ANALYSIS ON THE SITUATION OF FAMILIES HAVING CHILDREN WITH DISABILITIES

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ARTICLE INFO	ABSTRACT
	The research of the peculiarities of psycho-social functioning and needs of families having children with disabilities has lately gained great significance pursuing to ensure successful social integration of the families, and to develop an effective system of assistance for them, which would help to support the families as well as activate their internal and external relations. On the basis of the qualitative research, the paper analyzes the psycho-social situation of families having children with disabilities, and focuses on the following aspects: the impact of a child's disability on the family (the psycho-social condition of parents; interrelations in the family; relationship with the surrounding environment; parents' participation in the working and social activity, interpersonal partnership between specialists and families) and family needs which are important to ensure the functioning of such families and improvement of services.

Introduction

One of the most significant problems in the psychosocial structure of the disability phenomenon is the situation of a family having a child with disability. Scientific literary sources indicate that the main feature distinguishing families of children with disability from other families of nondisabled children of the same age is child disability due to which the entire family gets into the zone of child disability influence. The way parents react to child disability depends on personal, family and environmental factors. In critical situations, flexibility or rigidity of a family as a system in the most common sense gets prominent, i.e., its ability to change and adapt to the newly-emerging requirements (Jusienė, 1999). On the other hand, the family experiences constant interaction with the environment that creates mechanisms, helps overcome crises (e.g., birth of a child with disability) and stressors (biological, economic, social or psychological threats for the family as a system), and adapt to the changing conditions (Gerulaitis, Dėlkutė, 2008). Research performed in different countries reflects that the network of a family's social relations, family culture, emotional maturity of parents, existing values, strength of marriage bonds, relationships with other family members and relatives, social support, purposefulness of the help provided and the society's culture have influence on the psychosocial situation of the family and its further adaptation (Baxter; Cummins; Yiolitis, 2000; Woolfson, 2004; Nedelisky, 2004; Connell et al., 2007; Henderson, Brayan, 2011; Hallahan, Kauffman, Pullen, 2012, etc.).

Recently, works of authors analysing the psychosocial situation of families having children with disabilities actualise with growing frequency such families' strong sides and strategies by using which the families successfully solve their issues (Hastings, Taunt, 2002; Twoy, Connolly, Novak, 2007; Henderson, Brayan, 2011, etc.). In this context, authors emphasise the aspect of a family's empowerment and its social activity, as well as provision of complex support for the entire family with regard to its needs.

Recently, increasing attention is paid in Lithuania to families of children with disabilities. This is influenced by the laws passed and other documents (the Law on Social Integration of Persons with Disabilities" (2005), the National Family Policy Concept (2008), the Law Amending the Law on Education (2011), etc.) which stress the role of the family in the process of comprehensive development and social integration of a child with disability. The documents also foresee purposive measures helping solve psychosocial issues of families of children with disabilities. Integrity of help and support for the family is underlined embracing all of the family functions ensuring the family's material, social and moral welfare. In the National Family Policy Concept (2008), attention is paid to the importance of systematic and comprehensive research on family status and needs. Such research is significant for improvement of family-related social policies and strengthening of external and internal family resources.

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Issues of families of children with disabilities were started to analyse more widely in Lithuania in the recent decade. Works carried out by researchers (Butkevičienė, 2000, 2001; Ališauskienė, 2002; Gradeckienė, 2002; Kreivinienė, 2007; Gerulaitis, 2006, 2007; Ruškus, Mažeikis, 2007; Vaičekauskaitė, 2007; Pileckaitė-Markovienė, 2008; Ustilaitė, Kuginytė-Arlauskienė, Cvetkova, 2011) disclose various problems of aforementioned families that are difficult to solve under existing conditions and hinder ensuring of full-fledged functioning of families having children with disability: the social help network for families of children with disabilities is insufficient in Lithuania and does not always correspond to family needs; families lack psychological, social and educational support; in practice, the support system still remains oriented towards a person with disability rather than towards his or her closest environment (i.e., the family); while trying to cope with the emerging difficulties and needs, parents often encounter uncoordinated activities of different institutions providing support for children with disabilities and other family members, etc.

The ongoing research discourse reflects that, in order to ensure successful social integration of families having children with disability and to develop an efficient system of support for such families, it is important to perform systematic research that would help disclose the psychosocial functioning peculiarities of these families, establish their needs and distinguish what kind of help they lack and expect from formal and informal structures. The problem analysed can be described by the following questions:
-   What is the impact of child disability on the psychosocial situation of his or her family?
-   What are such families' needs that are important while ensuring functioning of the family and improving the services provided?

The object of the research is the psychosocial situation of families having children with disabilities. **The aim of the research** is to disclose the psychosocial situation of families having children with disabilities on the basis of parent experiences.

The methods of the research. The strategy of qualitative research was applied. Semi-structured interviewing was carried out. The data received was analysed using qualitative content analysis. The qualitative content analysis was performed regarding the following sequence (Creswell, 2009): repeated reading of the content of selected articles, distinction of meaning elements in the text analysed, grouping of the distinguished meaning elements into categories and sub-categories, integration of the categories into the context of the phenomenon analysed and description of their analysis.

The sample of the research. The target sample selection type was chosen. The main criteria of research participant selection: parents who have school-age children with moderate and severe disabilities. The research involved ten informants having children with intellectual impairment, autism and cerebral palsy. The research was carried out in 2011.

Research ethics. Qualitative research was performed without violating the research participants' rights and principles of research ethics: the research participants were acquainted with the goal of the research and data collection methods; all the participants voluntarily agreed to take part in the research; questions were presented to research participants related to personal details of their family lives, but respect for their choice was guaranteed in case they would not like to answer them; confidentiality was ensured (the participants were informed that participation in the research and the data obtained from them would not be used against them later). In order to ensure confidentiality for research participants, their names were coded using a letter.

Research results

The research was primarily aimed at disclosing **what impact child disability has on psychosocial functioning of a family**. Analysis of the data obtained has disclosed five qualitative categories: *psychological feeling of parents*, *relations inside the family*, *relationships with other close people*, *participation in societal life* and family's *co-operation with specialists*.

The category "**psychological feeling of parents**" is further on narrowed by distinguishing sub-categories: *experiences after acquaintance with child disability, acceptance of child disability*, and *experiences related to the child's future* (see Table 1).

Table 1. Psychological feeling of parents

Sub-category	Sample statements
Experiences after acquaintance with child disability	"I experienced great inner anxiety, pain, helplessness…"; "I was thinking, why us, and what for…"; "…it was a very hard time, everything happened: anger, and tears, and grief…"; "…I had heard numerous bad things about this impairment, therefore, I greatly feared and was worried…"; "…everything seemed annoying to me, I was angry, I didn't want to see anyone…"; "I felt guilty".
Acceptance of child disability	"…I accept everything as is and do not distress myself because of it … numerous possibilities still exist, it is only sometimes difficult to see them on my own, educators helped us much…"; "…I try to see not only the dark side, good things also exist, we learn many things together…"; "…I am an optimist, do not give up and go forward, I just accept everything as is, it is important to go on, although with small steps…"; "…when you accept of child disability, it is not so terrible anymore, you start seeing everything in a different light – life becomes brighter…"; "It was very hard, but other people's support and efforts not to give up to dark thoughts and feelings was a great help".
Experiences related to the child's future	"We have a feeling of certainty that everything is going to be all right, we see many positive changes, a person with disability has more possibilities presently, and further on, hopefully, still more is going to be achieved…"; "Our child has a future, has a family that is helpful, and will help to be independent"; "Optimistic thoughts and the feeling that everything is going to be all right"; "I believe in my child and rely on my child. The integration is slow but it is moving forward".
	"I feel anxious about the future, as it is unclear how he is going to live and what he will do after graduation from school"; "When I think about the child's future, I experience fear, anxiety, sad thoughts"; "…I am greatly worried, he can do few things, he will hardly achieve something, and will he be self-supporting…"; "The child's future is without prospects, just isolation. Very sad.".

The informants shared their experiences on their feelings and spiritual states after getting to know about their children's disability. Parent reactions to child disability are quite individual, yet it became clear that all of the research participants had experienced negative feelings, especially anxiety, fear, anger and loss. Some parents indicated that they felt guilty for their children's conditions. Similar trends are reflected in other research works (Baxter, Cummins, Yiolitis, 2000; Kearney, Griffin, 2001; Mansell, Morris, 2004) indicating that feelings of helplessness, hopelessness, anxiety and anger are typical of the majority of parents during this period. This indicates that a diagnosis of child impairment causes great stress to parents. According to Butkevičienė and Majerienė (2006), the crisis that parents experience during the period of child impairment diagnosis is the deepest and the most painful throughout the entire period of accepting the disability. During this stage, families are in great need of psychological support. Very special significance is attached to the moment of informing about presence of disability: when the diagnosis is communicated (delayed or not), what words (terms) are used and whether a dialogue takes place between parents and specialists.

The research data discloses that almost all the research participants have accepted with child disability: they are aware of the fact of disability, estimate child disability adequately, do not concentrate on child "inabilities" but, rather, put efforts to develop the potential their child has despite functional limitations of the child; they try to retain hope and optimism. Some of the parents described their families' lives in the context of child disability as valuable from the viewpoint that every day brings new and interesting things to them. They are happy to constantly meet new people willing to help them.

The participants of the research indicated that, in the process of child disability internalisation, psychological help and support from family members, relatives, other people and specialists is of great importance. Similar tendencies are disclosed in other research works (Britol, Gallagher, 2007; Jusienė, Bagdonaitė, 2004, etc.) indicating that parents who receive psychological support underline negative outcomes of child disability more seldom and positive ones more often; they experience fewer problems in the family, are less inclined to exaggerated child care, are less depressive and feel happier.

Accepting of disability is a process and depends on numerous factors: the cultural environment, parent experiences, feelings before childbirth, other family members' attitudes, parents' values, child disability peculiarities, support received, etc. (Hallahan & Kauffman, 2003; Woolfson, 2004; Nedelisky, 2004; Henderson, Brayan, 2011, etc.). Parents' acceptance of child disability embraces social and psychological

aspects of life of both the child and the entire family (Butkevičienė, 2000). On the other hand, parents' psychological unacceptance of child disability may have negative influence to the child's socialisation. In cases of disability rejection (negation of it or concentration onto it) the remaining potential powers of the person with disability are exploited unpurposefully or insufficiently (Gailienė, 2007).

The research results have disclosed parents' thoughts and feelings related to child future. It became clear that some of the informants were quite optimistic when looking at their children's future. Parents stated that they believed in their child's potential powers, and this is an important factor for empowerment of a person with disability. According to Ruškus and Mažeikis (2007), belief in potential powers of a person having disability of one or another kind opens important horizons of existence and opportunities for personality disclosure. Therefore, not accidentally did the parents say that, through belief in their child's possibilities, pay much attention in the family to development of child independence and his or her self-expression. Parents also see that education of people with disability, as well as other spheres of life, is increasingly opening to the experience of social inclusion. Therefore, parents foster hopes that the ongoing social inclusion of people having disability provides increasing opportunities of self-realisation of people with disability and their social participation.

On the other hand, some of the informants mentioned that they feel worried, fear about their child's future, and see poor opportunities for the child. Pessimistic thoughts are typical of them when thinking about further life of the child. This may be influenced by parents' attitudes towards disability, overestimation of it, looking at the child's possibilities through the prism of inability, as well as other factors related to the internal and external context of the family's life: communication in the family, the members' interrelations, family organisation, self-awareness and awareness of the environment typical of the family, family values and beliefs, the family life cycle, values dominating in the society, social relations, accessibility of social services, etc.

The content of another category, "**relations inside the family**", is reflected by distinction of the following sub-categories: *parent interrelations*, *parent relations with the child having disability*, *parent relations with other children*, and *relationship of healthy children with their brother/sister having disability* (see Table 2).

Table 2. Relations inside the family

Sub-category	Sample statements
Parent interrelations	"...not much has changed, the relations remain as good as previously, yet new troubles have emerged, we have to learn many things..."; "We have been supporting each other, we help each other"; "we have united more and become more hardened..."; "My husband helps me to a very great extent"; "...we put efforts to solve the emerging problems together..."; "We are together, we are support to each other..."; "...we communicate with each other openly, pour our hearts out and, look, it gets easier..."; "...what else could be done – constant talking over, consoling ourselves...".
	"...different things happen, quite often we get angry with each other..."; "...so we have always lived together, but as if in different worlds..."; "...more tension, weariness has appeared..."; "...at the beginning, relations were tense, we showed much anger, as if unable to find a place for ourselves..."; "...my husband does not want to speak much of it, and this annoys me, so I am often angry..."; "...helps me very little...".
Parent relations with the child having disability	"...great emotional relationship..."; "...maybe a little more to me, but she is also very affectionate to others..."; "...he maintains good relations with everyone in the family, well, sometimes in a bad mood or a little angry – comes closer, embraces..."; "We do not lock the child at home, he goes to school, attends various activities, we go to different events"; "...we try to raise reasonable requirements, but achieving as much independence as possible is a business of us all..."; "...very much patience is needed, as until the child learns something, oh, how much time you need..."; "...has duties as well as other children...".
	"...the disability is great, so he is not going to be independent..."; "...I try not to lose sight of the child, so that something bad doesn't happen"; "...not much can be required when such a level of disability is experienced...".
Parent relations with other children	"...we try to give our attention to all the children..."; "...in our family, we all have good relationships, and good relationships are very important for us..."; "...we all have open talks, it is the best drug against misunderstandings..."; "...maybe I am sometimes too imperative, it sometimes happens to hear, "I'm bored to death" or something alike"; "...sometimes says that we love the brother more, although, in reality, it is not true – all the children are equal, only, well, maybe we give more attention to him...".
Relationship of nondisabled children with their brother/sister having disability	"...maintains very good relations with brother..."; "...she willingly helps look after the sister, a real helper to me..."; "goes together everywhere, and goes together to visit friends willingly..."; "all of them interact beautifully, but a closer relationship exists between the girls..."; "Both neighbours and teachers tell me that communication between both our children is an eye candy"; "...different things happen, sometimes they quarrel, and, then, everything gets alright again".

Parents shared their experiences how child disability had changed their relations at a later stage. According to the research results, some of the informants said that their interrelations had not changed, some others indicated that their relations had strengthened, and the third group pointed out that tension was dominant in their mutual relations or they had worsened due to the state of the child. The above things indicate that it is complicated to decide on changes within a family following birth of a child with disability or emergence of a disability at a later stage. Scientific literary sources provide different data on structural changes in a family in an event of child disability: some of the authors state that child disability results more often in conflicts within families or divorces; meanwhile, other authors indicate that child disability is not a decisive factor for breakage of parents' relations and family rupture. Numerous factors play a role in the process. It is usually stressed that weak family bonds manifest themselves through withdrawal and minimal participation in family life of some family members (usually the father) when a family is unable to restructure their relationships following birth of a child having a disability or developing a disability later and when no help is received from outside (Ruškus, 2002; Mansell, Morris, 2004, etc.).

When speaking about their relations with a child having disability, almost all of the informants underlined that a close emotional relationship dominates in their interaction, and they educate their child with regard to his or her special needs, pay much attention to development of their child's independence, as well as put efforts to involve their child in various activities rather than stay at home. Nevertheless, some informants admit they attempt to do many things themselves rather than allowing their children with disability do it,

keep a close watch on their children in order to avoid bad things happening and put efforts to secure them from bad success. Such factors indicate that parents treat disability as a dominant feature of their child, they face difficulties understanding possibilities of educating a child having disability; they surround their child with exaggerated care thus limiting his or her activity and independent actions. Nitsch von Schelling (according to Vaičekauskaitė, 2006) stresses that children of too careful parents face difficulties in developing their independence, taking responsibilities and making independent decisions. Feeling timid and helpless due to receiving no confidence in them, they unconsciously transform their weakness into endless requirements. Parents' boundless care for their child turns their child into a victim of his or her own disability, as the child does not learn to manipulate his or her disability.

It is worthwhile mentioning that parents trying to cope with a stressful situation related to a child's disability may sometimes overlook the needs of other family members, especially nondisabled children. It should be noted that all of the research informants also have other children besides the child having disability. The research results indicate that although research participants try to give attention to every child, the child with disability receives their greater attention far more frequently. Some of them indicated that other children sometimes reproach them with being loved less. Yet the informants did not say that their relations with nondisabled children were tense: they willingly help their parents to take care of their brother or sister with disability and have beautiful interrelations. Some of them have indicated that sometimes their children have a quarrel and that nondisabled children reproach their parents with having to devote too much time to the brother or sister with disability, but no big conflicts arise due to this. Some of the participants have also presented remarks by people from outside regarding their children's beautiful relations and about them being true helpers in the family. Some of the participants underlined that a good microclimate in the family is of high importance for them; therefore, they seek good relations among family members and foster them. Presumably, the role of nondisabled children in the family is valued. Regard to needs of other family members, rather than sole devotion to the child with disability, allows maintaining balance of family relationships.

The category "**relations with other close people**" distinguished during the research is furthermore specified in two sub-categories: *relationships with relatives* and *relationships with friends* (see Table 3).

Table 3. Relationships with other close people

Sub-category	Sample statements
Relationships with relatives	"...have remained as previously..."; "remain good, we have close communication, often have meetings and in case help is necessary we can always apply..."; "...I get really great help from my sister: if necessary, she can stay with the child and bring the child where necessary...."; "...really great help comes from my husband's parents, and the child is closely attached to them..."; "... if not for the parents, we'd be having a hard time..."; "...we communicate very closely with the families of brother and sisters: they understand us, support us and help us as much as they can; they are the closest to us".
	"...no very close relations exist in our family – everyone stands for himself or herself..."; "...we have no time and meet seldom..."; "...the amount of different concerns has increased, so not too much time remains for meetings unless relatives come to visit us; and we set off to visit them very seldom..."; "I dislike too much attention; it seems they want to console us in every step we make, I am tired and embarrassed of such communication, so I try to meet as seldom as possible".
Relationships with friends	"...communication with the very closest friends has remained as previously, maybe they only offer their help more often..."; "...we had a number of very good friends, yet they left, so we often Skype each other..."
	"...we have moved to a new place, the friends live further away from us, so we meet seldom..."; "...so far not too much time remains for meetings..."; "Relationships with some of them have cooled down. I am embarrassed when they feel uncannily during our communication, as if afraid to insult, to cause pain; therefore, we have started to communicate less; why face those inconveniences..."; "...it is uncomfortable and causes anger when they depreciate the child and look at him with mercy; we don't need such communication".

Quite a number of research participants indicate that their relationships with their close relatives have remained the same. Some of them indicate their relationships with their very close relatives (e.g., the child's grandparents, aunts or uncles) have gained strength prominently: they share their worries and experiences with relatives, receive support and help. Parents also indicate that they maintain relationships with close

friends; their relationships have remained good, and their relatives provide help in need. Nevertheless, some of them pointed out that their relationships with relatives had weakened or broken. The most common reasons are as follows: previously weak relationships with friends and relatives; lack of time due to the increased amount of worries and problems related to raising of a child having disability; unwillingness to burden friends and relatives with their own troubles; disturbance due to exaggerated attention from relatives, their worries, constraint and unnatural communication; unwillingness of friends and relatives to maintain relationships.

The expression of the category "**participation in societal life**" is reflected in the contents of the following sub-categories: *attitudes of the society towards families having children with disabilities, parent participation in work activities, leisure time of the family*, and *parents' participation in the activities of communities and support groups* (see Table 4).

Table 4. Participation in societal life

Sub-category	Sample statements
Attitudes of the society towards families having children with disabilities	"Sincere and true people react adequately and understand us. We always receive their understanding and warm communication. The society is becoming more tolerant"; "The society's attitudes are changing, now they accept easier"; "…we receive support and understanding…"; "Possibilities are increasing for people with disabilities, and the society is starting step by step to look at them in a different light".
	"It is not always that we get some understanding"; "…this raises sympathy, and attitudes change slightly only after long communication…"; "The society is full of negative attitudes – it would be better if they didn't see them at all…"; "Indifference is felt from the side of the society: no sight – no pain"; "Sometimes people from outside accuse parents for child disability even without going deeper into the situation"; "In my opinion, the society has alienated to other people's pain. And this happens until they experience it themselves"; "People feel uncomfortable around a person with disability, they get lost, they do not know what they could do or say…"; "…even some neighbours look in an off-handed manner, leaving alone other people…".
Parents' participation in work activities	"My husband and I are both working people, the child attends school, and when he returns home, he stays with other children, or grandma takes care of him"; "…we work, yet it is sometimes a hard time coordinating my job and childcare…"; "I had to change my job; the new one has a more flexible timetable"; "I have recently reduced my workload; meanwhile, my husband has been working as previously"; "I had to resign from my job, my husband left for another town to work, and here are no centres where the child could stay"; "We consulted with my husband that the best way is that take care of the child, and he is presently studying at home".
Leisure time of the family	"…leisure activities have changed, more time should be spent at home…"; "…daily routine takes the majority of our time…"; "we can now devote less time to going outside or leaving for a longer period…"; "…we are more often spending time among our relatives, in the garden or in the nature"; "…when we have more time, we meet with our friends, relatives, at our home or another place, almost all of celebrations also take place at another site"; "we try not to sit at home, yet, possibly, we travel less to some extent"; "…we receive quite good help, so we coordinate everything"; "little time for me, and sometimes you want to relax or be with yourself so much…"
Parents' participation in the activities of communities and support groups	"…we communicate much with families like us, we do not feel alone as people understand one another here…"; "…there exists a group of parents having similar destinies, and we are also its members, we pour our hearts out, share both our worries and information, and we organise some excursion…"; "…we are members of the "Hope" community, we are greatly satisfied with it, and we receive loads of different kinds of help".

Parents expressed their opinions on the society's attitudes on children having disability and families having such children. Almost all of the informants indicated both positive and negative trends. Positive trends reflect that the society's attitudes are changing towards the positive side: tolerance is increasing, as well as understanding and acceptance of people having disability and their family members, they receive help and support.

On the other hand, parents have indicated that the society is still quite full of negative attitudes towards persons with disabilities and families who have children with disabilities: they experience segregated, and, sometimes, despising attitudes; they experience stigma or a lower social status and emotional tension. Parents have also mentioned that they receive the following reactions from people from outside: pity, indifference, accusations, alienation, and inner tension of other people during communication. Certainly, the society's segregationist attitudes towards people having disability that have stabilised over a long time most often become the basis to repudiate them, not to see their positive features and their opportunities, and to behave adversely or look at them with suspicion. Therefore, one of the propositions, trying to explain the research participants' opinions on the still dominant attitudes of the society towards children having disability and their families is their *personal experiences* arising from their personal interactions with their society or community.

The research has disclosed that almost all of the informants are working people. Some of the informants mentioned in their interviews that they had changed jobs in order to receive more flexible working conditions to coordinate childcare and work. Some of the parents indicated they had reduced their workload due to childcare. On the other hand, part of the parents state that they face difficulties achieving compatibility between their jobs and the increased worries in their families related to raising children with disability. Two female informants indicated they had to resign from their jobs due to states of their children having disability. The main reasons for changing jobs, reducing workloads or resigning from jobs, according to parents, were lack of help from their relatives or lack of responsible institutions providing services to children, especially in rural areas.

Leisure time and the structure of its distribution are among the essential psychosocial dimensions of a family having a child with disability. Research results indicate that such a family would very often spend their leisure time doing everyday jobs or with their family members at home. Part of the parents mentioned they would spend some time with their relatives or friends at home or elsewhere including meetings holidays, sometimes during weekends or vacations. Almost all of the parents mention in their responses that they devote rather little time to themselves. Some of the informants mentioned that their leisure time activities had not changed, and they would travel, participate in events or spend their time actively, both alone and with children. Possibly, such influence comes from peculiarities of child disability, the need for childcare, as well as the help parents receive from informal or formal structures.

Part of the families having children with disability attend different communities, organisations or support groups. Usually, the main motive for participation in such groups and organisations is the wish to communicate with other people or families having similar fates, not to feel alone, to share personal experiences, receive information, psychological support and understanding.

Another significant source of support for a family having children with disability is specialists of **different fields**. The content of the category "**the family's co-operation with specialists**" discloses both positive and negative experiences of parents in this field. The said things reflect in the content of the following sub-categories: *close co-operation with specialists in provision of help for a child*, *lack of co-operation with the family in the process of providing help for a child* and *lack of support for a family having a child with disability* (see Table 5).

Table 5. The family's co-operation with specialists

Sub-category	Sample statements
Close co-operation with specialists in provision of help for a child	"...I can say we feel welcome at the centre: they consult with us and listen to us..."; "...we discuss different issues that emerge together..."; "...they speak with us on how one or another problem should be solved..."; "...we are always informed on how things are going on for the child, and we often have common discussions..."; "We receive here much useful information or help..."; "...experienced specialists work here who always consult and provide pleasant communication..."; "...conditions are provided here for the child to learn with regard to the special needs, and they often consult with us...".
Lack of co-operation with the family in the process of providing help for a child	"...they do not put efforts to involve us unless we ask about something ourselves..."; "...in my opinion, there are not enough good specialists, and some of them work offhandedly..."; "...there is no sufficient information from specialists or common discussions on what to do; it seems this is your problem, and you should solve it yourself the way you can..."; "for some of them, our opinion is not very important or necessary...".
Lack of support for a family having a child with disability	"...nobody has informed us about self-help groups, such groups might not even exist here..."; "...we lack information where we could turn for help or who could help us..."; "...well, in our society it is not very common to help a family...".

Parents whose children attend special institutions indicate that they co-operate actively with specialists: they discuss together how one or another issue should be solved, receive useful information regarding child education and feel as partners of equal value. Meanwhile, parents whose children are training at homes indicate they feel a lack of specialists able to ensure necessary aids for children. Yet some parents indicate they even lack partnership with specialists at special institutions: the key expert roles are assigned to specialists. According to S. Ališauskienė (2002), difficulties regarding efficient communication may result due to both families and specialists. Specialists themselves might believe in partnership, yet they face difficulties involving parents in a systematic process. It happens often that specialists rely on the clinical model where a specialist is regarded as the only expert treating the issue. In such a case, communication receives a formal character. The paradigm of empowerment means treating support provided by specialists to families as an interactive phenomenon where all the members of the process become experts of coping with difficulties, and where all of the experiences and competences are recognised – not only those the specialists have, but also those of the family. A specialist acts not only in the name of the person seeking help (to a degree competences to provide help to people seeking new possibilities allow that make it possible to concentrate resources and support to overcome problems, adapt and develop in implementing numerous requirements that emerge) (Hallahan, Kauffman, Pullen, 2012).

Content analysis discloses that the entire family lacks support. Parents indicate that they do not receive sufficient information on such support, and such help is not provided to them. Similar tendencies are reflected in other research works (Ališauskienė, 2002; Gradeckienė, 2002; Butkevičienė, Merejienė, 2006; Kreivienė, 2007, etc.) showing that help is usually directed towards the child with a disability.

One of the aspects underlined in the research is ***needs of families*** having children with disabilities. According to R. Butkevičienė (2001), family needs are hard to describe, as they are very different in understanding of their own needs and their interpretation. Therefore, family needs are understood in the present research as desires of parents helping families in the future to overcome difficulties related to child disability. During the research, the informants were given a question what their families' needs are important for ensuring functioning of the family and improving the services received. After having performed analysis of research participant answers, 13 sub-categories constituting 7 category groups were distinguished (see Table 6).

Table 6. Needs of families having children with disabilities

Category	Sub-category
Need for information	Informing on the peculiarities of child impairments, development and education
	Informing on services provided to the child and the family
	Informing on technical aids for children having special needs
Material needs	Adaptation of the child's home with regard to his or her special needs
	Financial support
Need of respite care services	Institutions where children could stay temporarily
	Services of temporary childcare at home
Need for communication with specialists	Partnership-based interrelations
	Emotional support
Need for family help centres	Educational and consultative services provided by specialists allowing the family cope with the emerging problems and maintain successful functioning of the family
	Support groups
Need for self-realisation	Possibility to do favourite activities
	Possibility to improve in professional activities
Need for help from relatives and other close people	Emotional support from relatives
	Help for people having children with disabilities

The analysis of research data discloses that it is namely *information* that is important to parents and that would be helpful in recognising peculiarities of child disability, development and education. Parents also give importance to information on the services provided both to the child with disabilities and the entire family, technical aids for children having special needs (places to acquire them, new possibilities in this field and privileges acquiring the necessary aids). Parents would first of all like to receive such information from specialists.

The research also discloses that *material needs* are also important for parents, especially adaptation of environment at home for the child with regard to his or her special needs and greater financial support while purchasing technical aids. The research discloses that the need for *respite services* is important, especially for families having children with a severe disabilities. Parents state that services by institutions where children could stay temporarily are necessary, as well as services of temporary childcare at home (*"We are in a great need for such a centre where we could leave the child, in case of necessity, for half a day, weekend or at least several hours... Or at least a person who could look after our child at home"; "Our child's disability is severe, we all get tired, would like to relax a bit, but we live in a small town, and have no institutions providing childcare here"*). Such services would guarantee parents' possibilities to devote more attention and time to satisfaction of their individual and family needs for entertainment activities, self-realisation, professional development, regaining physical and spiritual powers in the family.

The research results indicate that parents need *communication with specialists*. They attach special importance to partnership-based relations when communicating with specialists. According to the research participants, they would like to feel greater confidence in the specialists, their possibilities and being partners of equal significance rather than being observers or performers of instructions, or standing outside when solving problems important for their children and families (*"...we sometimes feel that we are regarded as people having disabilities... we would like specialists to devote more time to communication with us, clarify how we see life, what we need and what we can..."; "... we would like more confidence in us..."*).

The research data indicates that development of *family help centres* is important where, according to parents, they could receive services of education and consulting which would solve problems emerging in families when having a child with disability, and to strengthen the family as an institution. The need for support *groups* also became clear. Parents indicate that understanding each other's problems, group members are able to share knowledge, personal experiences and feelings, help each other understand their possibilities, solve the problems that emerge or change the existing situation.

It is worthwhile paying attention to the fact that parents have indicated the importance of self-realisation: involvement in favourite activities and improvement in professional activities. As can be seen from this research and other works (Levickienė, 2005; Ruškus, Gerulaitis, Vaitkevičienė, 2004, etc.), interests related to

entertainment, satisfaction of needs suffer in the case of families or separate family members having children with disability, as the family devotes the majority of its time to the child with disability.

The research results also disclose the need for *support from relatives* and other close people especially emotional support and help in the case of having a child with disability. Parents state that it is important for them to share their experiences openly with their relatives, feel mutual attention and care for each other, relatives' insight into their needs and problems, response to them, understanding without the judging attitude, without debasing them, and seeking to better understand the child's powers rather than seeing only his or her inabilities. The importance of relatives' help for people having children with disabilities also became clear. Some of the research participants illustrated the importance of help from relatives giving examples and indicating that they can realise themselves in professional activities, learn and participate in societal life, as they receive help from relatives related to having a child with disability. Parents also stated that, knowing their relative would always helping need, they feel safer and more capable in overcoming difficulties.

Conclusions

1. The research data disclosed internal and social changes in families predetermined by child disabilities. After getting to know about child disability, parents experience numerous contradictory feelings: permanent tension and stress, the feeling of guiltiness due to child disability, helplessness, fear related to the child's future, and they experience difficulties accepting child disability. In the process of child disability internalisation, great importance lies in psychological help and support received from family members, relatives and other people, as well as specialists. Overcoming disability in a positive way indicates that parents are aware of the fact of disability, estimate child disability adequately and do not concentrate around child "inabilities", but rather put efforts to develop the potential their children have and, despite functional limitations of their children, they retain hope and optimism.

2. The research discloses that child disability is not a decisive factor for breakage of family bonds. Family relations between parents, parents and children, as well as the child having disability and his or her brothers/sisters are good in some families. In some of the families, child disability was a factor that united the family. Some participants mention that their relations have worsened. Supposedly, this could be impacted by previous negative relations, inability to change them and lack of support for families. It was noticed that only a small number of research participants indicated weakening or breakage of their relations with close people (relatives or friends). They indicate not only increased worries and lack of time related to child conditions, but also weak previous interrelations as a reason.

3. Families having a child with disability also experience issues related to social participation. Some of the parents who participated in the research indicated that having a child with disability had limited their participation in social life: some of them had given up jobs due to child disability, and some of the working ones experience difficulties while trying to match their work with the increased problems in the family having a child with disability; they can allow less leisure time for themselves, and free time is mostly spent doing everyday activities at home. From the viewpoint of research participants, despite the attitudes of the society regarding people with disabilities and families having children with disabilities changing in the positive direction, still many negative aspects remain in the society: such people experience pity, indifference, accusations, alienation or stigma from other people as well as other people's inner tension during communication. On the basis of parent experiences, it can be stated that, in order to maintain successful adaptation in a family having a child with disability, its internal functioning and social activity, the following factors are important: support from family members, other relatives and formal structures, and the society's attitudes towards them.

4. The research disclosed that the following needs are significant for parents having children with disabilities: the need for information helping recognise peculiarities of child impairment, development and education, as well as the need for information on services provided to children and families and technical aids for children having special needs; material needs, especially adaptation of the home environment to child needs and greater financial support for acquisition of technical aids; the need for respite services, i.e. development of services taking temporary childcare, both at a special institution and at home; the need for communication with specialists maintaining mutual partnership-based relations; development of family help centres; the possibility of self-realisation; emotional help and support in childcare received from relatives.

References

Ališauskienė S, 2002. Ankstyvosios reabilitacijos tarnybų veiklos optimizavimas konstruojant bendradarbiavimo su šeima modelį. Daktaro disertacija. Šauliai: Šiaulių universitetas.

Baxter Ch, Cummins R A, Yiolitis L, 2000. Parental stress attributed to family members with and without disability: A longitudinal study. Journal of Intellectual and Developmental Disability, 25 (2): 105-118.

Butkevičienė R, 2000. Šeimų, auginančių vaikus su klausos negalia, socialinė charakteristika. Daktaro disertacija. Kaunas: Kauno technologijos universitetas.

Butkevičienė R, 2001. Šeimų su neįgaliais vaikais problemos. Filosofija, sociologija, 1: 62–71.

Connell Ch M, Bergeran N, Katz K H, Saunders L, Tebes J K, 2007. Re-referral to child protective services: the influence of child, family, and case characteristics on risk status. Child abuse and neglect, 31 (5): 573–588.

Creswell J W, 2009. Research design: Qualitative, Quantative and mixed methods approaches. London: Sage.

Gailienė I, 2007. Neįgaliųjų nuostatų į negalią ir neįgaliuosius semantinis turinys. Specialusis ugdymas,7, 2(7): 8-17.

Gerulaitis D, 2006. Tėvų, auginančių neįgalų vaiką, socialinio dalyvavimo visuomenėje bruožų atskleidimas: barjerai ir galimybės. Jaunųjų mokslininkų darbai,4(11):89–93.

Gerulaitis D, 2007. Tėvų įsitraukimo į vaiko ugdymo(si) procesą plėtotė specialioje mokykloje. Daktaro disertacija. Šauliai: Šiaulių universitetas.

Gerulaitis D, Dėlkutė J, 2008. Veiksnių, susijusių su neįgalų vaiką auginančios šeimos psichosocialiniu atsparumu, identifikavimas. Jaunųjų mokslininkų darbai, 2(18): 91-97.

Gradeckienė S, 2002. Vaiko negalės įtaka visos šeimos gyvenimo kokybei. Biomedicina, 2(1): 2–10.

Hallahan D P, Kauffman J M , Pullen P C, 2012. Exeptional learners: An Introduction to Special Education (12th Ed.). New Jersey: Perason Education.

Hasting R P, Beck A, Hill Ch, 2005. Positive contributions made by children with an intellectual disability in the family: Mothers' and fathers' perceptions. Journal of Intellectual Disabilities, 9: 155-165.

Henderson G, Brayan W V, 2011. Psychosocial aspects of disability. Illinois: Charles Thomas Publisher.

Jusienė R, Bagdonaitė L, 2004. Socialinės paramos ryšys su neįgalius vaikus auginančių tėvų psichologiniu prisitaikymu. Socialinis darbas, 3(1): 105-115.

Kearney P M, Griffin T, 2001. Between joy and sorrow: being a parent of a child with developmental disability. Journal of Advanced Nursing, 34(5): 582-592

Kreivinienė B, 2007. Šeimos, auginančios neįgalų vaiką, gyvenimo kokybės palaikymo mechanizmas socialiniu aspekt. Specialusis ugdymas, 1 (16): 105-115.

Legkauskas V, Jurevičienė I, Gudonis V, 2007. Požiūrio į proto negalę turinčių žmonių stereotipiškumo ir išsilavinimo rodiklių sąsajos. Specialusis ugdymas, 2(17): 19-29

Lietuvos Respublikos neįgaliųjų socialinės integracijos įstatymas, 2004, Valstybės žinios, 83-1983.

Lietuvos Respublikos valstybinė šeimos politikos koncepcija, 2008. Valstybės žinios, 69–2624.

Lietuvos Respublikos švietimo įstatymo pakeitimo įstatymas, 2011. Valstybės žinios, 38-1804.

Mansell W, Morris K, 2004. A survey of parent's reactions to the diagnosis of an autistis spectum disorder by local service. Access to information and use of services, 8(4): 387−407.

Nedelisky A, 2004. Attachment relationships between children with physical disabilities and their caregivers. Graduate students journal of psychology, [http://www.tc.columbia.edu/i/a/722_Attachment-finalversion.pdf]

Ruškus J, 2002. Negalės fenomenas. Šauliai: Šiaulių universiteto leidykla.

Ruškus J, Mažeikis G, 2007. Neįgalumas ir socialinis dalyvavimas: kritinės patirties ir galimybių Lietuvoje refleksija. Šauliai: Šiaulių universiteto leidykla.

Twoy R, Connolly P M, Novak J M, 2007. Coping strategies used by parents of children with autism. Journal of the American Academy of nurse practitioners, 19: 251-260.

Ustilaitė S, Kuginytė-Arlauskienė I, Cvetkova L, 2011. Šeimų, auginančių neįgalius vaikus, vidinio ir socialinio gyvenimo pokyčiai. Socialinis darbas, 10(1): 20-26.

Vaičekauskaitė R, 2006. Auklėjimo sistema šeimoje, kai auginamas neįgalus vaikas: vaiko savarankiškumo aspektas. Specialusis ugdymas, 2(15): 88-98.

Woolfson L, 2004. Family well-being and disabled children: A psychosocial model of disability-related child behaviour problems. British Journal of Health Psyhology, 9 (1): 1-13.