Subjective attitudes of the parents of a child with disability to selected aspects of their quality of life

(scientific paper)

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"The paper is dedicated to the following project: 'Perception of subjective impact of health disability/presence of chronic disease and concept of health awareness and literacy' (IGA_PdF_2015_003)".

Abstract: *The quality of life of families caring for a disabled individual is a highly topical issue, which deserves due attention. In order to provide these families with quality special education care and support, first it is desirable to identify their needs in a comprehensive manner. Firstly, the paper defines the theoretical background and terminology of the issue. Then the paper presents the results of a research study, whose objective was to identify the subjective attitudes of the parents of a disabled child to selected aspects of the quality of their life. The research was carried out by means of the questionnaire method. The research involved 37 families of children with disability. The results of the research points out that a family caring for a child with disability is burdened both financially and physically, which influences the quality of life of all its members. The answers of the respondents also indicate a degree of dissatisfaction with the help of the state provided to families with a disabled child. Whether it be material support or a greater understanding on the part of the state and state institutions. The results also imply that caring for a child with disability has an effect on the partnership of the parents and their leisure time, it also brings intense feelings of fatigue. The research also indicates that a crucial role is played whether a family caring for a child with disability is assisted by another person or institution, who take over some responsibilities. The paper emphasises several areas that should be addressed with due attention in the future, and outlines possible solutions. The final part of the paper summarizes and compares the results of the present research with the results of other professionals. This issue is addressed by professionals both in the Czech Republic and abroad.*

Key words: *family, disability, quality of life, support, care, questionnaire*

1 Introduction

The quality of life of families caring for a disabled individual is a highly topical issue. A positive finding is that this issue is addressed by an increasing number of professionals both in the Czech Republic and abroad and that numerous research studies are performed in this area. See for example Michalík, 2010; Michalík, Valenta in Titzl, 2008; Kozáková, 2014, etc. The research presented in this paper builds on a research study carried out by means of a standardized questionnaire SEIQoL, and a research study using a questionnaire method to identify stressful and resilient factors and tendencies in persons caring for an individual with health disability (Kozáková, 2014).

Firstly the paper defines the basic terminology and theoretical background relating to the issue, then the paper presents a summary of selected results of the research study, the objective of which was to identify subjective attitudes of the parents of children with disability to selected aspects of the quality of their life.

2 Theoretical background and definition of terminology

The birth of a child with disability, or the discovery of a child's disability in the course of life is a significant life event and often represents a "test" for the whole family. What often happens is that the family is unable to withstand the burden and falls apart as a result of the imposed stress. It very much depends on how the family accepts the situation. Whether such situation is accepted as a "disaster" and the family remains isolated in their pain, or as a life challenge, when the family learns to accept the child with the disability, to be active, not to lock away the family or the child from the surrounding world, but with a desire to prepare the child for life. Each family member copes with a child's disability in an individual way. A key aspect is the decision of the parents to handle the situation, adopt the role of "the parents of a child with disability" and to create the best possible conditions for the life of the child and the whole family. (Vančura, 2007) Only after the parents accept the new situation and deal with it, they can do much good for the child and for themselves. Much precious and unique. (Matějček, 2005)

A significant role is also played by experts, financial and social support of families with disabled children, support provided by the state, organisations, facilities, and last but not least public education activities in the society.

This also presents a specific situation for **the sibling in the family**. A danger on the part of the parents might be focusing their parental care on one of the children, i.e. they primarily care for the child with disability and the sibling is expected to

show more mature behaviour than corresponds to his/her level of development. Or, conversely, they might focus their attention on the child without disability, which may serve as a means of compensation and is one of the possible defence mechanisms. Both approaches might place inadequate demands on the sibling, who might not be able to handle them. (Kozáková, 2005)

Parents caring for a child with disability are endangered by **the burnout syndrome**. More than anybody else, parents need to take a rest from mental overload, have an opportunity to do something else, think about something else and gain new strength. A preventive function might be fulfilled by meeting other parents of children with disability and transfer of experience, advice, worries and joys. (Kozáková, 2013)

Caring for a child with disability might affect the quality of life of the whole family. Most frequently, the term **quality of life** is based on a broader definition of health: *"it is to feel well from a physiological, psychological (mental) and social perspective."* (Prokešová, 2008, p. 17), the World Health Organization defines quality of life *"as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."* (Vaďurová & Mühlpachr, 2005, p. 11) It is a broad ranging concept affected in a complex way by the person's physical and mental state, social relationships, and personal beliefs in the context of their environment. The concept of the quality of life can be approached from two dimensions, subjective and objective. Today, experts tend to incline to the subjective assessment of the quality of life. They see it as crucial and decisive in the life of humans. (Vaďurová & Mühlpachr, 2005) In the research study, the results of which we would like to summarize, we focused on the subjective assessment of various aspects of the quality of life.

3 Methodological background of the research

Objectives of the research study

The objective of the research study was to identify subjective attitudes of the parents of a disabled child to selected aspects of the quality of their life.

Partial objectives were to identify:

- The extent to which the family of a child with disability subjectively perceives the degree of financial and physical burden as a result of child care,
- How the parents subjectively evaluate coping with their child's disability,
- Whether the presence of a child with disability in the family affected the partnership of the parents caring for the child,

- How the parents subjectively evaluate the amount of free time and whether the family is assisted by another person in terms of child care,
- Whether the child with disability has a sibling and how the parents evaluate the relationship between the siblings,
- How the parents subjectively perceive the positives and negatives resulting from their care for a child with disability.

Research methods

The research was carried out by means of a **questionnaire**. There are a number of standardised methods for identifying the quality of life, life satisfaction, etc. For the purposes of this research study a specific questionnaire was developed based on our experience from previous research. The questionnaire contains 21 items; 11 semi-closed, 4 open, 3 closed and 3 scale items. The closed questionnaire items offer a choice between two or more possible answers, for example yes – no – I don't know. Semi-closed items combine the advantages of closed and open items by adding the "other" option, which allows to express an own opinion even to a closed question. Open items provide the respondent with an opportunity to comment in detail and describe a broader framework. In this way, the respondents can point to important associations and contexts. (Svoboda, 2012)

The research questionnaire was divided into several parts. The first part focused on basic information about the respondents and their children. The next part asked about the experience and opinions of the respondents and their subjective perception of various aspects of the quality of life.

Description of the respondents and the analysed environment

For cooperation in the context of the research study we addressed the parents of pupils from an elementary school, practical elementary school, special elementary school, hospital elementary school, hospital nursery school, nursery school and practical school located in the Zlín Region.

A total of 60 questionnaires were distributed. Of the total of 60 questionnaires, 37 returned. The return rate was 62%. The research sample consisted of 37 parents of children with disability.

4 Presentation and interpretation of the research results

Basic information about the respondents and their children

In the course of the research, we firstly identified **basic information about the respondents and their children.** The first item of the questionnaire identified whether the questionnaire is completed by the **mother, father or another family member**. The questionnaire was completed by 34 (92%) mothers, and 3 (8%) fathers. The second item asked about the **age of the respondent**. As shown in Table 1, the most frequent age category of the respondents was 40–49 years (18; 49%). The next age category was 30–39 years (16; 43%). Other categories included one respondent each.

Table 1: Age of the respondents.

Age of the respondent	20–29 years	30–39 years	40–49 years	50–59 years	60 years and older	Total
Number	1	16	18	1	1	37
Percentage	2.67	43	49	2.67	2.67	100

The third item asked about the **age of the child with disability**, who the questionnaire is aimed at. Children aged 11–13 years represented the largest group (12; 32%). The number of children aged 8–10 years was 10 (27%). The number of children aged 14–16 years was 8 (22%), the number of children aged 4–7 years was 6 (16%). 1 (3%) child is older than 17 years (see Table 2).

Table 2: Age of the child with disability.

Age of the child	4–7 years	8–10 years	11–13 years	14–16 years	17 years and older	Total
Number	6	10	12	8	1	37
Percentage	16	27	32	22	3	100

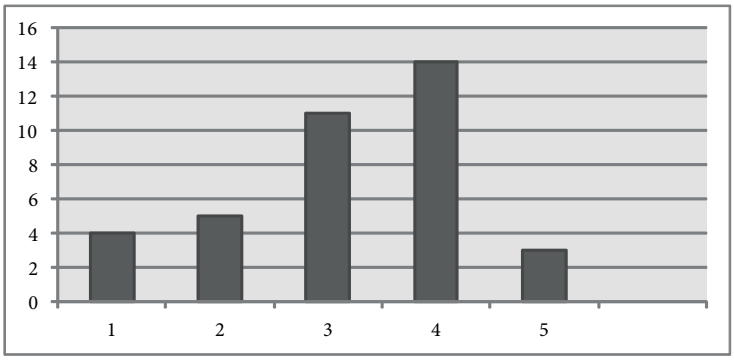
The fourth item identified the **type of disability.** The most frequent was **mental disability** (23; 62%). 11 (30%) respondents indicated **multiple disabilities**, 7 (16%) respondents indicated **physical disability**, 1 respondent indicated **sensory disability**. The respondents also had to indicate another type of disabilities. This opportunity was not used by any of the respondents.

The fifth item examined **when the parents discovered the disability of their child**. 13 (35%) respondents learned about the disability of their child right after birth, 9 (24%) respondents within six months after birth, 6 (16%) respondents during pregnancy. The option "at another time" was indicated by 7 respondents with the following comments: "*at the age of five weeks*", *"around five years of age"*, *"at the age of two years"*, *"during pre-school age"*, *"at the age of three years"* (2 respondents), *"at the age of four years*".

The sixth item asked whether the families use any of the **facilities for individuals with disability**. "Yes" was indicated by 27 (73%) respondents, "no" was indicated by 10 (27%) respondents. If "yes" was indicated, the respondents had an opportunity to specify the facility. 10 respondents indicated a school, 4 respondents indicated a charitable organization, 1 respondent indicated an educational and psychological counselling centre, 1 respondent indicated the Tamtam early intervention centre.

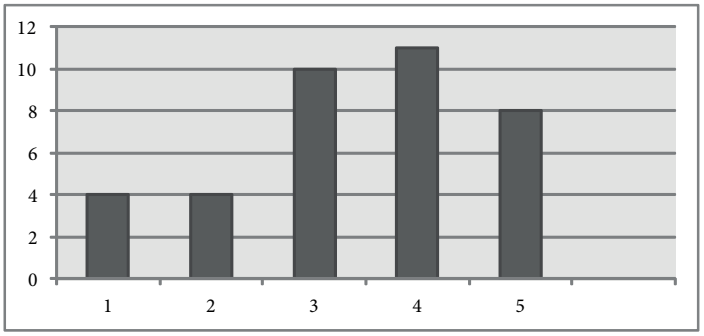
Financial and physical burden as a result of child care

The seventh item examined the subjectively perceived **degree of financial burden on the family**, resulting from the care for a child with disability. The respondents answered on a 1 to 5 scale, where 5 meant "most burdensome". The most numerous group of respondents indicated "4" (14 respondents; 38%), followed by "3" (11 respondents, 30%). The degree of burden "2" was indicated by 5 (14%) respondents, "1" and "5" jointly by 3 (8%) respondents. Graph 1 shows that most of the parents perceive the financial burden on the family as relatively high. The assessment of "4" and "5" was indicated by a total of 46% of the respondents, as opposed to those who do not perceive any financial burden as a result of child care (22%). The assessment of "3" can be regarded an average financial burden.



Graph 1: Subjective perception of financial burden on the family as a result of caring for a child with disability.

The eighth item examined the subjectively perceived **degree of physical burden on a caring person**. The respondents answered on a 1 to 5 scale, where 5 meant "most burdensome". The most numerous group of respondents chose "4", this was indicated by 11 (30%) respondents. This is followed by "3", which was indicated by 10 (27%) respondents. The degree of physical burden "5" was indicated by 8 (22%) respondents, "1" and "2" jointly by 4 (11%) respondents. Graph 2 shows that most of the parents perceive the physical burden on the caring person as relatively high. The assessment of "4" and "5" was indicated by a total of 52% of the respondents, as opposed to those who do not perceive any physical burden as a result of child care (22%). The assessment of "3" can be regarded an average physical burden.



Graph 2: Subjective perception of physical burden on the family as a result of caring for a child with disability.

Level of coping with the child's disability

The ninth item examined the subjectively perceived **level of coping with the child's disability**. Most of the interviewed respondents (17; 46%) state that they try to cope with the disability of their child. 9 (24%) respondents state that the "coping" took longer. **8 (22%) respondents state that they will never cope with their child's disability**. Only 3 (8%) respondents state that they have coped with their child's disability quickly. The "other" option was indicated by one respondent: *"it's hard"*.

Degree of influence on the partnership of the caring parents

The tenth item examined **whether the child's disability had an influence on the partnership of the caring parents**. The relationship of most of the parents (13; 35%) was from the beginning disrupted by the birth of a child with disability. 10 (27%) respondents state that the child's disability had no effect on their partnership. 7 (19%) respondents state that the relationship fell apart, on the contrary, 4 (11%) respondents consider their relationship more solid than before the birth of a child with disability. 2 (5%) respondents consider their relationship seriously disrupted.

Amount of free time of the parents and assistance with child care by another person

The eleventh item focuses on **free time of the caring parent, specifically its degree**. Very little free time is perceived by 25 (68%) respondents. A sufficient amount of free time is perceived by 9 (32%) respondents. The "other" option included the following answers: *"I have some free time in the morning, when he is at school"; "just about enough"; "when he is at school – no time during holidays"*. From experience we can say that the degree of free time of caring parents is generally very low – depending on the assistance of another person, they devote almost all free time to their child with disability.

In the twelfth item the caring parents were supposed to assess whether **a person assisting with the care for the child with disability in the parents' absence would be of any benefit**. 15 (41%) respondents state that they use the assistance of another person. 9 (24%) respondents state that they have not thought about this option. 5 (14%) respondents state that they do not need any assistance. 4 (11%) respondents are planning to ask for assistance, and 3 (8%) respondents state that they do not want anybody to assist them.

The thirteenth item examined whether the caring parents **are assisted by another person**. 31 (84%) respondents gave an affirmative answer, 6 (16%) respondent gave a negative answer. If the answer was "yes", the respondent was supposed to indicate who helps the most. The following answers were indicated: son, grandmother, family, parents, charitable organization, friend, grandparents, assistants, nurse. **The most commonly indicated response was the family (17 times).**

The next item of the questionnaire examined **the frequency of assistance by another person**. The most common assistance is occasional (12; 32%), followed by several times a week (8; 22%), several times a month (7; 19% of respondents) and daily (6; 16% of respondents).

The fifteenth item examined whether the caring parents **go out** with **their child with disability**. 34 (92%) respondents state that they go out with their child, 3 (8%) respondents state that they do not go out with their child. If the respondents gave a positive answer, they were supposed to indicate where they take their child. The respondents indicated swimming pool (21), trips (17), shopping (16), holidays (15), cinema (8), theatre (6), family centres (5), entertainment centres, family celebrations, visits, charitable organization, wherever I need to go, etc.

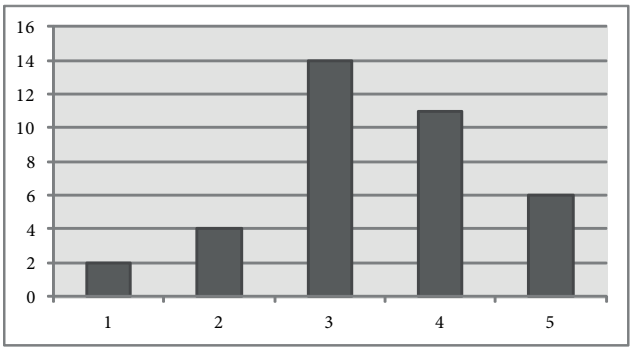
Sibling of a child with disability

The sixteenth item examined whether the child with disability has a sibling. 22 (59%) respondents gave an affirmative answer, "no" was indicated by 15 (41%) respondents. We were interested in the **relationship between the sibling and the child with disability**. A normal sibling relationship was indicated by 20 (91%) respondents, the option of indifference was indicated by 2 (9%) respondents. A very positive finding was that the remaining two options (*"the relationship seems to be disrupted", "he/she is ashamed of him/her"*) were not indicated by any of the respondents.

The eighteenth item examined **whether the parents give more care to the child with disability than his/her siblings**. 16 (73%) parents state that they "give more care to the child with disability than his/her siblings". 6 (27%) respondents state that they "give equal care to all children".

In the nineteenth item the caring parents were supposed to **subjectively assess and evaluate the assistance provided to families with disabled children by the state**. The respondents answered on a 1 to 5 scale, where 5 meant "the worst". Graph 3 shows that the most frequent answer is "3", which was indicated by 14 (38%) respondents, followed by "4", which was indicated by 11 (30%) respondents, "5" was indicated by

6 (16%) respondents, "2" was indicated by 4 (11%) respondents, and "1" by 2 (5%) respondents.



Graph 3: Subjective perception of the level of state assistance with the care for a child with disability.

Subjective perception of the positives and negatives resulting from the care for a child with disability

The twentieth item examined what the respondents consider **positive/negative to ensure the quality of life for themselves, their family and their child/children**. The answers are presented in Table 3.

Table 3: Positives/negatives in relation to ensuring the quality of life of families with a child with disability.

Positives	Negatives
• *"Possibilities of the school, social services."* (mother, 43 years old) • *"When we know that we have somebody to turn to, when the child is happy, when assisting organizations help us with child care."* (mother, 46 years old) • *"Establishment of schools and classes for children requiring extra care."* (mother, 39 years old)	• *"Subordination of my life to the needs of the child."* (mother, 35 years old) • *"Uncertainty in the future when the child is adult."* (mother, 39 years old) • *"We need to provide everything ourselves, little interest of the state and state institutions."* (mother, 40 years old) • *"Excessive integration at any cost."* (mother, 50 years old)

• *"Assistance provided by civic associations, educational organizations and teachers in the process of education, and the provision of the necessary equipment easing my child's disability."* (mother, 40 years old) • *"The positive is that we love each other, assistance provided by the family, friends, school, care allowance."* (mother, 38 years old) • *"The family holds together, mutual support, understanding of similar fates, empathy."* (mother, 31 years old) • *"Car allowance."* (father, 37 years old) • *"I know where the child is – school."* (mother, 31 years old) • *"Peace, comfort, pure love at home."* (mother, 42 years old)	• *"I'd like more assistance by the state in all respects."* (mother, 37 years old) • *"Minimum assistance by the state, lack of understanding of what it takes and what effect a child with disability has on the family."* (mother, 36 years old) • *"I am seriously ill myself, my husband is responsible for everything, I miss quality time with my daughter."* (mother, 39 years) • *"Restrictions for family members – in terms of time, space (hobbies, trips, visits) – according to the child's needs."* (mother, 29 years old) • *"The negative is the human environment."* (mother, 63 years old) • *"It is impossible to live actively as a family (sports and regular activities)."* (mother, 31 years old) • *"The care allowance is ridiculous, it should feed both my son and me, it's impossible for me to get a job, the care for my son is too demanding."* (mother, 50 years old) • *"Hopelessness, impossibility of improvement."* (mother, 33 years old) • *"Constant supervision of the child, increased attention, in the evening I'm completely exhausted."* (mother, 35 years old)

In the last, twenty-first item, the respondents had an opportunity to comment on the issue beyond the scope of the questions contained in the questionnaire. The text below presents the respondents' comments:

- *"My baby is so unique and I, my husband and the whole family take him as such."* (mother, 43 years old)
- *"I don't like the fact that non-walking children with mental disability are treated differently from walking children, the care for a walking child with mental disability is very demanding, especially mentally."* (mother, 41 years old)

- *"One gets used to anything, but if I could choose, I'm sure I wouldn't go for this voluntarily. A healthy sibling is a necessity in such family, if possible."* (mother, 38 years old)
- *"The financial support of the state could be higher, especially with increasing age of the child and the parents, a higher allowance would be desirable – assistance and relief services. There's a dilemma whether the parents can afford it. These services are paid, so their use is limited by the financial situation of the family."* (mother, 36 years old)
- *"The worst was to face the fact that I have a disabled child."* (mother, 40 years old)
- *"This is an involuntary situation, but one has to adapt, family support is important."* (mother, 38 years old)
- *"If it is possible and the parents manage, it is good to have more children, and especially not to fear that they will be disabled!"* (mother, 32 years old)
- *"What sometimes bothers me is the environment, I don't want people to watch us through rose-coloured glasses, we rather need a normal environment, not compassion."* (mother, 35 years old)

5 Conclusions and discussion of research results

The objective of the research study was to identify the subjective attitudes of the parents of a disabled child to selected aspects of the quality of their life. The research involved 37 families of children with disability. Firstly we examined basic personal data about the respondents and then asked about the experience and opinions of the respondents and their subjective perception of various aspects of the quality of life.

In the context of the partial objectives we were first interested in the extent to which the family of a child with disability subjectively perceives **the degree of financial and physical burden as a result of child care**. The respondents answered on a 1 to 5 scale, where 5 meant "most burdensome". In the case of financial burden the most numerous group of respondents indicated "4" (14 respondents; 38%), followed by "3" (11 respondents, 30%). The degree of burden "2" was indicated by 5 (14%) respondents, "1" and "5" jointly by 3 (8%) respondents. The assessment of "4" and "5" was indicated by a total of **46%** of the respondents, as opposed to those who do not perceive any financial burden as a result of child care (**22%**). The assessment of "3" can be regarded as an average financial burden. It can be concluded **that most of the parents perceive the financial burden on the family as relatively high**. The similar applies to subjectively perceived degree of physical burden on a caring person. The most numerous group of respondents chose "4", this was selected by 11 (30%) respondents. The score "3" was indicated by 10 (27%) respondents. In terms of physical burden, the score "5" was indicated by 8 (22%) respondents, "1" and "2" jointly by

4 (11%) respondents. The assessment of "4" and "5" was indicated by a total of **52%** of the respondents, as opposed to those who do not perceive any physical burden as a result of child care (**22%**). The assessment of "3" can be regarded as an average physical burden. It can be concluded that **most of the parents perceive physical burden on the caring person as relatively high.**

We were also interested in how the parents **subjectively evaluate coping with their child's disability**. Most of the interviewed respondents (17; 46%) state that they "try to cope with the disability of their child". 9 (24%) respondents state that the "coping" took longer. **8 (22%) respondents state that they will never cope with their child's disability**. Only 3 (8%) respondents state that they have coped with their child's disability quickly. The "other" option was indicated by one respondent: *"it's hard"*.

We were also interested in whether the presence of a child with disability in the family affected **the partnership of the parents caring for the child**. The relationship of most of the parents (13; 35%) was from the beginning disrupted by the birth of a child with disability. 10 (27%) respondents state that the child's disability had no effect on their partnership. **7 (19%) respondents state that the relationship fell apart**, on the contrary, 4 (11%) respondents consider their relationship more solid than before the birth of a child with disability. **2 (5%) respondents consider their relationship seriously disrupted**.

We were further interested in how the parents subjectively evaluate **the amount of free time and whether the family is assisted by another person in terms of child care**. Very little free time is perceived by 25 (68%) respondents. A sufficient amount of free time is perceived by 9 (32%) respondents. The "other" option included the following answers: *"I have time in the morning, when he is at school"; "just about enough"; "when he is at school – no time during holidays"*. From experience we can say that **the degree of free time of caring parents is generally very low – depending on the assistance of another person, they devote almost all free time to their child with disability**. 15 (41%) respondents use the assistance of another person. 9 (24%) respondents have not thought about this option, 5 (14%) respondents state that they do not need any assistance. 4 (11%) respondents are planning to ask for assistance, and 3 (8%) respondents state that they do not want anybody to assist them. Assistance is mostly provided by **the family (indicated 17 times),** son, grandmother, parents, charitable organization, friend, grandparents, assistants, nurse. The most common assistance is occasional (12; 32%), followed by several times a week (8; 22%), several times a month (7; 19% of respondents) and daily (6; 16% of respondents).

We were also interested in **whether the child with disability has a sibling and how the parents evaluate the relationship between the siblings**. 22 (59%) respondents gave an affirmative answer, "no" was indicated by 15 (41%) respondents. A normal sibling relationship was indicated by 20 (91%) respondents, the option of

indifference was indicated by 2 (9%) respondents. A very positive finding was that the remaining two options (*"the relationship seems to be disrupted", "he/she is ashamed of him/her"*) were not indicated by any of the respondents. 16 (73%) respondents state that they "give more care to the child with disability than his/her siblings". 6 (27%) respondents state that they "give equal care to all children".

We were also interested in **how the parents subjectively perceive the positives and negatives resulting from their care for a child with disability**. The parents were often satisfied with financial contributions, support provided by the school, relaxed atmosphere; on the other hand, they expressed fears and uncertainties in relation to the future of the child, the necessity to subordinate their life to the child, the low amount of financial contribution especially as the child becomes older, etc. Many of the parents recommend and encourage to have another child: *"If it is possible and the parents manage, it is good to have more children, and especially not to fear that they will be disabled!"* (mother, 32 years old)

6 Conclusion

The results of the research points out that a family caring for a child is burdened both financially and physically, which influences the quality of life of all its members. **A greater financial burden** is perceived by 46% of respondents. A greater physical burden of caring for a child with disability is perceived by 52% of respondents. The answers of the respondents also indicate a frequent **degree of dissatisfaction with the help of the state provided to families with a disabled child**. Whether it be material support or a greater understanding on the part of the state and state institutions. The results also point to an **influence on the partnership of the parents** caring for their child with disability – 41% partnerships undergo major or minor difficulties and 14% of the respondents state that their relationship fell apart. There is also an influence on **the area of free time of the parents** caring for their child with disability and the corresponding **high degree of fatigue**. The research also indicates that a crucial role is played whether a family caring for a child with disability is assisted by another person or institution, who take over some responsibilities. In 84% of cases the respondents are assisted in the care for their child with disability by another person, who is in most cases a family member. The respondents also seek help in school facilities and charitable organizations. Also, a very interesting issue is **coping with the disability of the child**, which provides opportunities for psychological support provided to families of children with disability. (8% of the respondents state that they will never cope with their child's disability.)

If we compare the observed problematic areas for example with the results of the research *"Quality of life of families caring for member with severe health disability"*,

which was carried out in the Czech Republic in 2010, also here some items such as **loss of the parents' ability to enjoy free time** or **feelings of great fatigue** were indicated by the caring persons quite often – in 34.10% and 43.35% of the respondents. (Michalík, 2010, available from http://www.sancedetem.cz/cs/hledam-pomoc/deti-se-zdravotnim-postizenim.shtml, [quoted 19 August 2015]) The results of the *Research of stressful and resilient factors and tendencies in persons caring for a family member with health disability in the capital city of Prague* show that the most common state reported by the caring persons is a loss of personal life perspectives (35.2%). 33.3% of the respondents experience a feeling of great fatigue and 29.8% a loss of the ability to enjoy free time. (Michalík & Valenta in Titzl, 2008)

It would surely be desirable to think about other ways of supporting the families of children with disability. In particular, the provision of appropriate information so that the parents are aware of the possibilities to resolve their situation and to use the services available in the Czech Republic, including, for example, voluntary services. A very important aspect is the development of a system of social, educational and health services, which the parents of a child with disability can use. Moreover, it is vital to focus on psychological support of families of children with disability, and to promote the partnerships among parents, stress coping strategies, abilities to accept a child with disability, relaxing techniques, etc. It is important to develop possibilities for the parents to relax and thus prevent feelings of great fatigue.

"Even though it is desirable to develop a system of supporting the families of children with disability, it is necessary to realize that the caring families do not represent a single monolith made up of identical elements, needs and possibilities. On the contrary – if there is a unity consisting of various elements, it has to be the families of children with health disability. This statement is the cause of numerous misunderstandings and problems. The systems of public support are, according to their nature, designed to address general social issues, they are usually unable to and cannot, in the context of general legislation, respond with sufficient sensitivity to specific problems of the families of children with disability, which are beyond the general model." (Michalík, 2010, p. 3)

In conclusion, I would like to thank the parents who participated in the questionnaire survey and who care for their children with love, understanding, empathy and a desire to provide for their children as well as for themselves a usual full life, although it is often not easy. Let me conclude by quoting one of the mothers who summarized the situation very aptly: *"What sometimes bothers me is the environment, I don't want people to watch us through rose-coloured glasses, we rather need a normal environment, not compassion."* (mother, 35 years old)

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