships. However, it cost a great deal of strength and energy and in the end the family split apart anyway. Radka: “My mother-in-law said I was a bad wife because I was spending more time with the child than with my husband. And, you know, the husband earns money for all of us and we would not have anything without him. I tried to do my best so that I could cook and clean for my husband, but after a while, I just couldn’t. Actually, I did not rest at all during the day, trying to keep house and take care of our little baby during the days. I did not sleep at night. I simply gave 200%. But for my mother-in-law that still wasn’t good enough. She kept saying that I was not good enough for her son.”

The female respondents whose partner did not manage to cope with

the child’s disability perceived that period of time in very difficult ways for the reason that they were spending a lot of energy to support their partners.

Klara: “I was constantly busy. Our baby was always crying. Doctors only told us bad news. And on top of all that, I had to calm my husband down by saying that everything would be okay and we would manage. But I myself was completely down, but I could not tell him, because it could mean the end.”

Despite the enormous efforts of everybody involved, the family failed to save itself and the marriage fell apart. In retrospect, all the female respondents said that they should have gotten divorced much sooner.

Personal Characteristics

Respondents agreed that the important personality traits required to cope with difficult situations (such as the birth of a disabled child) include patience, confidence, ability to listen to others, consistency, perseverance, orderliness, strong will, willingness to help each other with anything, willing to consult on what is better to do and how to do it.

Analyses indicated that fathers of children with disabilities experienced greater stress in daily parenting hassles, family life events and changes, parenting stress and health stress. A path-analysis model based on family stress theory indicated that whether or not fathers had children who were disabled was a major contributor to life satisfaction followed by parenting stress and stress from family life events and changes [19].

Furthermore, the respondents were aware of the importance of their own physical strength and health because they had many times found themselves in a state of great fatigue and exhaustion and it was only then that they realized how important it is to get some rest too. Most respondents recounted these states of exhaustion in the first months/years of life with a disabled child. They gradually found their own way to relax and rest.

Personality of a Disabled Child

Although a disabled child was not primarily observed in the course of research, it is very important to mention the disabled child as a significant sub-category influencing the way the family functioned as a whole. In most families it was often the disabled children who gave the parents the strength to cope with the situation. It was their smiles, contentment, inner strength to fight.

The personality traits of a child, particularly the child’s sociability, initiative, curiosity, positive attitude, inner strength, diligence, and perseverance are the driving forces that move the parents forward, and provide positive feedback and great motivation in often very difficult moments.

Parents are afraid of their ability to estimate the correct level of responsibility to be required of the child so that the child is independent but not overloaded.

Social Environment

In the data analysis, the categories of grandparents, friends and the public as well as the wider social environment were mentioned as important resources affecting the way the process of acceptance related to child’s disability was handled.

As is evident from the interviews, grandparents are still an important part in lives of adult individuals. The grandparents represent unique and irreplaceable social support. This support is available in most cases. Grandparents are willing to help, depending on their energy and potential. However, they also need time for gradual acceptance of the identity related to grandparents of a disabled child. They also need sufficient information related to the disability and potential of the child.

My research revealed that the support of loved ones is not as automatic as one might expect and as natural. There were several cases in which the families with disabled children did not receive any support from their immediate families. This lack of support is very stressful for families and affects relationships for a very long time.

If the parents do not get support especially in the early stages of coping with the problem, it is very hurtful for the family.

Experiences of some parents show that their network of relationships changed after the child's birth. There are also some changes in the number and behavior of friends. Many friends disappear after the birth of a disabled child, they are not willing to help – even by just being present with the family.

Of course, there were also some cases in which the friends remained and supported the family, often more than immediate relatives. But it was certainly not the rule. Families do not expect help with education and aids. They only want the friends to be there for them, to lend an ear, letting the parents talk and simply being with the parents.

Sometimes the nearest neighbors try to bring support to the family, but they often choose inappropriate ways of social support. People don't need to hear that people in the vicinity (friends, co-workers) recommended that the family place the child in an institution so as "not to complicate [their own] life". Many families faced the same experience and they responded in the identical ways. Even if at that time they thought about and considered various alternatives, this kind of black and white vision made them so angry that they decided to sever contact temporarily and it took a long time before those contacts were restored. However, the relationships were renewed but there remains a kind of mistrust that, in many cases, continues to these days. The people in proximity might have been motivated by an effort to help the family in a difficult situation by saying something which, according to them, the family is afraid of. However, the families do not need to hear such radical solutions. They just want someone to listen to them and be with them. Any decision about what to do is up to them. They do not expect their friends to make these decisions.

Attitude of the General Public

The overall attitude of the general public is also important for the family. This kind of attitude may significantly affect the process of coming to terms with the child's disability. Families were aware of the fact that the current attitude of the general public in relation to disabled people has changed thanks to the media. Most people are, according to them, "friendly" after having been influenced by the media. Unfortunately, parents of these children have another experience that cannot mentally help them – it is not only their disabled children who people in the vicinity consider as something strange, but the parents as well, speaking to them as if the parents were disabled too. Three families experienced this behavior and regarded it as the most traumatic experience of all they encountered.

Statements related to the reactions of people in propinquity to the families were sometimes very shocking. These statements often

contributed to the closure of the family to the outside world or moving away to another town. Families who live in smaller towns or villages mostly had good experiences with the other people in the vicinity.

It depends on the internal strength of the family as to how handle the reactions of people around them. Karla's husband told in this context: "Sometimes you hear things that you do not like, but we don't blame them. If people do not have any experience with the disabled, then they cannot imagine what it is like. I am not angry. They have the right to behave in such a way."

Communication with Other Families of Visually Impaired Children

At the beginning of a long process of coming to terms with the fact that the child is disabled, parents feel they are alone and that nobody can imagine how they feel, what they experience, what they expect and what they have to face. Now, with a detached view and after several years, they remember almost as salvation when they met with people who also had a disabled child. While being on short-term stays together with other families with disabled children, many parents felt like the world opened for them and the long-standing fears subsided. They suddenly began to see that things were possible- in other ways, but still possible. For me, Karla summarized the essence of meeting others in her situation very clearly: "You can see how other people do it. And then you suddenly you feel how you want to do it."

Karla's husband emphasized the need for these meetings with other families as an essential part of being a healthy, functioning family. In his opinion, it was vital to hear information from other families to see what they experience and what they face in their lives is common and normal and help the families avoid the feelings of being completely "abnormal". It is important to encounter real children who are blind and real problems and worries that you might have to deal with some day too.

Contemporary families with disabled children have another opportunity to be in contact with other families. The Virtual World offers on-line forums, discussions and professional articles. Many mothers use this service to search for professional information, find answers to questions related to education and opportunities for further development, rather than engaging in discussions. Some people prefer personal contacts; discussion forums on the Internet are too inundating and disturbing for them. They lead to mental imbalances and doubts.

Results of Quantitative Methods

Evaluation of FHI

From the processed questionnaires, the total FHI score, the arithmetic average of the individual scales, the standard deviation (for guidance only, no informational value due to the large skew), the minimum and maximum values, and the quartile distribution of individual sub-scales have been calculated.

The results of the entire research sample (n=19) are very positive, achieving the large overall coherence of the families. The sample achieved relatively high scores in the range of Commitment and Control.

Obtained scores in the sub-scale Commitment shows the readiness of families to take life as a challenge, families have a sense of purpose and accept the reality of life which they are able to face together, have the inner strength and are intrinsically linked. The results of the sub-scale Control show the belief that families have life under control and

are themselves able to influence events in the family. The lowest levels were in the Challenge sub-scale which may mean entering into less risky activities that changes what is considered as normal in life and that can deliver growth and profit, but must not threaten their security too much.

Evaluation of Social Support Questionnaire 6 (SSQ6)

The analysis of the results of the questionnaires showed that the most frequently chosen provider of support is the spouse / partner (n=43, ie. 37%), then parents (n=16, ie. 15%), friends (n=10.9%) and the spouse / partner together with friends (n=9.8%). Divorced women instead of choosing spouse / partner frequently indicated themselves, i.e., confirming the fact that they must rely on their own inner strength, in these cases the very next choice was a close female friend. Common phenomena could be traced here, which was that divorced women most often talked about their close female friend as a provider of social support, married women opted for the category intimate friends. In question number 3 which is associated with the search for social support in situations where a person “feels completely broken”, both groups confirmed that the most frequently chosen providers of social support were parents. Likewise, it is interesting that the choice “sister” appeared four times (in various cases). It was always an older sister, therefore a tendency associated with the principles of sibling constellations is indicated (however, I realize that the sample is too small for such a conclusion). Divorced Marie chose her daughter because this adult daughter is currently the only real support she has.

The value of satisfaction with social support could range from 0 (min.) to 36 (max.) points. Overall satisfaction of all respondents averaged 29.79 points.

I also wondered whether there would be significant differences between the responses to each question. The calculated arithmetic average is supplemented by individual quartiles (Q1 to Q3) and minimum and maximum values, which are used to further the characteristics of the data obtained from the research sample. Based on these data it can be concluded that the lowest degree of reliance on providers of social support expressed by respondents in question no. 3 “Who can you count on that will really help you when you feel completely broken?” The results also showed that the lowest value of the subjectively perceived level of social support has appeared in this question. It is possible that the given formulation of the question “feel completely broken” is subjectively perceived by parents as inadmissible,

as though their life experience does not allow the option that they could ever possibly feel completely broken. The findings are compared in the following Tables 1 and 2.

From the results it is clear that families are looking for sources of social support within the family, i.e., partners, parents, siblings, or if necessary, older children. A significant number of choices, however, represent also intimate and close friends, for which the level of satisfaction with social support provided by approaching potential maximum. However, the fact that respondents see them as a significant source of stress in social situations consideration, is significant for further work with a group families with children with disabilities. Singular choices such as marginal belief in God are rather exceptional choices, however, for a specific family, they provide substantial support in difficult life situations.

Discussion

The results of my research on the manner in which medical findings are communicated are confirmed by other research carried out in the Czech Republic [1,2]. The experience of families in the research group was the exception in that doctors informed the family with empathy, in a safe environment of a room or office, in the presence of both parents, and the doctors were willing to provide psychological support in difficult moments and respond even repeatedly and in various ways to the questions of parents relating to causes and consequences of disability. Communication with patients and parents, especially in bad situations, should be a basic skill of doctors and other health professionals.

Taking a critical view of the conducted research, it should be stated that the results of the analysis could have been more objective if more family members took an active part in the survey. Unfortunately, due to the complexity in the process of obtaining research samples, I had success only in a few cases where the partner, adult siblings or grandparents were also present. I am convinced no distortion occurred. The respondents provided their statements according to how they thought that the entire family experienced the situation. Given the fact that I was aware of this issue, I decided to inform the respondents of the results.

Research question #1: Did the family understand the cause of the child's disability and its consequences?

Lack of understanding as to the cause brings with it rumors,

FHI	N	Sum of gross scores	Arithmetic average	SD	min.	Q 1	Med.	Q 3	Max.	Max. possible value
Commitment	19	368	19,37	3,36	10	18	21	21,5	24	24
Challenge	19	241	12,68	2,34	6	11,5	13,5	14,5	15	18
Control	19	245	12,89	2,67	7	11	13	14,5	17	18
Total FHI score	19	854	44,95							

N = absolute frequency, SD = Standard deviation, Q 1 = lower quartile of the sub-scale, Med. = median, Q 3 = upper quartile of the sub-scale, Min. = the lowest value of the sub-scale, Max. = the highest value of the sub-scale, Max. possible value = the highest possible value of the sub-scale

Table 1: Evaluation of FHI for the whole research sample.

SSQ6	N	Sum of the values (max. 114)	Arithmetic average	SD	min.	Q 1	med.	Q 3	max.
Question # 1	19	95	5,00	1,2978	3	3,5	6,0	6,0	6
Question # 2	19	96	5,05	1,1909	3	4,5	6,0	6,0	6
Question # 3	19	87	4,58	1,1839	2	4,0	5,0	5,5	6
Question # 4	19	97	5,11	1,0709	3	4,0	6,0	6,0	6
Question # 5	19	93	4,89	1,0709	3	4,0	5,0	6,0	6
Question # 6	19	93	4,89	1,1190	3	4,5	5,0	6,0	6

Table 2: Values obtained in questions of the questionnaire (SSQ6) for the whole research sample.

accusations, and the entire family system may fall apart as a result of doubts. Most parents wish to obtain from the research sample truthful information from the doctors regarding the cause, course of possible treatment and consequences, no matter how bad it is. Similarly, it is very negative when the communication of these unpleasant facts is delayed. Again, as in the research of Vagnerova [1], many families already know very well that any delay in disclosure of the diagnosis and its consequences only prolongs the process of coming to terms with this fact. It is not that the problem would be easier and smaller when the diagnosis is given, but it reduces the feeling of helplessness and perceived powerlessness. Naming the problem makes it seem to be somehow solvable, and people then know “what they are fighting against.”

Research question #2: Was there a change in the relationship between partners after the birth of a child with disabilities?

It is not possible to say that the relationships have not changed at all. Relationships are always changing, over time and depending on the individual personal development of each family member. The strength of the partner relationship, personal maturity, experience with solving problems and coping with life crises, effective coping strategies, sharing responsibilities and open communication are prerequisites for proper management of the situation by the spouses/partners. Families in the research group positively ranked the following personality traits: patience, confidence, ability to listen to the others, consistency, perseverance, orderliness, strong will, willingness to help each other with anything, ability to consult together on what things should be done and in what ways.

From this list it follows that not every partner is excellent in every aspect. Things depend on mutual cooperation, respect and tolerance [20]. Of course, a good partner relationship influenced the functioning of the family as a whole. I can also apply the Biddulph principle [21] that if the parents love and are interested in each other, then their children are also satisfied and happy.

Research question #3: Have there been changes in social relationships and the support from the social support network?

The social environment can provide the family with social support in terms of understanding and assistance. A fully functioning social network represents a stabilizing element in the process of coping with the child's disability. The family needs to perceive the offered and provided social assistance as well as the opportunity to ask for such assistance and receive it. Although the social relationships in all families of the respondents changed, none of the surveyed families felt socially isolated [22,23].

The child's disability is a burden which requires a lot of energy and inner strength for the family to cope with this problem, look for solutions and adapt to this situation. Especially in the very beginning, many families must also devote a lot of energy to explain the situation to grandparents, friends and neighbors. Some respondents considered it as more exhausting than their own acceptance of disability. In this section, I would like to focus on the social support provided by grandparents and friends as well as the influence of the wider environment.

The support provided by grandparents is very important for respondents and can affect all aspects of family functioning in the future. If the family receives social support from grandparents, it is significantly strengthened, gets a new source of energy and is able to cope with the situation much better. The respondents who did not have

this experience say that it was very painful and stressful, similarly to the experiences of the parents involved in the research of Vagnerova. It was very painful and stressful for them because at the moment of greatest pain, they were disappointed by those closest to them.

Grandparents, siblings, relatives as well as the immediate family all go through the process of gradual adoption of the identity of a family with a disabled child. Whether the relationships in this family will be strengthened and if the people closest to them will be able to offer emotional support depends, as with the relationship between partners, on the level of personal maturity, ability to handle stressful situations, level of empathy and tolerance in addition to many other factors. In any case, these well-functioning social relationships form an important base for the family in which a disabled child was born and in which the disabled child is raised.

Research question #4: What are the recommendations for families who find themselves in a similar life situation?

Families with visually impaired children which made up the research group have already come a long way. It is a journey full of problems, joys, concerns, fears and empowerment. Their motivation for participation in the research was mainly that their experience could help families who are only at the beginning of their journey. The recommendations include the four following areas: health care professionals, partnership and family, the child's upbringing, and meetings with other families with visually impaired children.

It is important for the family to know what is going to happen in one, two or ten years. It may not seem so important, especially for families with very young children, but it is at this stage when it is very important indeed. Parents (as well as grandparents, siblings, aunts, uncles and friends) have no concrete idea of what their blind baby will do in the future. However, when they meet older children who crawl, run, ride a tandem bike, swim, read, use the computer or who are “just” angry, it can move them much further forward within their own line of development. Therefore, respondents recommend that even families with very young children visit a special school just to see what school-age children with similar disabilities are able to do.

The families consider meetings with other children, with families of these children with similar disabilities as key for managing everything. Suddenly these families no longer feel unusual (as one dad put it, “Finally, we've stopped feeling so exotic.”) in their situation that seems to be so intractable and full of sorrow and are able to move on. Shared concerns, problems and fears are alleviated. Families learn to see progress, set up small and realistic goals which they can “boast” about later to someone else. Each encounter the families share is stimulating, providing the parents the opportunity to learn new things as well as allowing them to share with others what they themselves have learned. They can take some of the strategies they hear from others and incorporate them as best suits their particular situation. This strengthening of the internal resources of the family has been a tremendous benefit of these meetings. If, from the beginning, the parents have a clear idea that the blind people can live and be happy, then the process of their coping with the disability will be made easier.

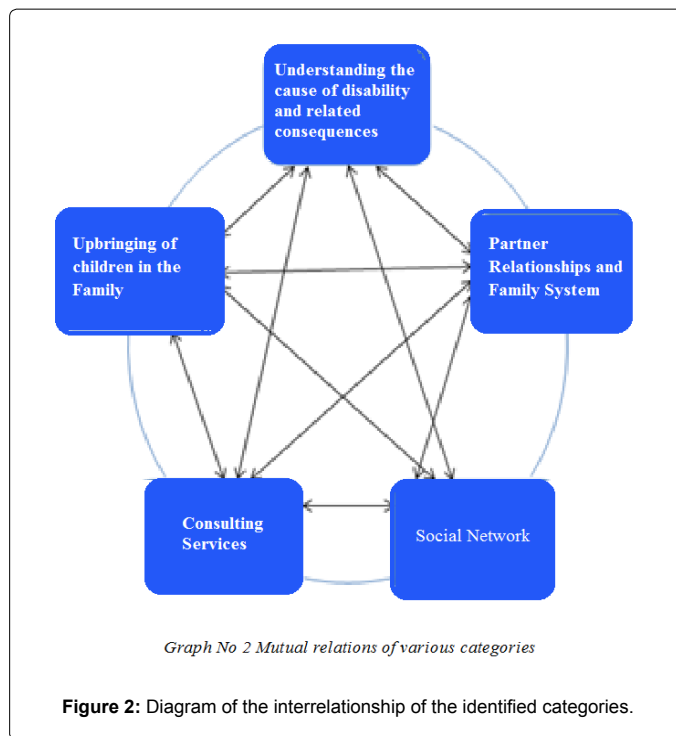
Scheme of needs related to families of visually impaired children important to manage the process of coping with the visual impairment of a child

Families of visually impaired children naturally tend to satisfy all the natural needs which lead to the stability of the family and healthy

functioning. The needs of families have already been described by Vagnerova [1]. She speaks of the need for stimulation, a purpose in life, emotional support, self-fulfillment, life prospects, etc. These aspects may be fulfilled in completely different ways with the birth of a disabled child or they may not be fulfilled at all. In this thesis, I will focus more on the needs in relation to the identified categories that arose from the sub-categories described by the research participants. Of course, it is necessary to state at this point that the scheme certainly does not delineate all the needs of families, but emphasizes only those needs which in the analysis of interviews with families of children with visual impairments often stood out as unfulfilled. It concerns the following fields of focus (Figure 1 and 2).

Diagram of the interrelationship of the identified categories

As follows from the data obtained by analyzing the process of coping with a child with disabilities, the subsequent reorganization and stable functioning of the family is affected by a number of factors throughout the life of the family. As the diagram shows, the understanding of the disability and its consequences can affect relationships and the family system, the upbringing of children in the family, the social network and consulting services. For example, if family did not understand the cause and/or consequences of the disability, this may affect relationships (rallying or blame) will also influence the services provided (“we do not need the service”, “our child does not have a problem”, only prolonging denial), the social network (negative: the family either keeps its distance from others or others are keeping their distance from the family: “Who knows what is wrong with him?”, positively: people around the family help find the answer, or support the family), as well as the education of children in the family (negatively: inappropriate parenting style, immature compensatory mechanisms, positively: Even though we do not know the cause of this, but we will handle it). The chart shows clearly how vulnerable the family is, what all can go wrong and stop the process of coping with a disabled child, or, on the contrary, what will hasten and get it under control.



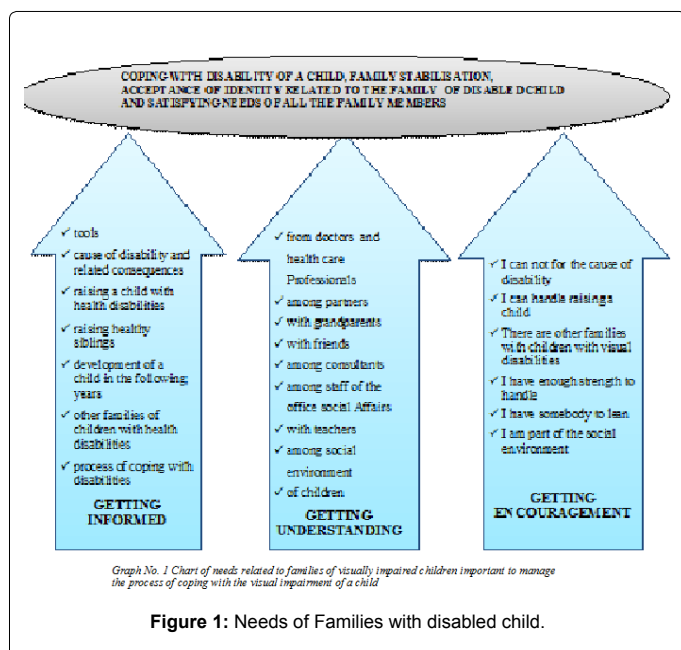
Conclusion

1. It is very important how a doctor communicates the diagnosis. It is also important how they understand and accept the child's disability, including knowledge of the child's potential and limitations.

The research showed that the process could be significantly slowed down from the very beginning due to improper communication of the medical diagnosis to patients. Information tactfully presented to both the parents in a safe environment and in a sufficiently understandable way was the exception rather than the rule in the research group. If this is not correctly done, the family loses a lot of energy and time searching for answers, blaming and looking for someone to blame, fearing the deterioration of relationships, speculating on future developments. These aspects only deepen the trauma itself.

2. The basis for managing the entire situation consists in the quality of partnership and functional families, and respecting the needs of individual family members.

Respondents in the research group considered the following traits as vital in partnerships: mutual trust, willingness to support each other and help each other, shared solving of problems and everyday worries, patience, openness in communication, ability to listen, consistency, perseverance, orderliness, strong will. However, they did not forget to mention the sharing of joy, small successes and hopes with each other. The healthy functioning of the family system is subject to respecting the needs of each individual member, not only the parents but also their disabled children and their siblings and grandparents. If any imbalance occurs in this respect, then the family as a whole may be endangered in terms of its development. The research confirmed that the birth of a child with a visual impairment is a severe test for poorly functioning relationships and family ties which families cannot usually handle, and the already challenging situation of the life of a disabled child is made even more difficult.



3. A functional social support network creates a safe and supportive environment for the family. It provides the necessary social support.

A family must perceive the offered and provided social support and must have the option to ask for such support and gain it. Respondents confirmed that reaction of those around them, which tend to be encouraging but also those pitying or evading, would in terms of psychological coping with the situation affect a family much more than the family is ever willing to admit. Feelings of regret, resistance, anger, and attempts to ignore all take a lot of energy, which definitely does not help the process of coping with the situation.

4. The system of counseling services should respect the needs of families. The system should be coherent and cooperative and its offer should be extended.

The counseling services have significant impact on the process of coping with disabilities. Early care services are of great importance not only for children with visual impairments, their cognitive and emotional development, but also for the family as a whole. However, it was found that families see a significant problem in the continuity of service. Families greatly miss bilateral meetings, sharing in the experience of integrated schools and kindergartens, experience with assistants, teachers, school principals, siblings, social assistants, and doctors. In the last twenty years associations such as the Association of Parents and Friends of Blind and Weak-Eyed Children in the Czech Republic, and Tandem Association were gradually formed

Finally, I must note that families having children with visual impairments at early age lacked the services of psychologists. Families need a psychologist who can encourage them, who is available to them and will help them overcome difficult moments and crisis situations in the family. These families need them only to help them find the strength, their own resources and determination to face the situation.

Parents will eventually learn to perceive that even blind children need love, security, belonging, order, purpose, and that they have their hobbies. However, they also need boundaries, discipline and instruction like other children. And just like any other children, they can give the adult hope, support, delight and joy. A statement to sum it up: "The best part is when our daughter gives us a smile and we know that she is well and not worried, that she is content. Then it is much easier to endure anything."

References

1. Vagnerova M (2009) Národnímaterství: býtmatkoupostiženéhodítě. Karolinum, Praha.
2. Vancura J (2007) Zkušenostrodicudětí s mentálnímpostižením. Brno: Společnost pro odbornouliteraturu - Barrister & Principal.
3. Feoktistova VA (1993)Vospitanieslepychdetejdoškolkolnovovozrasta v semje. Moskva: Logos.
4. Garwood SG (1983) Educating Handicapped Children: A Developmental Approach. An aspen Publication, London.
5. Jacob N, Niemann S (2000) Helping Children Who Are Blind. The Hesperian Foundation, California.
6. Schmitt P, Armenta-Schmitt F (1999) Fathers: A common ground. Blind Childrens Center, Los Angeles.
7. Burke P (2004) Brothers and Sisters of Disabled Children. Jessica Kingsley Publishers, London.
8. Wawrowska E(2011) W rodzinieniewidomegodziecka. In: LIBERSKA, H. a kol. Rodzina z dzieckiemniepełnosprawnym. Możliwościograniczeniarozwoju, s. 112-135. Warszawa: DifinSpółkaAkcyjna.
9. Day JN, Kleinschmidt J (2005) The Efficacy of Family Camp Experience for Families Who Have Children with Visual Impairments. Journal of Visual Impairment & Blindness 99: 775-786.
10. Sobotkova I (2004)Intrapsychickáztráta (Intrapsychical loss). In ŠPATENKOVÁ, N. Krizováintervence pro praxi77-85.
11. Matejcek Z (2001)Psychologienemocných a zdravotnepostiženýchdetí. preprac. vyd. Jinocany: H & H.
12. Krivohlavý J (2002) Negativnísociálníprojevy. In MARES, J. a kol. Sociálníopora u dětí a dospívajících II, 64-69. Hradec Králové: Nucleus.
13. Mares J (2003)Necitlivéposkytovanásociálníopora – obtežujícíopora. In: MARES, J. a kol. Sociálníopora u dětí a dospívajících III. Nucleus, Hradec Králové.
14. Kerrova S (1997)Dítě se speciálnímpotřebami. Praha: Portál.
15. Kolarikova M (2012)Významporadenství pro rodiny s detmi se zrakovýmpostiženímranéhoveku. In: Kolariková M, Calonová D, Hermanová M, Hendrych I, Janiš K (Eds.),Sborníkpríspevku z konferencí ÚPPV a DC Ctyrlístek z let 2008-2010. Opava: Slezskáuniverzita v Opave s 37-52.
16. Ceskystatistickýurad (2013) Výberovéšetrenízdravotnepostiženýchosob (The sample survey of persons with disabilities). Dostupné z.
17. McCubbin HI, Thompson AI, McCubbin MA (1996) Family assesment: Resiliency, coping and adaptation – inventories for research and practice. University of Wisconsin Publisher, Madison.
18. Krivohlavý J (2001)Psychologiezdraví. Portál, Praha.
19. Darling CA, Senatore N, Strachan J (2012) Fathers of children with disabilities: stress and life satisfaction. See comment in PubMed Commons below Stress Health 28: 269-278.
20. Beresford BA (1994) Resources and strategies: how parents cope with the care of a disabled child. See comment in PubMed Commons below J Child Psychol Psychiatry 35: 171-209.
21. Biddulph S (2002) The Secret of Happy Children: A Guide for Parents. Da Capo Press,Boston.
22. Deluca KD, Salerno SC (1984) Helping professionals connect with families with handicapped children. Charles C. Thomas.
23. Mares J (2001) Sociálníopora u dětí a dospívajících I. Hradec Králové: Nucleus.